



the  
christopher  
project

# Report to the Myotonic Dystrophy Community

**DATA SUPPLEMENT**

## Note to Reader

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The Christopher Project is a collaborative research project between national patient advocacy organizations, healthcare providers, and patients and families in the USA and Canada. It was designed to complement existing research by directly surveying patients and their family members/caregivers about their experience living with myotonic dystrophy.

To accomplish this, a large survey was distributed to patients in the summer of 2014 and a follow-up survey was distributed to family members/caregivers in early 2015. This Data Supplement is a summary of all of the responses to the questions asked on both surveys, presented as 'frequency tables' (i.e., how 'frequently' each answer appeared).

This Data Supplement is a companion to the main Christopher Project *Report to the Myotonic Dystrophy Community*, which can be found online at: [www.christopherproject.org](http://www.christopherproject.org).

## Terms / Definitions

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<b>Overall:</b>	all patient survey respondents (including cDM1-71, cDM1-94, DM1, DM2, and U/U)
<b>cDM1-71:</b>	patient survey respondents who reported they have congenital myotonic dystrophy type 1 and an age of onset at birth and a diagnosis within their first two years of life
<b>cDM1-94:</b>	patient survey respondents who reported they have congenital myotonic dystrophy type 1 but did not report an age of onset at birth and/or did not receive a diagnosis within their first two years of life
<b>DM1:</b>	patient survey respondents who reported they have myotonic dystrophy type 1
<b>DM2:</b>	patient survey respondents who reported they have myotonic dystrophy type 2
<b>U/U:</b>	patient survey respondents who reported they do not know or are unsure of their type (Unknown/Unsure)
<b>n:</b>	number of respondents in a particular group or subgroup (n=number)
<b>No response:</b>	percentage of missing responses for a particular question
<b>The subject:</b>	the original patient survey respondent on which the family member/caregiver reported (i.e., the patient, the patient survey respondent)

## Data Access

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The extensive data gathered through the Christopher Project is available to qualified researchers subject to a formal application and review process. Inquiries regarding access to the anonymized Christopher Project dataset can be made to: [support@christopherproject.org](mailto:support@christopherproject.org).

Additional information can be found at [www.christopherproject.org](http://www.christopherproject.org).

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### CARDIORESPIRATORY Symptoms

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### PSYCHOLOGICAL Symptoms

Table S-95a	Rate how much LEARNING DIFFICULTIES/CHALLENGES impact the subject's daily life:
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Table S-95c	Rate how much DEPRESSION impacts the subject's daily life:
Table S-95d	Rate how much ANXIETY impacts the subject's daily life:

### HORMONAL and ENDOCRINE Symptoms

Table S-96a	Rate how much DIABETES impacts the subject's daily life:
Table S-96b	Rate how much SEXUAL/INTIMACY PROBLEMS impact the subject's daily life:
Table S-96c	Rate how much FERTILITY PROBLEMS impact the subject's daily life:
Table S-96d	Rate how much BALDING/THINNING HAIR impacts the subject's daily life:

### OTHER Symptoms

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Table S-97b	Rate how much DROOPING EYELIDS (PTOSIS) impacts the subject's daily life:
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- Table S-102d Rate how much of a challenge STANDING (FOR ANY LENGTH OF TIME) is for the subject:
- Table S-102e Rate how much of a challenge MAINTAINING YOUR BALANCE is for the subject:
- Table S-102f Rate how much of a challenge DRIVING A CAR is for the subject:

### **HOUSEHOLD and PERSONAL NEEDS Activities**

- Table S-103a Rate how much of a challenge PREPARING MEALS is for the subject:
- Table S-103b Rate how much of a challenge HOUSEKEEPING is for the subject:
- Table S-103c Rate how much of a challenge HANDLING OBJECTS is for the subject:
- Table S-103d Rate how much of a challenge USING CUTLERY AND KITCHEN UTENSILS is for the subject:
- Table S-103e Rate how much of a challenge SWALLOWING, EATING, DRINKING is for the subject:
- Table S-103f Rate how much of a challenge WASHING is for the subject:
- Table S-103g Rate how much of a challenge DRESSING is for the subject:

### **COMMUNICATION Activities**

- Table S-104a Rate how much of a challenge SPEAKING (PRONOUNCING WORDS) is for the subject:
- Table S-104b Rate how much of a challenge WRITING (HOLDING A PEN) is for the subject:

### **PSYCHOLOGICAL Activities**

- Table S-105a Rate how much of a challenge CONCENTRATING is for the subject:
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- Table S-105c Rate how much of a challenge PUTTING THOUGHTS INTO WORDS is for the subject:
- Table S-105d Rate how much of a challenge PLANNING DAILY ACTIVITIES is for the subject:
- Table S-105e Rate how much of a challenge REMEMBERING THINGS is for the subject:

### **SOCIAL Activities**

- Table S-106a Rate how much of a challenge ROMANTIC, EMOTIONAL, INTIMATE LIFE is for the subject:
- Table S-106b Rate how much of a challenge RELATIONSHIPS/INTERACTIONS WITH OTHERS are for the subject:
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### **DOCTORS' OFFICE Activities**

- Table S-110a Rate how much of a challenge PREPARING FOR A VISIT TO THE DOCTOR is for the subject:
- Table S-110b Rate how much of a challenge ADVOCATING FOR APPROPRIATE CARE is for the subject:
- Table S-110c Rate how much of a challenge BOOKING/TRACKING APPOINTMENTS is for the subject:

### **WORK/SCHOOL Activities**

- Table S-111a Rate how much of a challenge COMPLETING YOUR EDUCATION/SCHOOLING is for the subject:
- Table S-111b Rate how much of a challenge EMPLOYMENT (OBTAINING/RETAINING WORK) is for the subject:
- Table S-111c Rate how much of a challenge PERFORMING YOUR TASKS AT WORK/SCHOOL is for the subject:
  
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- Table S-113 What do you think is the subject's biggest obstacle in managing their myotonic dystrophy in their daily life?

# Patient Survey Data Tables

## Section 1: Your Participation

**TABLE S-1:** Are you an adult respondent or a family member/caregiver responding on behalf of a minor?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
18 or older and completing survey on my own behalf	65%	11%	46%	74%	75%	65%
Adult on behalf of minor living with myotonic dystrophy	11%	66%	22%	7%	3%	8%
No response	23%	23%	32%	19%	22%	27%

## Section 2: About You

**TABLE S-2:** What country do you live in?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
USA	80%	72%	71%	88%	86%	69%
Canada	20%	28%	29%	12%	14%	31%

**TABLE S-3:** What state or province do you live in? (reported by region)

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
USA: New England (CT, ME, MA, NH, RI, VT)	4%	4%	1%	4%	7%	4%
USA: Middle Atlantic (NJ, NY, PA)	12%	8%	6%	11%	22%	10%
USA: East North Central (IN, IL, MI, OH, WI)	13%	11%	12%	14%	15%	13%
USA: West North Central (IA, KS, MN, MO, NE, ND, SD)	9%	10%	10%	11%	10%	5%
USA: South Atlantic (DE, DC, FL, GA, MD, NC, SC, VA, WV)	15%	14%	11%	14%	16%	16%
USA: East South Central (AL, KY, MS, TN)	2%	1%	5%	2%	1%	3%
USA: West South Central (AR, LA, OK, TX)	7%	7%	7%	8%	4%	8%
USA: Mountain (AZ, CO, ID, NM, MT, UT, NV, WY)	6%	4%	5%	9%	4%	4%
USA: Pacific (AK, CA, HI, OR, WA)	11%	11%	14%	15%	9%	7%
Canada: Atlantic (NL, PE, NS, NB)	1%	4%	2%	<1%	-	2%
Canada: Quebec (QC)	1%	1%	-	<1%	-	2%
Canada: Ontario (ON)	11%	13%	19%	7%	10%	15%
Canada: Prairies (AB, MB, SK)	4%	8%	3%	2%	2%	8%
Canada: British Columbia (BC)	3%	1%	4%	2%	2%	5%
No response	<1%	-	-	-	-	1%

**TABLE S-4:** What is your date of birth (D.O.B.)? (reported as age in years at time of survey completion)

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
<10	3%	39%	4%	2%	-	1%
10 thru 19	6%	34%	15%	5%	2%	3%
20 thru 29	8%	17%	11%	8%	5%	7%
30 thru 39	14%	8%	15%	20%	6%	13%
40 thru 49	22%	1%	18%	28%	19%	22%
50 thru 59	24%	-	18%	21%	25%	35%
60+	20%	-	17%	16%	42%	18%
No response	1%	-	2%	1%	3%	1%
<b>Average age of respondent (calculated mean)</b>	<b>45.4</b>	<b>14.4</b>	<b>40.3</b>	<b>44.7</b>	<b>55.1</b>	<b>48.5</b>

**TABLE S-5:** What is your gender?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Female	59%	49%	54%	60%	65%	56%
Male	40%	46%	45%	39%	33%	43%
No response	2%	4%	1%	1%	3%	1%

