

Form Approved OMB No. 0920-New Expiration Date: XX/XX/XXXX

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 <u>assist</u> 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)

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- 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 <u>must</u> be read out loud
- Text in UPPERCASE letters must not be read out loud

Participant ID:	Page 2/24 F
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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 <u>SETTING CALLBACK TIME WHILE</u>
 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?

Participant ID:	Page 3/24 F
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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 \rightarrow 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.

Participant ID:	Page 4/24 F
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SETTING CALLBACK TIME WHILE COMPLETING A SURVEY

Any additional Notes about Callback:

-	a participant may need to leave the telephone call after staring the survey with you. When ou 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 s What day and time is best for you?	
	[SET CALLBACK]	
	Day of the week:	
	Date:	
	Time:	



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 STAR*net*) 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 <i>Do Not Record</i> "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.

Participant ID:	Page 6/24 F
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The first set of questions are about you and your household.	6. What is your current employment status?
your nousenoid.	☐ Employed for wages (Go to next question,
1 What is your athnisity? Are you Hispania ar	 otherwise → Go to question 8) □ Self-employed (Go to next question,
1. What is your ethnicity? Are you Hispanic or Latino?	otherwise → Go to question 8)
	☐ Out of work for a year or more
Yes, Hispanic or Latino	☐ Out of work for less than a year
□ No, Not Hispanic or Latino	☐ Homemaker
O New Law wains to wood a list of actoroxics	☐ Student
2. Now, I am going to read a list of categories. Please choose one or more of the following	☐ Retired
categories to describe your race. What race	
do you identify with?	☐ Unable to work
☐ American Indian/Alaska Native	☐ Other, please specify: Do not read:
☐ Asian	
☐ Black or African American	☐ I don't know
□ Native Hawaiian or Pacific Islander	☐ I prefer not to answer
White	7 . 16
□ Other	7. If employed, how many hours per week are
U Other	you working?
Are you currently attending a school or	☐ Less than 20 hours per week
college?	☐ 20-40 hours per week
□ Yes	☐ More than 40 hours per week Do not read:
□ No	
Do not read:	☐ I don't know
☐ I don't know	☐ I prefer not to answer
☐ I prefer not to answer	9 During the last 12 months, what was your
T prefer not to unswer	8. During the last 12 months, what was your yearly total household income before taxes?
4. What is the highest level of education you	Was it
completed? Is it	□ \$40 to \$9,999
☐ Elementary school (grades 1 through 8)	□ \$10,000 to \$24,999
Some high school (grades 9 through 11)	□ \$25,000 to 49,999
Graduated high school (grade 12)	□ \$50,000 to 74,999
Some college or technical school	□ \$75,000 to 99,999
Graduated college or technical school	□ \$100,000 to 149,999
☐ Graduate school	□ \$150,000 and greater
Do not read:	Do not read:
☐ I don't know	☐ I don't know
☐ I prefer not to answer	☐ I prefer not to answer
T . Protos	
5. Do you own or rent your home?	
D Own	
□ Rent	
☐ Other arrangement	
Do not read:	
☐ I don't know	
☐ I prefer not to answer	
·	

and influenza.	COVID vaccine.
9. To your knowledge, have you had COVID-19?	☐ I would like to get it but have not been able to☐ I am worried about the side effects of the
□ Yes	vaccine
☐ No → Go to question 13	☐ I do not like vaccines or needles
Do not read:	☐ I am not worried about getting COVID-19
\square I don't know \rightarrow Go to 13	☐ I already had COVID-19
\square I prefer not to answer \rightarrow Go to 13	☐ I have a medical condition that prevents me from getting the vaccine
10. Was your infection confirmed by a test?	☐ I do not think the vaccine is effective
☐ Yes, confirmed by test	☐ I just don't want the vaccine
☐ No, not confirmed by test	□ Other
Do not read:	☐ <i>[If "other selected]</i> Please
☐ I don't know	specify the reason:
☐ I prefer not to answer	
11. Describe the level of care you received. Would	Do not read:
you say you	☐ I don't know
☐ Did not seek medical care	☐ I prefer not to answer
Received medical care but was not	15. Have you ever received a flu vaccine?
hospitalized	☐ Yes
☐ Were hospitalized Do not read:	□ No → Go to question 17
☐ I don't know	Do not read:
☐ I prefer not to answer	☐ I don't know → Go to question 18
i prefer not to answer	\Box I prefer not to answer \rightarrow Go to 18
12. How would you characterize your symptoms?	
Would you say you had	16. Did you receive the flu vaccine any time in the
☐ No symptoms	last 12 months?
☐ Mild symptoms (Such as low-grade fever,	☐ Yes → Go to question 18
cough, shortness of breath)	□ No
☐ Moderate symptoms (Such as moderate	Do not read:
difficulty breathing, body aches, fatigue)	☐ I don't know → Go to 18
☐ Severe symptoms (Such as severe difficulty	\square I prefer not to answer \rightarrow Go to 18
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	17. What are the reasons you have not received
\square I prefer not to answer \rightarrow Go to 15	the flu vaccine during the past 12 months?
	will read a list of potential reasons. Please tell
	me whether each one is a reason you have
14. What are the reasons you have not received a	not had the flu vaccine in last 12 months.
COVID-19 vaccine? I will read a list of	☐ I would like to get it but have not been able to
potential reasons. Please tell me whether	

☐ I am worried about the side effects of the	☐ Morning
vaccine	☐ Afternoon
☐ I do not like vaccines or needles	☐ Evening and night
☐ I am not worried about getting the flu	Do not read:
☐ I already had the flu	☐ I don't know
☐ I have a medical condition that prevents me	☐ I prefer not to answer
from getting the vaccine I do not think the vaccine is effective	
☐ I do not think the vaccine is effective☐ I just don't want the vaccine	21. Where in your body do you typically have
☐ Other	pain? I will read a list of potential responses
☐ [If "other selected] Please	Please tell me whether this is a part of your body where you typically have pain.
briefly specify the reason:	Check all that apply.
shory opening the reaction	☐ Head
	□ Neck
	☐ Shoulders
	□ Arms
	☐ Back
	☐ Chest
	☐ Stomach
	☐ Hips
Do not read:	Legs
☐ I don't know	Feet
☐ I prefer not to answer	Other
The payt set of questions ask about your	☐ <i>[If "other selected]</i> Please specify the other area where you
The next set of questions ask about your	have pain:
experience with chronic pain and fatigue related to your muscular dystrophy.	πανε μαπ.
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	Do not read:
body?	☐ I don't know
Do not read response options:	☐ I prefer not to answer
_	
number of days	
☐ I cannot recall having muscular dystrophy-	
related pain in the last 30 days \rightarrow Go to	The west supportions are about however, box
<i>question 52</i> \Box I prefer not to answer \rightarrow <i>Go to 52</i>	The next questions are about how you have
☐ I prefer hot to answer → GO to 52	managed your pain in the past 30 days.
	22. Do you use over-the-counter/non-
19. Is your pain managed by medication or other	prescription pain medications such as
methods?	aspirin, ibuprofen, or acetaminophen to
☐ Yes	manage the pain related to your muscular
□ No	dystrophy?
Do not read:	☐ Yes
☐ I don't know	□ No → Go to question 25
\square I prefer not to answer	Do not read:
	☐ I don't know→ Go to 25
00.144	\square I prefer not to answer \rightarrow Go to 25
20. What time of day is your pain the worst?	
Please tell me all that apply.	

23. How often do you use any combination of	☐ Reduce pain so you can manage my
this type of medication to manage your	normal activities
pain?	☐ Provide some relief but not enough that you
☐ Every day	can resume normal activities
☐ 2-6 days per week	☐ Provide little or no pain relief
☐ Once a week	Do not read:
☐ Once a month	☐ I don't know
☐ Not in the last month	☐ I prefer not to answer
Do not read:	'
☐ I don't know	28. Do you use cannabidiol (CBD) or any other
☐ I prefer not to answer	marijuana-based treatment products to
	manage the pain related to your muscular
24. How helpful are any combination of these	dystrophy?
medications in managing your pain? Do	□ Yes
they	\square No \rightarrow Go to question 31
☐ Completely relieve the pain	Do not read:
☐ Reduce pain so you can manage your	☐ I don't know→ Go to 31
normal activities	\square I prefer not to answer \rightarrow Go to 31
☐ Provide some relief but not enough that y	ou
can resume normal activities	29. How frequently do you use any combination
☐ Provide little or no pain relief	of CBD or marijuana-based treatment
Do not read:	products to manage your pain?
☐ I don't know	□ Every day
☐ I prefer not to answer	☐ 2-6 days per week
E i prefer not to answer	☐ Once a week
25. Do you use prescription opioid pain	☐ Once a month
medications – such as Percocet	□ Not in the last month
(oxycodone), Vicodin (hydrocodone), or	Do not read:
Ultram (tramadol) – to manage the pain	
related to your muscular dystrophy?	☐ I don't know
☐ Yes	☐ I prefer not to answer
☐ No → Go to question 28	20. How halpful are any combination of CDD or
Do not read:	30. How helpful are any combination of CBD or marijuana-based treatment products in
☐ I don't know→ Go to 28	managing your pain?
☐ I prefer not to answer → Go to 28	☐ Completely relieve the pain
26. How often do you use any combination of	☐ Reduce pain so I can manage my normal
26. How often do you use any combination of	activities
this type of medication to manage your pain?	☐ Provide some relief but not enough that I can resume normal activities
□ Every day	☐ Provide little or no pain relief
☐ 2-6 days per week	Do not read:
☐ Once a week	
☐ Once a week	☐ I don't know
□ Not in the last month	☐ I prefer not to answer
Do not read:	
☐ I don't know	31. Do you use alternative medications – such
	as herbal supplements – to manage the pain
☐ I prefer not to answer	related to your muscular dystrophy?
27. How helpful are any combination of these	☐ Yes
medications in managing your pain? Do	□ No → Go to question 34
they	Do not read:
☐ Completely relieve the pain	☐ I don't know → Go to 34
- Completely relieve the pain	\square I prefer not to answer \rightarrow Go to 34