**TABLE S-6:** How would you describe your living situation?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
I live alone	11%	-	9%	9%	16%	13%
I live with my spouse/partner	55%	1%	38%	63%	68%	51%
I live with my child/children	18%	-	11%	26%	16%	15%
I live with my parent(s)	26%	89%	43%	22%	8%	24%
I live with my sibling(s) and/or other relative(s)	10%	37%	16%	7%	4%	9%
I live with a roommate(s)	2%	3%	2%	2%	2%	2%
I live with a professional caregiver (in my home)	1%	3%	1%	1%	1%	1%
I live in a care facility/retirement home/group home	2%	1%	5%	<1%	3%	2%
Other	1%	-	-	<1%	1%	1%
No response	<1%	-	1%	<1%	1%	1%

NOTE: Percentages can add up to more than 100% because multiple responses were permitted

**TABLE S-7:** What is your current employment status?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Student	11%	51%	19%	10%	3%	5%
Employed full-time	12%	1%	10%	15%	17%	7%
Employed part-time	10%	7%	9%	12%	8%	9%
Retired	18%	-	18%	15%	34%	17%
Unemployed by choice	6%	-	2%	11%	3%	5%
Seeking employment	2%	3%	3%	3%	2%	2%
Unable to work due to myotonic dystrophy	44%	18%	39%	42%	38%	59%
Unable to work due to other reasons	6%	3%	4%	5%	8%	8%
Disability/disability insurance	1%	-	1%	2%	1%	1%
Self-employed	1%	-	1%	1%	1%	1%
Minor/not of working age	1%	20%	1%	<1%	-	-
Other	<1%	-	-	<1%	-	1%
No response	1%	3%	1%	<1%	1%	<1%

NOTE: Percentages can add up to more than 100% because multiple responses were permitted

**TABLE S-8:** What is the highest level of education you have completed?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Currently in primary/secondary school	7%	55%	18%	5%	2%	2%
Some high school (no diploma)	6%	10%	11%	4%	3%	10%
High school graduate/high school equivalent	23%	17%	24%	17%	17%	34%
Some college	20%	1%	12%	23%	22%	20%
Trade/technical/vocational certification	8%	-	5%	9%	12%	8%
College/university graduate	25%	-	19%	29%	34%	21%
Post graduate degree	8%	-	7%	12%	11%	4%
Baby/toddler/preschool	1%	13%	-	<1%	-	-
Other	1%	4%	2%	1%	1%	1%
No response	<1%	-	1%	<1%	1%	1%

**TABLE S-9:** What is your annual PERSONAL income?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
None	22%	63%	22%	24%	12%	15%
\$1K to \$10K	27%	28%	31%	26%	17%	34%
>\$10K to \$25K	24%	1%	18%	24%	27%	28%
>\$25K to \$40K	7%	-	7%	6%	14%	7%
Over \$40K	14%	-	11%	18%	24%	6%
No response	7%	7%	11%	3%	6%	10%

**TABLE S-10:** What is your annual TOTAL HOUSEHOLD income?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
<\$25K	28%	31%	28%	23%	18%	40%
\$25K to \$50K	20%	14%	14%	21%	21%	23%
>\$50K to \$75K	15%	11%	16%	15%	24%	10%
>\$75K to 100K	10%	9%	7%	12%	13%	7%
Over \$100K	16%	24%	20%	21%	16%	6%
No response	11%	11%	15%	8%	9%	15%

## Section 3: Your Current Health

**TABLE S-11:** In general, would you say your health is:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Excellent	3%	4%	2%	4%	1%	2%
Very good	14%	27%	20%	16%	14%	9%
Good	34%	39%	34%	38%	37%	28%
Fair	36%	21%	32%	32%	36%	45%
Poor	11%	7%	10%	9%	12%	14%
No response	2%	1%	2%	1%	1%	2%

**TABLE S-12:** Body Mass Index (BMI)

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
BMI > 18.5: Underweight	10%	45%	14%	11%	2%	7%
BMI 18.5 - 24.9: Normal	36%	42%	45%	41%	32%	31%
BMI 25 - 29.9: Overweight	29%	4%	21%	26%	36%	33%
BMI 30 - 34.9: Obese	14%	1%	15%	12%	18%	18%
BMI 35 - 39.9: Severely Obese	4%	-	1%	5%	5%	5%
BMI > 40: Morbidly Obese	4%	1%	2%	4%	6%	3%
No response	3%	6%	2%	1%	2%	3%
<b>Average Body Mass Index (BMI)</b>	<b>25.8</b>	<b>18.9</b>	<b>24.7</b>	<b>25.5</b>	<b>27.8</b>	<b>26.8</b>

NOTE: BMI calculated from height/weight responses provided

**TABLE S-13:** Are you a cigarette smoker?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	9%	1%	9%	9%	5%	14%
No	90%	99%	89%	90%	94%	85%
No response	1%	-	2%	<1%	1%	1%

## Section 4: Your Diagnosis

**TABLE S-14a:** What type of myotonic dystrophy do you have?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Congenital myotonic dystrophy type 1 (CDM1)	14%	100%	100%	-	-	-
Myotonic dystrophy type 1 (DM1)	39%	-	-	100%	-	-
Myotonic dystrophy type 2 (DM2)	17%	-	-	-	100%	-
Unknown/unsure (U/U)	28%	-	-	-	-	100%
No response	2%	-	-	-	-	-

**TABLE S-14b:** What type of myotonic dystrophy do you have? (reclassified\*)

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
*Congenital myotonic dystrophy type 1 with age of onset at birth and diagnosis less than or equal to two years of age (CDM1-71)	6%	100%	-	-	-	-
*Congenital myotonic dystrophy type 1 with age of onset older than birth and diagnosis greater than two years of age (CDM1-94)	8%	-	100%	-	-	-
Myotonic dystrophy type 1 (DM1)	39%	-	-	100%	-	-
Myotonic dystrophy type 2 (DM2)	17%	-	-	-	100%	-
Unknown/unsure (U/U)	28%	-	-	-	-	100%
No response	2%	-	-	-	-	-

**TABLE S-15a:** About how old were you when you first noticed significant symptoms (Age, in years)? (age at onset)

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
0 (birth)	11%	100%	18%	2%	1%	7%
1 thru 9	8%	-	21%	8%	4%	8%
10 thru 19	18%	-	21%	22%	11%	21%
20 thru 29	16%	-	13%	18%	15%	21%
30 thru 39	19%	-	9%	23%	21%	18%
40 thru 49	13%	-	11%	13%	19%	12%
50 thru 59	7%	-	1%	6%	20%	6%
60+	2%	-	3%	2%	6%	1%
No response	2%	-	2%	2%	1%	3%
I do not experience symptoms	3%	-	1%	5%	2%	3%
<b>Average age at onset (calculated mean)</b>	<b>25.7</b>	<b>0.0*</b>	<b>17.3</b>	<b>27.2</b>	<b>36.5</b>	<b>25.1</b>

\* by reclassification criteria

**TABLE S-15b:** What was the first symptom you noticed?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Muscle Weakness	41%	39%	49%	35%	47%	44%
Myotonia	28%	1%	27%	35%	27%	24%
Balance, Mobility Issues	6%	-	4%	6%	10%	7%
Sleep, Fatigue, Energy	7%	1%	2%	8%	6%	8%
Pain	5%	-	-	5%	5%	5%
Neonatal Problems	3%	28%	6%	-	1%	1%
Cataracts, Eyes	3%	-	2%	4%	5%	2%
Cognitive, Developmental Delays	3%	-	9%	3%	2%	4%
Speech, Swallowing	3%	1%	-	4%	2%	6%
Cardiac	2%	-	-	3%	4%	2%
Gastrointestinal Problems	2%	1%	4%	4%	2%	1%
Other	5%	11%	7%	4%	4%	4%
I do not experience symptoms	3%	-	1%	5%	2%	3%
No response	7%	23%	7%	4%	2%	11%

NOTE: Grouped accordingly from first written response provided

**TABLE S-16:** About how old were you when you received a medical diagnosis for myotonic dystrophy (Age, in years)? (age at diagnosis)

	Overall (n=1,180)	CDM1-71 (n=71)	CDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
<=2	9%	100%*	6%	3%	2%	5%
3 thru 9	6%	-	29%	5%	1%	5%
10 thru 19	13%	-	23%	14%	7%	14%
20 thru 29	17%	-	13%	19%	9%	24%
30 thru 39	21%	-	14%	28%	18%	21%
40 thru 49	15%	-	7%	16%	22%	15%
50 thru 59	10%	-	-	9%	25%	7%
60+	5%	-	5%	4%	16%	2%
No response	1%	-	1%	1%	1%	2%
I do not have a medical diagnosis for myotonic dystrophy	2%	-	1%	2%	1%	5%
<b>Average age at medical diagnosis (calculated mean)</b>	<b>30.1</b>	<b>0.2</b>	<b>20.1</b>	<b>31.5</b>	<b>43.7</b>	<b>29.1</b>

\* by type reclassification criteria

**TABLE S-17:** Were you the first person in your family to receive a diagnosis for myotonic dystrophy?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	39%	56%	33%	37%	48%	35%
No	57%	41%	64%	60%	49%	57%
Unknown	2%	3%	2%	2%	3%	3%
I do not have a medical diagnosis for myotonic dystrophy	1%	-	1%	1%	-	3%
No response	1%	-	-	1%	-	2%

**TABLE S-18:** If you received a medical diagnosis, was it confirmed through genetic testing?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	70%	83%	64%	77%	84%	52%
No	21%	10%	28%	19%	13%	30%
Unknown	6%	7%	7%	2%	3%	12%
I do not have a medical diagnosis for myotonic dystrophy	2%	-	1%	1%	-	4%
No response	1%	-	-	1%	1%	2%

**TABLE S-19a:** Did you receive a repeat count at the time of your genetic confirmation?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	50%	70%	40%	69%	47%	24%
No	45%	28%	54%	28%	46%	68%
No response	5%	1%	5%	3%	7%	8%

**TABLE S-19b:** If you received a repeat count, what is it?

	Overall (n= 585)	cDM1-71 (n=49)	cDM1-94 (n=39)	DM1 (n=317)	DM2 (n=94)	U/U (n=80)
<100	6%	-	5%	9%	2%	3%
100 thru 399	20%	-	11%	29%	8%	12%
400 thru 699	14%	-	6%	22%	3%	8%
700 thru 999	9%	14%	21%	12%	2%	5%
1000 thru 1999	8%	50%	21%	2%	1%	6%
2000 thru 9999	2%	12%	3%	1%	4%	-
10000+	5%	-	-	<1%	29%	-
I do not remember my repeat count	36%	24%	34%	25%	50%	68%

NOTE: Grouped accordingly from written responses provided

**TABLE S-20:** If you do not have a genetically confirmed diagnosis, please tell us why:

	Overall (n=355)	cDM1-71 (n=12)	cDM1-94 (n=34)	DM1 (n=103)	DM2 (n=32)	U/U (n=158)
Others in family confirmed	13%	-	24%	17%	9%	9%
Clinical presentation/symptomatology	10%	17%	12%	11%	6%	11%
I don't know/I don't remember	10%	33%	6%	9%	13%	11%
Alternate testing (e.g., biopsy, EMG, EIM)	7%	-	12%	8%	13%	5%
I do have confirmation (e.g., blood test)	6%	-	3%	10%	6%	4%
Genetic confirmation was not offered	6%	-	3%	3%	13%	8%
Cost/insurance cost/insurance risk	5%	-	3%	6%	-	6%
Genetic confirmation was not available	3%	8%	-	4%	-	2%
Unnecessary/no need	3%	8%	3%	3%	-	2%
Other	<1%	-	-	-	-	1%
No response	39%	33%	35%	30%	41%	42%

NOTE: Grouped accordingly from written responses provided

**TABLE S-21:** What type of assistance DID YOU RECEIVE around the time of your diagnosis?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Referrals to specialist doctors	67%	89%	67%	68%	64%	62%
Directed to a patient organization	42%	59%	43%	45%	37%	38%
Handout/information package	28%	38%	29%	30%	22%	26%
Referrals to other health care providers	26%	68%	32%	21%	26%	22%
Genetic counseling	21%	37%	22%	25%	22%	12%
No assistance provided/offered	21%	1%	24%	18%	24%	25%
School accommodations	8%	25%	19%	6%	5%	5%
Psychological/emotional support	6%	7%	3%	9%	5%	3%
Workplace accommodations	3%	1%	4%	3%	5%	3%
SSI/disability/financial assistance	1%	4%	1%	1%	2%	<1%
Specific interventions including meds, devices, aids	1%	3%	1%	1%	1%	1%
Internet/research (on own)	1%	-	1%	1%	2%	1%
Other	<1%	-	-	-	-	-
I do not have a diagnosis for myotonic dystrophy	2%	-	-	1%	1%	3%
No response	2%	3%	3%	2%	2%	3%

NOTE: Percentages can add up to more than 100% because multiple responses were permitted

**TABLE S-22:** What was the MOST helpful assistance you received around the time of your diagnosis?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Referrals to specialist doctors	29%	48%	28%	33%	28%	19%
Directed to a patient organization	12%	7%	11%	15%	12%	11%
Referrals to other health care providers	6%	21%	13%	3%	5%	5%
Handout/information package	5%	6%	4%	6%	3%	4%
Genetic counseling	4%	1%	5%	7%	3%	3%
Psychological/emotional support	3%	1%	3%	4%	3%	4%
Assistance received was not helpful	3%	1%	2%	2%	3%	5%
No assistance received	2%	-	2%	2%	2%	1%
School accommodations	2%	3%	10%	2%	3%	2%
Diagnosis/finding out what I/we had	2%	-	1%	1%	5%	1%
Information	2%	1%	1%	2%	2%	2%
All assistance received was helpful	2%	3%	2%	2%	2%	2%
Workplace accommodations	1%	-	-	-	1%	1%
SSI/disability/financial assistance	1%	-	1%	1%	1%	1%
Specific interventions including meds, devices, aids	1%	1%	2%	1%	3%	<1%
Internet/research	1%	1%	-	2%	2%	1%
No response	31%	18%	23%	25%	34%	42%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because multiple responses were received

**TABLE S-23:** What type of assistance WOULD HAVE BEEN HELPFUL but was not offered?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Information	10%	8%	10%	12%	13%	8%
Referrals to specialist doctors	8%	3%	7%	10%	9%	6%
Psychological/emotional support	8%	6%	4%	10%	9%	5%
Directed to a patient organization	5%	6%	3%	6%	8%	3%
SSI/disability/financial assistance	5%	7%	7%	4%	3%	5%
Referrals to other health care providers	3%	1%	4%	4%	4%	2%
Genetic counseling	2%	1%	-	2%	-	2%
Handout/information package	2%	3%	1%	2%	3%	1%
Workplace accommodations	2%	-	-	2%	2%	2%
Specific interventions including meds, devices, aids	2%	-	4%	2%	3%	2%
School accommodations	1%	-	3%	1%	1%	-
Diagnosis/finding out what I/we had	1%	-	3%	<1%	2%	2%
Anything/everything would be helpful	1%	1%	1%	<1%	4%	2%
A cure	1%	-	-	1%	3%	2%
No response	54%	63%	55%	50%	46%	62%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because multiple responses were received

**TABLE S-24:** What were the specific challenges surrounding your diagnosis?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Emotional impact	52%	48%	43%	62%	48%	46%
Lack of resources available about my disease	43%	32%	39%	42%	49%	42%
Financial impact/expense	26%	21%	23%	26%	23%	29%
Length of time it took	24%	10%	37%	21%	38%	21%
Incompleteness of explanation	21%	17%	21%	20%	23%	22%
Received incorrect diagnosis	8%	1%	13%	8%	13%	7%
Provided incorrect information about my disease	5%	6%	5%	4%	7%	4%
Other	2%	1%	2%	2%	3%	1%
No response	10%	23%	7%	8%	6%	13%

NOTE: Percentages can add up to more than 100% because multiple responses were permitted

## Section 5: Information and Resources

**TABLE S-25a:** How HELPFUL has your GENERAL PRACTITIONER/FAMILY DOCTOR been for you as a source of information?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	17%	31%	19%	15%	13%	19%
Somewhat Helpful	30%	41%	32%	32%	22%	29%
Not Very Helpful	34%	20%	30%	35%	46%	29%
Never Used	19%	8%	18%	18%	20%	22%
No response	<1%	-	1%	-	-	<1%

**TABLE S-25b:** How HELPFUL have OTHER MEDICAL SPECIALISTS been for you as a source of information?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	37%	49%	33%	41%	34%	32%
Somewhat Helpful	41%	45%	43%	43%	39%	37%
Not Very Helpful	12%	6%	11%	10%	18%	14%
Never Used	5%	-	6%	2%	4%	10%
No response	5%	-	7%	4%	6%	7%

**TABLE S-25c:** How HELPFUL have FAMILY/FRIENDS been for you as a source of information?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	31%	38%	32%	33%	21%	31%
Somewhat Helpful	31%	24%	29%	33%	33%	29%
Not Very Helpful	19%	24%	15%	18%	26%	17%
Never Used	11%	11%	11%	9%	11%	14%
No response	8%	3%	14%	6%	10%	9%

**TABLE S-25d:** How HELPFUL have PATIENT ORGANIZATIONS (i.e., MDA, MDF, MDC) been for you as a source of information?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	32%	31%	27%	37%	37%	23%
Somewhat Helpful	35%	42%	26%	39%	33%	34%
Not Very Helpful	13%	8%	24%	11%	12%	13%
Never Used	14%	15%	14%	9%	14%	20%
No response	6%	3%	10%	4%	5%	10%

**TABLE S-25e:** How HELPFUL have GENERAL HEALTH-RELATED WEBSITES been for you as a source of information?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	10%	6%	4%	12%	16%	6%
Somewhat Helpful	31%	37%	26%	37%	36%	20%
Not Very Helpful	19%	24%	18%	21%	17%	16%
Never Used	32%	31%	37%	25%	19%	47%
No response	8%	3%	15%	5%	11%	10%