	☐ Reduce pain so you can manage your
32. How frequently do you use any combination	normal activities
of this type of medication to manage your	☐ Provide some relief but not enough that you
pain?	can resume normal activities
☐ Every day	☐ Provide little or no pain relief
☐ 2-6 days per week ☐ Once a week	Do not read:
☐ Once a week ☐ Once a month	☐ I don't know
☐ Not in the last month	☐ I prefer not to answer
Do not read:	27 De yeu yee any other method or thereny to
☐ I don't know	37. Do you use any other method or therapy to
☐ I prefer not to answer	manage your pain? □ Yes
Li prefer flot to answer	□ No → Go to question 41
33. How helpful are any combination of these	Do not read:
medications in managing your pain?	
☐ Completely relieve the pain	☐ I don't know→ Go to 41
☐ Reduce pain so you can manage my	\square I prefer not to answer \rightarrow Go to 41
normal activities	20 What other methods or therenies do yell
☐ Provide some relief but not enough that you	38. What other methods or therapies do you use?
can resume normal activities	use:
☐ Provide little or no pain relief	39
Do not read:	39
☐ I don't know	39
☐ I prefer not to answer	39
Li prefer not to answer	39
34. Do you use nonpharmacological methods	39
such as biofeedback, physical therapy,	39
behavioral modifications, better sleep	How frequently do you use any combination of
practices, better hygiene practices, or diet to	these other methods to manage your pain?
manage the pain related to your muscular	□ Every day
dystrophy?	☐ 2-6 days per week
□ Yes	☐ Once a week
□ No → Go to question 37	☐ Once a month
Do not read:	□ Not in the last month
☐ I don't know→ <i>Go to</i> 37	Do not read:
☐ I prefer not to answer→ <i>Go to 37</i>	☐ I don't know
in prefer not to answer 7 Go to 37	☐ I prefer not to answer
35. How frequently do you use any combination	Li prefer not to answer
of these methods to manage your pain?	40. How helpful are any combination of these
☐ Every day	other methods in managing your pain?
☐ 2-6 days per week	☐ Completely relieve the pain
☐ Once a week	☐ Reduce pain so I can manage my normal
☐ Once a month	activities
☐ Not in the last month	☐ Provide some relief but not enough that I
Do not read:	can resume normal activities
☐ I don't know	☐ Provide little or no pain relief
☐ I prefer not to answer	Do not read:
p. 5. 5	☐ I don't know
36. How helpful are any combinations of these	☐ I prefer not to answer
methods in managing your pain?	i profer not to answer
☐ Completely relieve the pain	
Landy Successive Remit	
Participant ID:	Page 11/24 F
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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. 45. **In the past 7 days,** how much did pain interfere with work around the home? Was 41. In the past 7 days, how intense was your pain at its worst? Was it... it... ☐ No pain ☐ Not at all ☐ Mild □ A little bit ☐ Moderate ☐ Somewhat ☐ Ouite a bit ☐ Severe ☐ Very severe ☐ Very much Do not read: Do not read: ☐ I don't know ☐ I don't know \square I prefer not to answer ☐ I prefer not to answer 46. In the past 7 days, how much did pain 42. In the past 7 days, how intense was your interfere with your ability to participate in average pain? Was it... social activities? Was it... ☐ No pain ☐ Not at all ☐ Mild ☐ A little bit ☐ Moderate □ Somewhat ☐ Severe ☐ Ouite a bit ☐ Very severe □ Very much Do not read: Do not read: ☐ I don't know ☐ I don't know ☐ I prefer not to answer ☐ I prefer not to answer 43. What is your level of pain right now? Is it... 47. In the past 7 days, how much did pain ☐ No pain interfere with your household chores? Was ☐ Mild it... ☐ Moderate ☐ Not at all ☐ Severe ☐ A little bit ☐ Very severe □ Somewhat Do not read: ☐ Quite a bit ☐ I don't know □ Very much ☐ I prefer not to answer Do not read: ☐ I don't know The next questions are about the impact of ☐ I prefer not to answer pain on your activities. For each item, please select the option that best describes how often 48. In the past 7 days, how much did pain the impact of pain occurred in the past 7 days. interfere with the things you usually do for fun? Was it... 44. In the past 7 days, how much did pain ☐ Not at all interfere with your day to day activities? ☐ A little bit □ Not at all □ Somewhat ☐ A little bit ☐ Quite a bit ☐ Somewhat ☐ Very much ☐ Quite a bit Do not read: □ Very much ☐ I don't know