**TABLE S-25f:** How HELPFUL have PRINTED MATERIALS/BOOKS been for you as a source of information?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	16%	17%	12%	21%	18%	8%
Somewhat Helpful	44%	45%	52%	46%	47%	38%
Not Very Helpful	14%	15%	10%	15%	12%	17%
Never Used	19%	20%	15%	14%	14%	31%
No response	7%	3%	12%	4%	10%	7%

**TABLE S-26:** Who or what has been the MOST helpful source of information for you?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Medical specialists	31%	42%	35%	33%	32%	25%
Patient organizations	22%	14%	16%	29%	23%	16%
Family/friends	17%	18%	20%	17%	14%	20%
Printed materials/books	12%	4%	11%	14%	13%	9%
Websites/Internet	10%	10%	7%	11%	15%	8%
General practitioner/family doctor	9%	13%	11%	7%	6%	14%
Not specified	12%	13%	12%	7%	12%	18%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because multiple responses were received

**TABLE S-27:** What are the BEST ways for you to receive information about myotonic dystrophy?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Receiving information by LETTERMAIL (printed)	61%	44%	53%	60%	66%	65%
Talking with health care providers	55%	62%	57%	57%	47%	53%
Reading books and other printed material	43%	44%	38%	46%	42%	38%
Receiving information by EMAIL (electronically)	38%	41%	31%	45%	49%	24%
Visiting patient organization websites (i.e., MDA, MDF, MDC)	36%	39%	23%	46%	43%	21%
Talking with friends/family	30%	25%	29%	35%	23%	32%
Attending support group meetings	18%	17%	16%	20%	20%	14%
Visiting other health-related websites	14%	10%	11%	17%	19%	9%
Participating in online discussion forums/chat rooms	8%	13%	7%	10%	15%	3%
Other	5%	1%	1%	6%	5%	3%
No response	2%	6%	5%	2%	2%	2%

NOTE: Percentages can add up to more than 100% because multiple responses were permitted

**TABLE S-28:** Which areas would you like to get more information about?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Available treatments/medications	70%	54%	67%	74%	69%	69%
Clinical trials	51%	37%	49%	62%	60%	35%
Exercise	49%	32%	43%	53%	54%	47%
Scientific research	44%	39%	37%	49%	52%	38%
Cardiac implications	41%	45%	35%	44%	40%	40%
Nutrition	40%	39%	34%	46%	38%	37%
Financial assistance	39%	41%	37%	40%	32%	45%
Anesthesia risks	36%	38%	33%	38%	35%	35%
Where to find specialists/disease experts	34%	32%	26%	35%	36%	36%
Patient organizations (i.e., MDA, MDF, MDC)	25%	17%	17%	27%	27%	26%
Community supports	21%	31%	22%	24%	16%	17%
Health insurance	20%	13%	16%	25%	13%	20%
Technical aids	20%	21%	17%	22%	20%	20%
Disclosure (talking with others about my disease)	20%	15%	20%	21%	25%	18%
Psychological supports	20%	15%	19%	25%	15%	18%
Genetic counseling/family planning	13%	14%	15%	14%	11%	14%
Workplace accommodations	10%	10%	9%	14%	6%	7%
School accommodations/assistance	8%	31%	15%	8%	2%	3%
Other	3%	3%	4%	2%	4%	2%
No response	5%	7%	7%	3%	4%	5%

NOTE: Percentages can add up to more than 100% because multiple responses were permitted

**TABLE S-29:** How often do you use a computer/device to search the Internet and/or check email?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Daily	48%	37%	45%	58%	54%	35%
Weekly	16%	13%	14%	16%	19%	15%
Monthly	5%	3%	6%	5%	7%	5%
Rarely	12%	11%	15%	9%	8%	18%
Never	18%	30%	20%	11%	11%	27%
No response	1%	6%	-	1%	3%	1%

**TABLE S-30:** How often do you access information about myotonic dystrophy?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Daily	2%	6%	5%	2%	3%	-
Weekly	11%	10%	10%	16%	14%	3%
Monthly	22%	18%	11%	29%	33%	10%
Rarely	43%	24%	47%	37%	40%	56%
Never	20%	38%	26%	14%	8%	29%
No response	2%	4%	2%	2%	3%	2%

**TABLE S-31a:** Have you registered in a patient registry?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	43%	44%	37%	54%	52%	25%
No	29%	34%	29%	24%	20%	40%
Unknown	26%	23%	33%	20%	25%	33%
No response	2%	-	1%	2%	3%	2%

**TABLE S-31b:** If yes, which registry(ies)?

	Overall (n=505)	cDM1-71 (n=31)	cDM1-94 (n=35)	DM1 (n=245)	DM2 (n=104)	U/U (n=83)
Myotonic Dystrophy Foundation (MDF)/MDF Family Registry	23%	29%	29%	29%	17%	7%
Muscular Dystrophy Association (MDA)/MDA Clinic	22%	26%	20%	17%	27%	32%
National Registry for FSHD/DM/URMC/Strong Memorial Hospital	17%	16%	14%	22%	18%	4%
Can't recall/Don't remember	7%	10%	9%	7%	7%	5%
Other Clinics/Hospitals	5%	-	9%	4%	2%	11%
Muscular Dystrophy Canada (MDC)	4%	6%	9%	3%	2%	7%
Canadian Neuromuscular Disease Registry (CNDR)	1%	-	-	1%	-	1%
Stanford/Stanford Registry	1%	-	-	2%	1%	-
Indiana University/Cardiac Registry	1%	-	-	1%	-	-
No response	31%	32%	26%	28%	40%	35%

NOTE: Grouped accordingly from written responses provided; responses were categorized based upon those received even if the response is not an actual or active myotonic dystrophy patient registry; percentages can add up to more than 100% because multiple responses were received

**TABLE S-32a:** Have you ever participated in a research study or another survey about myotonic dystrophy?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	20%	18%	18%	29%	22%	8%
No	73%	75%	69%	66%	71%	83%
Unknown	6%	7%	10%	4%	7%	8%
No response	1%	-	3%	1%	-	1%

**TABLE S-32b:** If yes, which one(s)?

	Overall (n=237)	cDM1-71 (n=13)	cDM1-94 (n=17)	DM1 (n=134)	DM2 (n=44)	U/U (n=28)
University of Rochester (including registry)	13%	-	6%	16%	18%	-
Clinical studies (various sites/topics)	12%	38%	6%	9%	9%	25%
Indiana (Groh)/cardiac	5%	-	6%	4%	-	21%
Other survey/questionnaire	4%	-	-	4%	5%	4%
Pregnancy survey	4%	-	-	7%	-	4%
University of Minnesota	4%	15%	6%	4%	-	-
MDF (including surveys and registry)	4%	-	-	5%	7%	-
University of Washington	3%	-	12%	1%	2%	4%
MDA (including burden of disease survey)	3%	-	6%	4%	-	7%
Mexilitene	2%	-	-	4%	-	-
Creatine	2%	-	6%	1%	2%	4%
Iplex/IGF	2%	-	-	3%	-	-
Stanford University	2%	-	12%	1%	-	-
UC Davis	2%	-	6%	2%	-	-
Interventional studies (not explicit)	1%	-	-	1%	-	7%
Alertech/Modafinil	1%	-	6%	1%	-	4%
Aging	1%	-	-	-	7%	-
No response	34%	46%	29%	31%	50%	21%

NOTE: Grouped accordingly from written responses provided; if response indicated an affiliated site, it was grouped as such; responses that referred to a specific intervention without a site affiliation were grouped by intervention

**TABLE S-33:** Would you attend a support group meeting if one was available in your area?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Not likely	45%	45%	61%	39%	36%	53%
Yes, if one was available	48%	52%	33%	49%	58%	43%
I already attend my local support group	6%	1%	5%	9%	5%	2%
No response	2%	1%	1%	2%	1%	1%

## Section 6: Your Symptoms

### MUSCLE Symptoms

**TABLE S-34a:** Rate how much MYOTONIA (DIFFICULTY RELAXING MUSCLE) impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	17%	13%	20%	17%	16%	19%
Have Symptom with MODERATE Impact	31%	28%	29%	33%	30%	31%
Have Symptom with MINOR Impact	24%	14%	21%	28%	24%	22%
Have Symptom but NO Impact	10%	14%	10%	9%	12%	9%
Do Not Experience Symptom	17%	31%	20%	12%	19%	18%
No response	<1%	-	-	-	1%	1%

**TABLE S-34b:** Rate how much MUSCLE WEAKNESS impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	47%	52%	45%	41%	52%	50%
Have Symptom with MODERATE Impact	32%	30%	36%	34%	29%	31%
Have Symptom with MINOR Impact	12%	10%	14%	14%	12%	12%
Have Symptom but NO Impact	4%	3%	3%	6%	1%	2%
Do Not Experience Symptom	3%	1%	1%	4%	4%	2%
No response	2%	4%	1%	2%	2%	3%

**TABLE S-34c:** Rate how much MUSCLE ACHES, CRAMPS impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	22%	6%	19%	22%	20%	27%
Have Symptom with MODERATE Impact	28%	25%	24%	25%	33%	29%
Have Symptom with MINOR Impact	21%	23%	21%	22%	24%	17%
Have Symptom but NO Impact	9%	10%	13%	9%	6%	8%
Do Not Experience Symptom	18%	32%	20%	20%	15%	14%
No response	3%	4%	2%	1%	3%	5%

**TABLE S-34d:** Rate how much MUSCLE PAIN impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	21%	8%	13%	19%	24%	26%
Have Symptom with MODERATE Impact	24%	14%	24%	26%	25%	24%
Have Symptom with MINOR Impact	20%	27%	20%	19%	24%	17%
Have Symptom but NO Impact	9%	4%	12%	9%	7%	10%
Do Not Experience Symptom	23%	37%	27%	26%	19%	17%
No response	4%	10%	4%	2%	2%	6%

## GASTROINTESTINAL Symptoms

**TABLE S-35a:** Rate how much DIFFICULTY SWALLOWING (DYSPHAGIA) impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	12%	20%	12%	11%	8%	14%
Have Symptom with MODERATE Impact	21%	10%	26%	22%	18%	20%
Have Symptom with MINOR Impact	23%	21%	23%	25%	21%	22%
Have Symptom but NO Impact	12%	11%	9%	15%	10%	10%
Do Not Experience Symptom	31%	37%	30%	26%	42%	30%
No response	2%	1%	1%	1%	2%	4%

**TABLE S-35b:** Rate how much DIARRHEA impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	12%	8%	14%	14%	10%	12%
Have Symptom with MODERATE Impact	16%	10%	15%	20%	11%	15%
Have Symptom with MINOR Impact	20%	18%	18%	21%	19%	21%
Have Symptom but NO Impact	10%	17%	9%	9%	10%	13%
Do Not Experience Symptom	38%	41%	37%	35%	48%	34%
No response	4%	6%	7%	2%	3%	5%

**TABLE S-35c:** Rate how much CONSTIPATION impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	13%	28%	16%	11%	13%	14%
Have Symptom with MODERATE Impact	19%	17%	12%	21%	20%	18%
Have Symptom with MINOR Impact	23%	15%	23%	25%	24%	22%
Have Symptom but NO Impact	12%	13%	7%	11%	11%	13%
Do Not Experience Symptom	33%	27%	41%	32%	33%	33%
No response	<1%	-	-	-	1%	1%

**TABLE S-35d:** Rate how much FREQUENT HICCUPS impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	5%	6%	7%	6%	2%	5%
Have Symptom with MODERATE Impact	10%	13%	10%	12%	6%	10%
Have Symptom with MINOR Impact	15%	23%	17%	17%	13%	13%
Have Symptom but NO Impact	18%	17%	12%	21%	13%	18%
Do Not Experience Symptom	49%	39%	51%	44%	63%	48%
No response	3%	3%	3%	1%	4%	7%

**TABLE S-35e:** Rate how much ABDOMINAL PAIN impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	11%	10%	15%	13%	5%	12%
Have Symptom with MODERATE Impact	15%	8%	9%	18%	12%	16%
Have Symptom with MINOR Impact	19%	25%	22%	20%	18%	18%
Have Symptom but NO Impact	14%	17%	13%	13%	14%	14%
Do Not Experience Symptom	38%	34%	38%	34%	49%	35%
No response	4%	6%	3%	2%	4%	5%

**CARDIORESPIRATORY Symptoms****TABLE S-36a:** Rate how much ABNORMAL HEART RHYTHM impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	11%	4%	10%	13%	12%	10%
Have Symptom with MODERATE Impact	9%	7%	5%	9%	10%	9%
Have Symptom with MINOR Impact	13%	15%	13%	9%	16%	15%
Have Symptom but NO Impact	16%	18%	15%	19%	16%	13%
Do Not Experience Symptom	48%	52%	54%	47%	43%	48%
No response	3%	3%	3%	2%	5%	5%

**TABLE S-36b:** Rate how much RECURRENT LUNG INFECTIONS/PNEUMONIA impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	5%	13%	4%	4%	7%	5%
Have Symptom with MODERATE Impact	7%	15%	10%	6%	4%	7%
Have Symptom with MINOR Impact	8%	10%	4%	8%	10%	7%
Have Symptom but NO Impact	7%	10%	2%	8%	6%	8%
Do Not Experience Symptom	70%	51%	76%	73%	68%	69%
No response	3%	1%	4%	2%	6%	5%

**TABLE S-36c:** Rate how much SHORTNESS OF BREATH impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	8%	4%	6%	6%	9%	12%
Have Symptom with MODERATE Impact	13%	10%	4%	13%	18%	13%
Have Symptom with MINOR Impact	16%	6%	15%	16%	14%	19%
Have Symptom but NO Impact	15%	7%	12%	17%	14%	15%
Do Not Experience Symptom	46%	70%	60%	46%	43%	38%
No response	3%	3%	3%	2%	4%	4%

**TABLE S-36d:** Rate how much DIZZINESS/FAINTING impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	5%	1%	4%	4%	5%	7%
Have Symptom with MODERATE Impact	7%	3%	6%	7%	8%	8%
Have Symptom with MINOR Impact	13%	-	7%	14%	18%	14%
Have Symptom but NO Impact	14%	3%	10%	20%	10%	14%
Do Not Experience Symptom	57%	90%	69%	53%	55%	53%
No response	3%	3%	3%	2%	5%	5%

**SLEEP and FATIGUE Symptoms****TABLE S-37a:** Rate how much DAYTIME SLEEPINESS impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	31%	11%	24%	41%	21%	30%
Have Symptom with MODERATE Impact	25%	18%	21%	25%	26%	27%
Have Symptom with MINOR Impact	21%	27%	30%	17%	28%	18%
Have Symptom but NO Impact	10%	15%	11%	10%	10%	10%
Do Not Experience Symptom	12%	27%	13%	6%	16%	13%
No response	1%	1%	1%	1%	2%	2%

**TABLE S-37b:** Rate how much FATIGUE impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	34%	20%	28%	39%	30%	35%
Have Symptom with MODERATE Impact	29%	24%	22%	32%	33%	25%
Have Symptom with MINOR Impact	18%	27%	20%	14%	22%	17%
Have Symptom but NO Impact	9%	13%	12%	7%	8%	11%
Do Not Experience Symptom	9%	15%	17%	7%	7%	10%
No response	1%	1%	1%	1%	2%	2%

**TABLE S-37c:** Rate how much DIFFICULTY FALLING ASLEEP impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	15%	4%	9%	16%	19%	16%
Have Symptom with MODERATE Impact	15%	11%	16%	15%	22%	13%
Have Symptom with MINOR Impact	15%	7%	10%	18%	17%	15%
Have Symptom but NO Impact	10%	7%	9%	10%	10%	11%
Do Not Experience Symptom	42%	70%	55%	40%	32%	43%
No response	2%	-	2%	2%	1%	2%

**TABLE S-37d:** Rate how much TROUBLE BREATHING DURING SLEEP (APNEA) impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	17%	17%	12%	18%	16%	17%
Have Symptom with MODERATE Impact	11%	11%	10%	11%	9%	12%
Have Symptom with MINOR Impact	10%	8%	14%	10%	10%	12%
Have Symptom but NO Impact	9%	7%	6%	12%	5%	8%
Do Not Experience Symptom	51%	56%	56%	47%	60%	47%
No response	2%	-	2%	2%	1%	4%

**PSYCHOLOGICAL Symptoms****TABLE S-38a:** Rate how much LEARNING DIFFICULTIES/CHALLENGES impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	15%	59%	29%	11%	7%	11%
Have Symptom with MODERATE Impact	13%	25%	16%	10%	14%	15%
Have Symptom with MINOR Impact	14%	8%	13%	15%	17%	13%
Have Symptom but NO Impact	9%	1%	6%	11%	5%	12%
Do Not Experience Symptom	46%	4%	35%	53%	54%	45%
No response	2%	1%	1%	1%	4%	5%

**TABLE S-38b:** Rate how much DIFFICULTY CONCENTRATING impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	11%	39%	18%	8%	10%	9%
Have Symptom with MODERATE Impact	18%	25%	24%	17%	18%	15%
Have Symptom with MINOR Impact	21%	17%	17%	24%	25%	19%
Have Symptom but NO Impact	12%	3%	7%	14%	11%	13%
Do Not Experience Symptom	35%	13%	32%	35%	34%	39%
No response	3%	3%	1%	2%	2%	5%

**TABLE S-38c:** Rate how much DEPRESSION impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	11%	3%	10%	11%	12%	14%
Have Symptom with MODERATE Impact	14%	3%	7%	16%	16%	12%
Have Symptom with MINOR Impact	19%	13%	12%	22%	19%	19%
Have Symptom but NO Impact	12%	7%	13%	10%	13%	14%
Do Not Experience Symptom	44%	75%	59%	40%	39%	41%
No response	<1%	-	-	-	1%	-

**TABLE S-38d:** Rate how much ANXIETY impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	12%	13%	11%	12%	10%	14%
Have Symptom with MODERATE Impact	16%	14%	14%	18%	18%	14%
Have Symptom with MINOR Impact	19%	20%	22%	21%	20%	17%
Have Symptom but NO Impact	13%	8%	13%	12%	16%	14%
Do Not Experience Symptom	37%	42%	37%	36%	35%	38%
No response	3%	3%	3%	1%	3%	4%