Participant ID:

Do not read:

☐ I don't know

☐ I prefer not to answer

☐ I prefer not to answer

49. In the past 7 days, how much did pain	\square Rarely
interfere with your enjoyment of social	☐ Sometimes
activities?	☐ Often
\square Not at all	☐ Always
☐ A little bit	Do not read:
☐ Somewhat	☐ I don't know
☐ Quite a bit	☐ I prefer not to answer
☐ Very much	in prefer flot to answer
Do not read:	E4 In the past 7 days, how often was the
☐ I don't know	54. In the past 7 days, how often was the
	statement "I felt fatigued" true?
☐ I prefer not to answer	□ Never
50 to the coast 7 days becomes hid as in	☐ Rarely
50. In the past 7 days, how much did pain	☐ Sometimes
interfere with your enjoyment of life?	☐ Often
□ Not at all	☐ Always
☐ A little bit	Do not read:
☐ Somewhat	☐ I don't know
☐ Quite a bit	☐ I prefer not to answer
☐ Very much	
Do not read:	55. In the past 7 days, how often was the
☐ I don't know	following statement true? "I was too tired
☐ I prefer not to answer	to do my household chores."
•	□ Never Î
51. In the past 7 days, how much did pain	☐ Rarely
interfere with your family life?	☐ Sometimes
□ Not at all	☐ Often
☐ A little bit	☐ Always
□ Somewhat	Do not read:
☐ Quite a bit	☐ I don't know
□ Very much	☐ I prefer not to answer
Do not read:	i prefer flot to answer
☐ I don't know	E6. In the past 7 days, how often was the
	56. In the past 7 days, how often was the following statement true? "I was too tired
☐ I prefer not to answer	to leave the house."
The west assessing are about how tired you	
The next questions are about how tired you	□ Never
felt during the past week and how feeling tire	- The state of the
impacted your daily activities.	☐ Sometimes
50 lasth a sant 7 days have after some the	☐ Often
52. In the past 7 days, how often was the	□ Always
statement "I felt exhausted." true?	Do not read:
□ Never	☐ I don't know
Rarely	☐ I prefer not to answer
☐ Sometimes	
Often	57. In the past 7 days, how often was the
☐ Always	following statement true? "I was frustrated
Do not read:	by being too tired to do the things I wanted
☐ I don't know	to do."
☐ I prefer not to answer	☐ Never
	☐ Rarely
53. In the past 7 days, how often was the	☐ Sometimes
statement "I felt like I had no energy" true	
□ Never	☐ Always