**HORMONAL and ENDOCRINE Symptoms****TABLE S-39a:** Rate how much DIABETES impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	5%	-	5%	3%	8%	5%
Have Symptom with MODERATE Impact	3%	-	2%	1%	8%	5%
Have Symptom with MINOR Impact	3%	-	4%	3%	5%	4%
Have Symptom but NO Impact	3%	1%	1%	2%	6%	2%
Do Not Experience Symptom	84%	99%	87%	90%	71%	81%
No response	2%	-	-	1%	3%	3%

**TABLE S-39b:** Rate how much SEXUAL/INTIMACY PROBLEMS impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	11%	3%	4%	10%	15%	13%
Have Symptom with MODERATE Impact	8%	-	3%	9%	11%	7%
Have Symptom with MINOR Impact	8%	-	5%	9%	10%	7%
Have Symptom but NO Impact	5%	-	9%	5%	7%	5%
Do Not Experience Symptom	66%	94%	74%	67%	52%	63%
No response	3%	3%	4%	1%	5%	5%

**TABLE S-39c:** Rate how much FERTILITY PROBLEMS impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	10%	1%	9%	11%	11%	10%
Have Symptom with MODERATE Impact	2%	1%	-	2%	1%	2%
Have Symptom with MINOR Impact	2%	-	-	2%	4%	2%
Have Symptom but NO Impact	2%	-	1%	3%	4%	2%
Do Not Experience Symptom	77%	90%	85%	77%	74%	73%
No response	7%	7%	5%	5%	8%	9%

**TABLE S-39d:** Rate how much BALDING/THINNING HAIR impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	19%	7%	12%	20%	16%	24%
Have Symptom with MODERATE Impact	13%	4%	11%	14%	12%	14%
Have Symptom with MINOR Impact	10%	4%	13%	9%	12%	11%
Have Symptom but NO Impact	10%	6%	15%	12%	11%	8%
Do Not Experience Symptom	46%	77%	49%	45%	45%	40%
No response	2%	1%	1%	1%	4%	3%

**OTHER Symptoms****TABLE S-40a:** Rate how much HEADACHES, MIGRAINES impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	5%	1%	3%	5%	4%	8%
Have Symptom with MODERATE Impact	9%	3%	10%	10%	12%	9%
Have Symptom with MINOR Impact	14%	3%	7%	14%	16%	16%
Have Symptom but NO Impact	15%	13%	12%	16%	15%	14%
Do Not Experience Symptom	53%	77%	66%	53%	50%	47%
No response	3%	3%	2%	1%	4%	6%

**TABLE S-40b:** Rate how much DROOPING EYELIDS (PTOSIS) impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	17%	11%	16%	16%	13%	21%
Have Symptom with MODERATE Impact	14%	6%	13%	15%	12%	19%
Have Symptom with MINOR Impact	16%	14%	15%	17%	16%	15%
Have Symptom but NO Impact	15%	17%	16%	18%	14%	13%
Do Not Experience Symptom	35%	51%	40%	32%	44%	28%
No response	2%	1%	-	2%	3%	4%

**TABLE S-40c:** Rate how much HEARING LOSS impacts your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	9%	3%	9%	6%	14%	11%
Have Symptom with MODERATE Impact	11%	-	10%	8%	21%	12%
Have Symptom with MINOR Impact	12%	10%	5%	13%	13%	10%
Have Symptom but NO Impact	<1%	1%	-	<1%	1%	-
Do Not Experience Symptom	66%	83%	77%	71%	49%	63%
No response	2%	3%	-	1%	3%	4%

**TABLE S-40d:** Rate how much BALANCE ISSUES impact your daily life:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Have Symptom with MAJOR Impact	36%	30%	44%	32%	35%	43%
Have Symptom with MODERATE Impact	19%	18%	15%	18%	23%	19%
Have Symptom with MINOR Impact	19%	17%	16%	20%	20%	17%
Have Symptom but NO Impact	8%	10%	6%	9%	9%	7%
Do Not Experience Symptom	16%	20%	19%	20%	10%	12%
No response	2%	6%	-	2%	3%	2%

**TABLE S-41:** Of all the problems/symptoms you experience, which ones IMPACT YOUR LIFE THE MOST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Muscle symptoms	44%	34%	41%	49%	52%	38%
Sleep and fatigue symptoms	34%	24%	22%	43%	36%	25%
Other physical problems/symptoms (including balance issues)	32%	17%	30%	29%	33%	40%
Psychological symptoms	21%	46%	33%	21%	15%	17%
Gastrointestinal symptoms	19%	27%	19%	25%	11%	17%
Cardiorespiratory symptoms	10%	11%	5%	10%	10%	11%
Biological, hormonal, endocrine symptoms	6%	-	6%	6%	9%	5%
No response	10%	4%	14%	9%	8%	12%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because multiple responses were permitted (up to three)

## Section 7: Your Healthcare Related Experience

**TABLE S-42a:** Since your diagnosis, how OFTEN do you see or have you seen a GENERAL PRACTITIONER/FAMILY DOCTOR?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	68%	90%	72%	68%	73%	60%
INFREQUENTLY (every two to five years)	12%	8%	15%	14%	7%	12%
Only ONCE with planned follow- up	6%	1%	5%	5%	5%	8%
Only ONCE with NO planned follow- up	8%	-	2%	8%	7%	11%
Never	6%	-	5%	5%	8%	10%
No response	<1%	-	-	-	1%	-

**TABLE S-42b:** Since your diagnosis, how OFTEN do you see or have you seen a NEUROLOGIST/NEUROMUSCULAR SPECIALIST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	49%	63%	49%	54%	54%	35%
INFREQUENTLY (every two to five years)	17%	21%	16%	18%	16%	15%
Only ONCE with planned follow- up	9%	7%	9%	8%	13%	8%
Only ONCE with NO planned follow- up	11%	4%	14%	9%	11%	17%
Never	12%	4%	11%	9%	7%	20%
No response	2%	-	2%	1%	1%	5%

**TABLE S-42c:** Since your diagnosis, how OFTEN do you see or have you seen a CARDIOLOGIST (HEART DOCTOR)?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	44%	54%	40%	50%	45%	35%
INFREQUENTLY (every two to five years)	15%	23%	18%	16%	14%	13%
Only ONCE with planned follow- up	8%	6%	11%	6%	9%	10%
Only ONCE with NO planned follow- up	12%	8%	10%	10%	14%	15%
Never	18%	8%	19%	15%	17%	24%
No response	3%	1%	2%	2%	3%	3%

**TABLE S-42d:** Since your diagnosis, how OFTEN do you see or have you seen a GASTROENTEROLOGIST (STOMACH DOCTOR)?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	11%	18%	13%	11%	7%	10%
INFREQUENTLY (every two to five years)	12%	15%	7%	13%	15%	10%
Only ONCE with planned follow- up	6%	6%	5%	6%	8%	6%
Only ONCE with NO planned follow- up	12%	13%	17%	12%	10%	14%
Never	55%	46%	50%	56%	55%	54%
No response	4%	1%	7%	2%	7%	5%

**TABLE S-42e:** Since your diagnosis, how OFTEN do you see or have you seen a PULMONOLOGIST (BREATHING SPECIALIST)?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	18%	38%	12%	19%	15%	17%
INFREQUENTLY (every two to five years)	7%	8%	10%	7%	9%	6%
Only ONCE with planned follow- up	7%	4%	2%	6%	8%	9%
Only ONCE with NO planned follow- up	12%	6%	13%	14%	14%	10%
Never	51%	42%	57%	49%	53%	52%
No response	4%	1%	6%	3%	3%	6%

**TABLE S-42f:** Since your diagnosis, how OFTEN do you see or have you seen an OPHTHALMOLOGIST (EYE DOCTOR)?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	47%	61%	47%	50%	49%	42%
INFREQUENTLY (every two to five years)	24%	15%	30%	26%	23%	25%
Only ONCE with planned follow- up	9%	7%	10%	9%	10%	8%
Only ONCE with NO planned follow- up	7%	8%	3%	6%	6%	9%
Never	10%	8%	9%	8%	10%	12%
No response	3%	-	2%	2%	4%	5%

**TABLE S-42g:** Since your diagnosis, how OFTEN do you see or have you seen a GENETIC COUNSELOR?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	2%	6%	2%	2%	2%	2%
INFREQUENTLY (every two to five years)	2%	4%	5%	1%	2%	1%
Only ONCE with planned follow- up	2%	3%	1%	3%	2%	1%
Only ONCE with NO planned follow- up	22%	27%	18%	29%	24%	11%
Never	72%	61%	72%	65%	71%	85%
No response	<1%	-	1%	<1%	-	-

**TABLE S-42h:** Since your diagnosis, how OFTEN do you see or have you seen a PSYCHIATRIST/PSYCHOTHERAPIST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	8%	6%	5%	10%	6%	7%
INFREQUENTLY (every two to five years)	3%	3%	3%	5%	4%	2%
Only ONCE with planned follow- up	2%	-	5%	1%	3%	3%
Only ONCE with NO planned follow- up	7%	4%	13%	7%	8%	5%
Never	76%	83%	68%	73%	78%	77%
No response	4%	4%	5%	3%	3%	7%

**TABLE S-42i:** Since your diagnosis, how OFTEN do you see or have you seen a NURSE/NURSE CASE MANAGER?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	10%	34%	11%	8%	9%	8%
INFREQUENTLY (every two to five years)	3%	3%	6%	3%	2%	3%
Only ONCE with planned follow- up	2%	1%	1%	1%	1%	3%
Only ONCE with NO planned follow- up	5%	3%	6%	5%	5%	6%
Never	76%	56%	68%	80%	80%	74%
No response	4%	3%	7%	3%	3%	6%

**TABLE S-42j:** Since your diagnosis, how OFTEN do you see or have you seen a PHYSICAL THERAPIST/PHYSIOTHERAPIST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	18%	62%	27%	14%	18%	11%
INFREQUENTLY (every two to five years)	9%	10%	9%	9%	12%	8%
Only ONCE with planned follow- up	7%	3%	10%	6%	9%	8%
Only ONCE with NO planned follow- up	12%	1%	12%	15%	14%	11%
Never	50%	24%	38%	52%	46%	56%
No response	4%	-	5%	3%	4%	5%

**TABLE S-42k:** Since your diagnosis, how OFTEN do you see or have you seen a SPEECH/SWALLOWING SPECIALIST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	9%	48%	19%	6%	4%	7%
INFREQUENTLY (every two to five years)	4%	7%	5%	4%	4%	4%
Only ONCE with planned follow- up	5%	8%	3%	5%	5%	5%
Only ONCE with NO planned follow- up	16%	8%	17%	19%	8%	16%
Never	62%	20%	49%	63%	80%	63%
No response	4%	8%	6%	3%	2%	5%

**TABLE S-42l:** Since your diagnosis, how OFTEN do you see or have you seen a SLEEP SPECIALIST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	8%	13%	3%	12%	6%	5%
INFREQUENTLY (every two to five years)	7%	11%	9%	9%	4%	6%
Only ONCE with planned follow- up	8%	6%	10%	9%	9%	8%
Only ONCE with NO planned follow- up	12%	7%	11%	14%	13%	11%
Never	60%	61%	62%	54%	67%	64%
No response	4%	3%	6%	3%	3%	5%

**TABLE S-42m:** Since your diagnosis, how OFTEN do you see or have you seen an OCCUPATIONAL THERAPIST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	11%	59%	17%	8%	5%	6%
INFREQUENTLY (every two to five years)	6%	7%	10%	5%	8%	5%
Only ONCE with planned follow- up	3%	4%	5%	2%	1%	5%
Only ONCE with NO planned follow- up	9%	4%	4%	11%	9%	10%
Never	67%	21%	54%	71%	74%	68%
No response	5%	4%	10%	3%	3%	6%

**TABLE S-42n:** Since your diagnosis, how OFTEN do you see or have you seen a NUTRITIONIST/DIETICIAN?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	5%	20%	6%	4%	4%	4%
INFREQUENTLY (every two to five years)	3%	6%	1%	3%	5%	2%
Only ONCE with planned follow- up	3%	6%	2%	4%	2%	2%
Only ONCE with NO planned follow- up	10%	8%	14%	9%	13%	10%
Never	75%	58%	72%	77%	76%	76%
No response	4%	3%	4%	3%	2%	5%

**TABLE S-42o:** Since your diagnosis, how OFTEN do you see or have you seen a SOCIAL WORKER?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	8%	25%	11%	7%	4%	8%
INFREQUENTLY (every two to five years)	4%	4%	7%	3%	3%	5%
Only ONCE with planned follow- up	2%	3%	5%	1%	1%	3%
Only ONCE with NO planned follow- up	8%	11%	5%	9%	8%	6%
Never	74%	54%	67%	77%	81%	72%
No response	4%	3%	4%	3%	5%	5%

**TABLE S-42p:** Since your diagnosis, how OFTEN do you see or have you seen a PSYCHOLOGIST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
FREQUENTLY (once a year or more)	6%	7%	2%	7%	5%	5%
INFREQUENTLY (every two to five years)	3%	1%	2%	4%	4%	2%
Only ONCE with planned follow- up	1%	1%	3%	1%	2%	1%
Only ONCE with NO planned follow- up	5%	6%	11%	5%	4%	4%
Never	80%	79%	76%	79%	80%	83%
No response	5%	6%	6%	3%	5%	6%

**TABLE S-43:** Of all of the healthcare providers above, which ones HELP YOU THE MOST in managing your disease?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Neurologist/neuromuscular specialist	48%	42%	43%	56%	59%	32%
General practitioner/family doctor	28%	23%	34%	25%	31%	30%
Cardiologist (heart doctor)	22%	15%	12%	30%	18%	16%
Physical therapist/physiotherapist	9%	24%	14%	7%	7%	7%
Pulmonologist (breathing specialist)	8%	21%	3%	7%	8%	8%
Ophthalmologist (eye doctor)	8%	7%	10%	9%	6%	9%
Gastroenterologist (stomach doctor)	4%	4%	9%	4%	3%	4%
Occupational therapist	4%	15%	9%	3%	2%	2%
Psychiatrist/psychotherapist	3%	4%	6%	3%	3%	1%
Speech/swallowing specialist	3%	10%	11%	3%	2%	2%
Sleep specialist	3%	1%	3%	6%	1%	2%
Psychologist	2%	1%	-	4%	3%	1%
Genetic counselor	1%	1%	4%	1%	-	1%
Nurse/nurse case manager	1%	4%	2%	-	-	2%
Nutritionist/dietician	1%	-	1%	1%	1%	<1%
Social Worker	1%	3%	1%	2%	-	1%
Other	8%	20%	17%	5%	18%	6%
No response	24%	17%	16%	20%	20%	34%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because up to three responses were permitted

**TABLE S-44:** How satisfied are you with the OVERALL medical care you receive?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Satisfied	17%	30%	15%	18%	14%	15%
Satisfied	41%	52%	50%	44%	39%	35%
Neutral	30%	14%	28%	29%	32%	32%
Dissatisfied	7%	3%	6%	6%	9%	10%
Very Dissatisfied	3%	1%	-	2%	5%	6%
No response	2%	-	1%	1%	3%	3%

**TABLE S-45:** How much do you know about the general anesthesia risks associated with myotonic dystrophy?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Not aware of the specific risks	25%	18%	20%	15%	28%	38%
Aware but have NOT discussed with medical professional	24%	14%	30%	27%	26%	20%
Aware and have discussed with medical professional	49%	65%	47%	57%	45%	39%
No response	2%	3%	3%	1%	2%	2%

**TABLE S-46:** How much do you know about the cardiac complications associated with myotonic dystrophy?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Not aware of the complications	18%	23%	22%	11%	16%	28%
Aware but have NOT discussed with medical professional	24%	20%	20%	22%	23%	28%
Aware and have discussed with medical professional	56%	55%	54%	66%	60%	42%
No response	2%	3%	3%	1%	1%	2%

**TABLE S-47:** Have you ever had your heart tested? (e.g., electrocardiogram (ECG, EKG), echocardiogram, cardiac MRI, etc.)

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	94%	90%	91%	96%	96%	90%
No	4%	7%	9%	3%	3%	5%
Unknown	1%	3%	-	<1%	1%	3%
No response	1%	-	-	1%	-	2%

**TABLE S-48:** Have you ever been diagnosed with an abnormal heartbeat/heart conduction problem?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	43%	42%	38%	44%	46%	42%
No	50%	56%	56%	50%	48%	47%
Unknown	6%	1%	5%	4%	6%	9%
No response	1%	-	-	1%	1%	2%

## Section 8: Treatments and Interventions

**TABLE S-49a:** Do you take medication for myotonia (difficulty relaxing muscles)?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	17%	1%	17%	14%	26%	18%
No	82%	97%	82%	84%	74%	79%
Unknown	1%	1%	1%	<1%	1%	2%
No response	1%	-	-	2%	1%	1%

**TABLE S-49b:** If YES, which medication(s) do you take for myotonia?

	Overall (n=196)	cDM1-71 (n=1)	cDM1-94 (n=16)	DM1 (n=64)	DM2 (n=51)	U/U (n=60)
1. Mexiletine	19%	-	44%	36%	12%	2%
2. Gabapentin	9%	-	-	11%	14%	5%
3. Baclofen	7%	-	-	8%	12%	3%
3. Cyclobenzaprine	7%	-	6%	8%	6%	8%
5. Phenytoin	6%	-	6%	5%	-	10%

NOTE: a total of 35 medications were reported; only the top five are presented in rank order above

**TABLE S-49c:** If you take medication for myotonia, how satisfied are you with its effect?

	Overall (n=196)	cDM1-71 (n=1)	cDM1-94 (n=16)	DM1 (n=64)	DM2 (n=51)	U/U (n=60)
Extremely satisfied	5%	-	6%	6%	2%	3%
Very satisfied	16%	100%*	13%	20%	16%	13%
Moderately satisfied	32%	-	31%	33%	35%	27%
Slightly satisfied	20%	-	19%	17%	22%	23%
Not at all satisfied	10%	-	6%	9%	10%	12%
No response	17%	-	25%	14%	16%	22%