Do not read:	☐ Coffee and/or other caffeine containing
☐ I don't know	beverages
\square I prefer not to answer	☐ Prescription medications
•	☐ Non-prescription medications
	58. ☐ Dietary Supplements
	58. ☐ Sleep
	58.
	58. Other, specify
	58. Do not read:
	_ : 5:5:5: ::5: :5:5::5:
	58.
	61. Please tell us anything else about your
	experience with pain or fatigue:
In the past 7 days, how often was the	
statement "I felt tired" true?	The next questions are about your experience
☐ Never	with muscular dystrophy and family planning.
☐ Rarely	
☐ Sometimes	62. At what age were you diagnosed with
☐ Often	muscular dystrophy?
☐ Always	
Do not read:	Do not read:
☐ I don't know	□ I don't know
☐ I prefer not to answer	
in prefer not to answer	☐ I prefer not to answer
59. In the past 7 days, how often was the	00 11
	63. Have you ever talked with a genetic
statement following statement true? "I	counselor or other medical provider about
had to limit my social activity because I wa	
tired."	members to have muscular dystrophy?
□ Never	☐ Yes
Rarely	□ No → Go to question 66
☐ Sometimes	Do not read:
☐ Often	☐ I don't know→ Go to 66
☐ Always	\square I prefer not to answer \rightarrow Go to 66
Do not read:	·
☐ I don't know	64. When did you talk with the genetic counselor
☐ I prefer not to answer	or medical provider?
,	☐ Before considering or having children
If the respondent's response to all of the	☐ During a pregnancy
statements 52-59 was 'Never' or 'Rarely',	☐ Between pregnancies
please go to question 61.	\square After I was done having children \rightarrow Go to
produce go to question our	question 66
	Do not read:
	☐ I don't remember/I don't know → <i>Go to 66</i>
	\square I prefer not to answer \rightarrow Go to 66
	CF Have did an addition with the
60 How have you managed your fatigue is the	65. How did speaking with this person affect
60. How have you managed your fatigue in the	
past 7 days? Please tell me all that apply	, , ,
Stimulants	have children
☐ Exercise	☐ You decided not to have your own children
	☐ You decided to adopt

\square You decided to see a medical provider who	□ No		
could help me have children without muscular	☐ I don't know		
dystrophy □ Other	☐ I prefer not to answer		
[If "other selected] Please specify the effect on your decision to have children	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:		
not road.	times		
not read: ☐ I don't know	☐ I don't know		
☐ I prefer not to answer	☐ I prefer not to answer		
66. Have you ever been pregnant?	71. In your <i>first</i> pregnancy, how many babies were you carrying?		
Do not read: ☐ Yes ☐ No	Do not read (If the person is confused, say "Would you say" and read response options).		
☐ I don't know			
☐ I prefer not to answer	□ 2 (twins)		
	☐ 3 or more (triplets or more)		
Did you ever have trouble getting pregnant or were	☐ I don't know		
unable to get pregnant?	☐ I prefer not to answer		
Do not read:			
☐ Yes ☐ No	72. What was the outcome(s) of the pregnancy?		
☐ I have not tried to get pregnant			
☐ I don't know	Read if multiple babies indicated in previous question: If applicable, you		
☐ I prefer not to answer	can select more than one option.		
68. Were you ever told by a medical provider that			
you would not be able to get pregnant or migh			
have a hard time getting pregnant due to your muscular dystrophy?	☐ Baby was born alive at less than 37 weeks of pregnancy (early or preterm)		
Do not read:	☐ Baby was born alive at 37 weeks or		
□ Yes	later (term)		
□ No	☐ Miscarriage (fetal loss) before 20		
☐ I don't know	weeks of pregnancy		
☐ I prefer not to answer	☐ Stillbirth (fetal loss) at 20 weeks of		
69. Did you ever decide not to become pregnant			
because it would be a risk to your own health?	Abortion (pregnancy medically ended for any reason)		
Do not read:	Do not read:		
□ Yes	□ I don't know		

67.

\square I prefer not to answer	☐ I prefer not to answer
73. When did this pregnancy end? Please tell me the month and year/ (mm/yyyy)	If respondent had only two pregnancies, please go to question 86.
Do not read:	77
☐ I don't know	77. In your <i>third</i> pregnancy, how many babies were you carrying?
☐ I prefer not to answer	were you carrying:
	Do not read:
If the respondent only had one pregnancy (S	See
Q70), please go to question 86.	□ 2 (twins)
	☐ 3 or more (triplets or more)
	☐ I don't know
	☐ I prefer not to answer
74. In your second pregnancy, how many	70 What was the sutcemp(s) of the presence of
babies were you carrying?	78. What was the outcome(s) of the pregnancy? If you carried more than one baby, please
	check all that apply.
□ 2 (twins)	☐ Baby was born alive at less than 37
☐ 3 or more (triplets or more)	weeks of pregnancy (early or preterm)
Do not read:	☐ Baby was born alive at 37 weeks or
☐ I don't know	later (term)
☐ I prefer not to answer	☐ Miscarriage (fetal loss) before 20
75. What was the outcome(s) of the pregnanc	weeks of pregnancy
Read if multiple babies indicated in	Stillbirth (fetal loss) at 20 weeks of pregnancy or later
<i>previous question:</i> If applicable, yo	
can select more than one option.	ended for any reason)
	Do not read:
☐ Baby was born alive at less than 3	I don't know
weeks of pregnancy (early or preterm)	☐ I prefer not to answer
☐ Baby was born alive at 37 weeks	or .
later (term)	79. When did this pregnancy end?
☐ Miscarriage (fetal loss) before 20	/ (mm/yyyy)
weeks of pregnancy	Do not read:
☐ Stillbirth (fetal loss) at 20 weeks o	of □ I don't know
pregnancy or later	☐ I prefer not to answer
☐ Abortion (pregnancy medically	
ended for any reason)	If the respondent only had three
Do not read:	pregnancies, please go to question 86.
☐ I don't know	
☐ I prefer not to answer	80. In your <i>fourth</i> pregnancy, how many babies were you carrying?
76. When did this pregnancy end?	were you carrying:
/ (mm/yyyy)	Do not read:
Do not read:	
☐ I don't know	□ 2 (twins)
_ ruon entrow	☐ 3 or more (triplets or more)

☐ I don't know	☐ Baby was born alive at 37 weeks or
☐ I prefer not to answer	later (term)
	☐ Miscarriage (fetal loss) before 20 weeks of pregnancy
	\square Stillbirth (fetal loss) at 20 weeks of
	pregnancy or later
	☐ Abortion (pregnancy medically
81. What was the outcome(s) of the pregnancy	
If you carried more than one baby, please	
check all that apply.	☐ I don't know
☐ Baby was born alive at less than 37 weeks of pregnancy (early or preterm)	of Mile Park in the driswer
Baby was born alive at 37 weeks or	
later (term)	/ (mm/yyyy)
☐ Miscarriage (fetal loss) before 20	Do not read:
weeks of pregnancy	☐ I don't know
☐ Stillbirth (fetal loss) at 20 weeks of pregnancy or later	☐ I prefer not to answer
☐ Abortion (pregnancy medically	The following questions are about the <i>first</i> time
ended for any reason)	you were pregnant.
Do not read:	
☐ I don't know	86. How old were you when you became
☐ I prefer not to answer	pregnant with your first pregnancy?
82. When did this pregnancy end?	years Do not read:
/ (mm/yyyy)	
Do not read:	☐ I don't know
☐ I don't know	☐ I prefer not to answer
☐ I prefer not to answer	87. Did you or your partner use any of the following assisted technologies to get pregnant with your <i>first</i> pregnancy? <i>Please</i>
If you only had four pregnancies, please go to	
question 86.	☐ No assistance needed
83. In your <i>fifth</i> pregnancy, how many babies	☐ Hormone therapy or medications
were you carrying?	☐ In-vitro fertilization (IVF)
	☐ Pre-implantation diagnosis. (Genetic
□ 2 (twins)	testing of the embryo before implantation
□ 3 or more (triplets or more)	following IVF)
Do not read:	☐ Artificial insemination with your
☐ I don't know	partner's sperm
☐ I prefer not to answer	☐ Artificial insemination with donor
i prefer flot to answer	sperm
84. What was the outcome(s) of the pregnancy	
If you carried more than one baby, please	3
check all that apply.	☐ Treatment for varicocele
Baby was born alive at less than 37	Other types of medical help
weeks of pregnancy (early or preterm)	

Do not read:	90. Did your first baby have any of the following
☐ I don't know	problems?
☐ I prefer not to answer	☐ Born too small (Low birth weight)
88. Did you have any of the following problems	☐ Died before she/he was 1 month old
with your first pregnancy? <i>Please indicate</i>	□ Neither of these problems
all that apply.	Do not read:
☐ No problems	☐ I don't know
☐ Gestational Hypertension (high	☐ I prefer not to answer
blood pressure that started during this	The next questions are about how your
pregnancy)	muscular dystrophy symptoms changed during
☐ Pre-eclampsia or eclampsia	your first pregnancy.
☐ Significant bleeding with delivery	For each of the following symptoms of muscular
☐ Significant bleeding while pregnant	dystrophy, please tell me how the symptom
☐ Infection	changed <i>during</i> your first pregnancy.
☐ Gestational diabetes (diabetes that started during this pregnancy)	91. During your pregnancy, was your muscle weakness
☐ Too much amniotic fluid	□ Worse
☐ Too little amniotic fluid	□ Better
☐ Labor pains more than 3 weeks	☐ About the same
before my baby was due (preterm or early	☐ Did not have muscle weakness
labor)	before or during pregnancy
☐ Water broke more than 3 weeks before your baby was due (preterm	Do not read:
premature rupture of membranes or	☐ I don't know
PPROM)	☐ I prefer not to answer
☐ Bad reaction to the anesthetic used during delivery	92. During your pregnancy, was your muscle pain
Do not read:	□ Worse
☐ I don't know	□ Better
☐ I prefer not to answer	☐ About the same
If respondent's first pregnancy did not end	☐ Did not have pain before or during
in a live birth (Q78), please go to question	pregnancy
91.	Do not read:
89. How was your first baby delivered?	☐ I don't know
☐ Unassisted vaginal delivery	☐ I prefer not to answer
☐ Assisted vaginal delivery (forceps o	r 02 During vous prognancy ware vous much
vacuum extraction)	cramps
☐ Planned cesarean section	□ Worse
Unplanned cesarean section,	Better
including emergency C-section	☐ About the same, or
Do not read:	☐ Did not have muscle cramps before
☐ I don't know	or during pregnancy
☐ I prefer not to answer	Do not read:
	☐ I don't know

☐ I prefer not to answer	☐ Did not have pain before, during or
94. During your pregnancy, was any difficulty	after pregnancy Do not read:
you had walking	□ I don't know
□ Worse	☐ I prefer not to answer
□ Better	·
☐ About the same, or	98. After your pregnancy ended, were your
☐ Did not have difficulty walking before or during pregnancy	muscle cramps □ Worse
Do not read:	□ Better
☐ I don't know	☐ About the same, or
☐ I prefer not to answer	☐ Did not have muscle cramps before
·	during or after pregnancy
95. During your pregnancy, did you need mor help with daily activities?	e Do not read:
Do not read:	☐ I don't know
□ Yes	☐ I prefer not to answer
□ No	99. After your pregnancy ended, was any
☐ About the same	difficulty you had walking
☐ Did not need help with daily	□ Worse
activities before or during my pregnancy	□ Better
☐ I don't know	☐ About the same. or
☐ I prefer not to answer	☐ Did not have difficulty walking
	before, during or after pregnancy Do not read:
Now, please tell me how each of the following symptoms of muscular dystroph	
changed after your first pregnancy ended	☐ I prefer not to answer
compared to your symptoms during the	·
pregnancy.	100. After your pregnancy ended, did you need more help with daily activities than you did
96. After your pregnancy ended, was your	during your pregnancy?
muscle weakness	□ Yes
□ Worse	□ No
☐ Better	☐ About the same
☐ About the same, or☐ Did not have muscle weakness	☐ Did not need help with daily
before, during or after pregnancy	activities before, during or after my pregnancy
Do not read:	Do not read:
☐ I don't know	☐ I don't know
☐ I prefer not to answer	☐ I prefer not to answer
97. After your pregnancy ended, was your	
muscle pain	
□ Worse	
□ Better	
☐ About the same	

	any symptoms related to muscular	Ш	Other types of medical help
-	ophy in your first pregnancy affect your	Do not re	ead:
	on to have future pregnancies?	☐ I don't know	
	Yes No		I prefer not to answer
		105. Did \	you have any of the following problems
Do not read:		-	our most recent pregnancy? Please
	I don't know	checi	k all that apply.
	I prefer not to answer		No problems
	your first pregnancy, did a doctor,		Gestational Hypertension (high
	, or other health care worker tell you		pressure that started during this
-	ou had depression?	· -	nancy)
	Yes		Pre-eclampsia or eclampsia
	No		Significant bleeding with delivery
Do not re	ead:		Significant bleeding while pregnant
	I don't know		Infection
	I prefer not to answer		Gestational diabetes (diabetes that
If the res	pondent only had one pregnancy,	starte	ed during this pregnancy)
	to question 119		Too much amniotic fluid
The follow	ving questions are about the most		Too little amniotic fluid
	ast time you were pregnant.		Labor pains more than 3 weeks
100 How			e my baby was due (preterm or early
	old were you when you became ant with your most recent pregnancy?	labor)	
pregn	ant with your most recent pregnancy:	☐ Water broke more than 3 weeks before your baby was due (preterm	
Do not re	ead:		ature rupture of membranes or
	years	PPRO	•
	I don't know	П	Bad reaction to the anesthetic used
	I prefer not to answer	 during	g delivery
104 Did v	ou or your partner use any of the	Do not re	ead:
	ring assistive technologies to get		I don't know
	ant with your most recent pregnancy?		I prefer not to answer
	se check ALL that apply.	If the part	icipant's last pregnancy did not end
	No assistance needed	-	rth, go to question 119.
	Hormone therapy or medications		, 3
	In-vitro fertilization (IVF)		
	Pre-implantation diagnosis. (Genetic		your most recent baby have any of the
	g of the embryo before implantation		ving problems?
follow	ing IVF)		Born too small (Low birth weight)
	Artificial insemination with your		Died before she/he was 1 month old
partne	er's sperm		Neither of these problems
	Artificial insemination with donor	Do not re	ead:
sperm			I don't know
	Drugs to improve ovulation		I prefer not to answer
	Surgery to correct blocked tubes	107 How	was your most recent baby delivered?
	Treatment for varicocele	107.11000	That your most recent baby delivered:

Page 20/24**F**

	Unassisted vaginal delivery		Did not have muscle cramps before	
	Assisted vaginal delivery (forceps or			
vacuum	n extraction)	Do not read:		
	Planned cesarean section		I don't know	
□ includin	Unplanned cesarean section, ag emergency C-section		I prefer not to answer	
Do not rea			ng your pregnancy, was any difficulty	
	I don't know	•	ad walking	
	I prefer not to answer		Worse	
_	, proto to distorte		Better	
The next a	uestions are about if and how your		About the same, or	
muscular	dystrophy symptoms changed	hofor	Did not have difficulty walking	
during you	r last pregnancy.		e or during pregnancy	
For each of	the following symptoms, please tell	Do not re		
	symptom changed during your most		I don't know	
<i>recent</i> preg	nancy compared to right before your		I prefer not to answer	
most recen	<i>t</i> pregnancy.		ng your pregnancy, did you need more	
108. During	your pregnancy, was your muscle	help v	vith daily activities?	
weakne			Yes	
	Worse		No	
	Better		About the same, or	
	About the same, or		Did not need help with daily	
	Did not have muscle weakness		ties before or during my pregnancy	
before (or during pregnancy	Do not re		
Do not rea	d:		I don't know	
	I don't know		I prefer not to answer	
	I prefer not to answer			
109. During pain	your pregnancy, was your muscle	symptoms	e tell me how each of the following changed after your most recent	
•	Worse		r ended compared to your symptoms recent pregnancy.	
П	Better			
	About the same, or		your most recent pregnancy ended,	
_	Did not have pain before or during	•	your muscle weakness	
pregna	. 2		Worse	
Do not rea			Better	
	I don't know		About the same, or	
	I prefer not to answer	⊢	Did not have muscle weakness e, during or after pregnancy	
110 D		Do not re		
cramps	your pregnancy, were your muscle		I don't know	
	Worse		I prefer not to answer	
	Better		ו אוכוכו ווטג נט מווששפו	
	About the same, or		your most recent pregnancy ended,	
	About the surie, of	•	our muscle pain	
			Worse	

	Better		after your most recent pregnancy, did you	
	About the same, or		eed more help with daily activities than yo	u
	Did not have pain before, during	or alc	d during your pregnancy? Yes	
	regnancy			
Do not rea				
	I don't know		Did not need help with daily	
	I prefer not to answer	 -	ctivities before, during or after my	
	your most recent pregnancy ender our muscle cramps	d, pre □	egnancy I don't know	
	Worse			
	Better			
	About the same, or		after your most recent baby was born or	
	Did not have muscle cramps bet		our most recent pregnancy ended, did a octor, nurse, or other health care worker	
	or after pregnancy		Il you that you had depression?	
Do not rea		Do no	ot read:	
	I don't know			
	I prefer not to answer		No	
116. After	your most recent pregnancy ende	_		
was ar	ny difficulty you had walking		I prefer not to answer	
	Worse		·	
	Better	110 D	Please tell us anything else about your	
	About the same, or		sperience with pregnancy or family	
□ hefore	Did not have difficulty walking , during or after pregnancy		anning.	
Do no				
	I don't know			
	I prefer not to answer			
	·			
This is	s the end of the survey. Additional	information on MD	STAPnet can be found at	
	s the end of the survey. Additional llowing links:	I I I I I I I I I I I I I I I I I I I	OTAMIEL CAIT DE TOUTIL AL	
	9		https://v	www.cdc.go
А	ND			

Page 22/24**F**

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.

Participant ID:	Page 23/24 F