\* based on answer from only one respondent

**TABLE S-50a:** Do you take medication for daytime sleepiness and/or fatigue?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	17%	1%	20%	27%	10%	10%
No	82%	99%	80%	72%	90%	88%
Unknown	<1%	-	-	<1%	1%	-
No response	1%	-	-	1%	-	2%

**TABLE S-50b:** If YES, which medication(s) do you take for daytime sleepiness and/or fatigue?

	Overall (n=199)	cDM1-71 (n=1)	cDM1-94 (n=19)	DM1 (n=122)	DM2 (n=19)	U/U (n=34)
1. Modafinil	42%	-	47%	48%	16%	41%
2. Methylphenidate	18%	100%*	32%	18%	21%	9%
3. Adderall	9%	-	-	12%	11%	3%

\* based on answer from only one respondent

NOTE: a total of 20 medications were reported; only the top three are presented in rank order above

**TABLE S-50c:** If you take medication for daytime sleepiness and/or fatigue, how satisfied are you with its effect?

	Overall (n=199)	cDM1-71 (n=1)	cDM1-94 (n=19)	DM1 (n=122)	DM2 (n=19)	U/U (n=34)
Extremely satisfied	7%	-	11%	7%	5%	6%
Very satisfied	29%	-	47%	34%	5%	15%
Moderately satisfied	28%	100%*	37%	25%	21%	35%
Slightly satisfied	10%	-	-	10%	11%	15%
Not at all satisfied	7%	-	-	6%	21%	6%
No response	20%	-	5%	18%	37%	24%

\* based on answer from only one respondent

**TABLE S-51a:** Do you take medication for gastrointestinal problems associated with myotonic dystrophy?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	24%	34%	34%	28%	21%	18%
No	71%	65%	63%	68%	76%	75%
Unknown	2%	1%	2%	2%	2%	5%
No response	2%	-	1%	3%	2%	3%

**TABLE S-51b:** If YES, which medication(s) do you take for gastrointestinal problems?

	Overall (n=288)	cDM1-71 (n=24)	cDM1-94 (n=32)	DM1 (n=128)	DM2 (n=41)	U/U (n=58)
1. Polyethylene glycol	14%	46%	9%	13%	15%	9%
2. Omeprazole	11%	8%	-	13%	15%	12%
3. Loperamide	8%	-	-	13%	2%	7%
4. Esomeprazole	6%	-	3%	9%	5%	7%
5. Ranitidine	5%	4%	3%	6%	2%	2%

NOTE: a total of 51 medications were reported; only the top five are presented in rank order above

**TABLE S-51c:** If you take medication for gastrointestinal problems, how satisfied are you with its effect?

	Overall (n=288)	cDM1-71 (n=24)	cDM1-94 (n=32)	DM1 (n=128)	DM2 (n=41)	U/U (n=58)
Extremely satisfied	6%	4%	16%	5%	5%	7%
Very satisfied	31%	33%	28%	31%	39%	24%
Moderately satisfied	38%	38%	34%	41%	27%	43%
Slightly satisfied	12%	8%	9%	15%	15%	9%
Not at all satisfied	2%	4%	-	2%	2%	3%
No response	10%	13%	13%	7%	12%	14%

**TABLE S-52:** Compiled listing of ALL medications reported, presented by drug class

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
<b>ANTICONVULSANTS</b>						
Gabapentin	2%	-	1%	2%	6%	3%
Phenytoin	1%	-	1%	1%	-	3%
Topiramate	<1%	-	1%	<1%	1%	1%
Other (includes 3 various anticonvulsant meds)	1%	-	1%	<1%	2%	-
<b>CARDIAC MEDS</b>						
Metoprolol	1%	-	2%	1%	-	2%
Carvedilol	1%	-	-	1%	-	1%
Lisinopril	1%	-	1%	1%	1%	1%
Other (includes 23 various cardiac meds)	3%	-	4%	3%	7%	5%
<b>CNS/ PSYCHO MEDS</b>						
Modafinil	8%	-	12%	13%	3%	9%
Methylphenidate	4%	4%	6%	5%	3%	2%
Adderall	2%	-	-	4%	1%	1%
Other (includes 22 other CNS/cognition meds)	7%	1%	5%	11%	9%	5%
<b>GI MEDS</b>						
Polyethylene glycol	4%	15%	5%	4%	4%	4%
Omeprazole	3%	3%	2%	5%	4%	4%
Loperamide	2%	-	-	4%	1%	4%
Other (includes 35 various GI meds)	14%	14%	20%	18%	11%	13%
<b>MUSCLE RELAXANTS</b>						
Mexiletine	3%	-	9%	5%	3%	1%
Cyclobenzaprine	2%	-	2%	2%	2%	3%
Baclofen	1%	-	-	1%	4%	1%
Other (includes 9 various muscle relaxants)	3%	-	3%	2%	9%	3%
<b>PAIN MEDS</b>						
Ibuprofen	2%	-	1%	3%	2%	6%
Acetaminophen	2%	-	3%	2%	2%	4%
Oxycodone	2%	-	1%	2%	3%	3%
Other (includes 12 other non-opioid and opioid pain meds)	7%	-	5%	7%	11%	7%
<b>DIET AND LIFESTYLE</b>						
Diet/food choice	6%	4%	5%	8%	8%	6%
Vitamins and minerals	5%	4%	5%	6%	5%	7%
Fibre supplements	2%	1%	2%	3%	3%	2%
Other (includes 5 various supplement/ lifestyle choices)	3%	7%	-	4%	4%	4%
<b>OTHER MEDS</b>						
Levothyroxine	1%	-	4%	2%	2%	2%
Melatonin	1%	4%	2%	<1%	1%	1%
Testosterone	1%	-	-	1%	1%	1%
Other (includes 11 various 'other' types of medication)	2%	-	4%	2%	3%	2%

**TABLE S-53:** List and other MEDICATIONS, HOMEOPATHIC REMEDIES, OR NATURAL PRODUCTS that have been helpful:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Diet	6%	4%	5%	7%	7%	3%
Vitamins and minerals	5%	4%	5%	6%	5%	4%
Acetaminophen	2%	-	2%	2%	1%	2%
Ibuprofen	2%	-	-	2%	1%	3%
ASA	1%	-	3%	2%	1%	<1%

NOTE: a total of 104 medications were reported; only the top five are presented in rank order above

**TABLE S-54a:** Has your doctor ever recommended that you receive a pacemaker or a defibrillator for your heart?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes, a pacemaker	11%	1%	13%	12%	7%	15%
Yes, a defibrillator	2%	-	1%	2%	4%	2%
Yes, both	4%	-	2%	6%	5%	3%
No, neither	79%	94%	83%	78%	80%	77%
Unknown	1%	3%	1%	1%	1%	2%
No response	2%	1%	-	2%	3%	2%

**TABLE S-54b:** If YES, did you go ahead with it?

	Overall (n=206)	cDM1-71 (n=1)	cDM1-94 (n=15)	DM1 (n=89)	DM2 (n=32)	U/U (n=63)
Yes	72%	100%*	67%	75%	78%	65%
No	22%	-	27%	19%	13%	30%
No response	6%	-	7%	6%	9%	5%

\* based on answer from only one respondent

**TABLE S-54c:** If a pacemaker/defibrillator was recommended but you DID NOT go ahead with it, please tell us why:

	Overall (n=57)	cDM1-71 (n=0)	cDM1-94 (n=5)	DM1 (n=22)	DM2 (n=7)	U/U (n=22)
Timing/not yet	49%	-	80%	50%	43%	41%
Medical concern/advice	12%	-	20%	18%	-	9%
Cost	5%	-	-	5%	-	9%
Other	16%	-	-	9%	29%	23%
No response	18%	-	-	18%	29%	18%

**TABLE S-55a:** Has your doctor ever recommended that you use a device to help you breathe at night (e.g., CPAP or BiPAP)?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	33%	35%	27%	36%	30%	33%
No	62%	63%	68%	59%	66%	61%
Unknown	1%	-	-	1%	1%	1%
No response	4%	1%	5%	3%	4%	5%

**TABLE S-55b:** If YES, do you use a device to help you breathe at night (e.g., CPAP or BiPAP)?

	Overall (n=392)	cDM1-71 (n=25)	cDM1-94 (n=25)	DM1 (n=165)	DM2 (n=59)	U/U (n=110)
Yes	43%	60%	32%	44%	41%	41%
No	33%	20%	48%	32%	29%	36%
No response	24%	20%	20%	24%	31%	23%

**TABLE S-55c:** If you do use a device to help you breath at night (e.g., CPAP or BiPAP), how satisfied are you with its effect?

	Overall (n=225)	cDM1-71 (n=10)	cDM1-94 (n=17)	DM1 (n=93)	DM2 (n=35)	U/U (n=65)
Extremely Satisfied	2%	-	-	-	6%	5%
Very Satisfied	10%	20%	6%	13%	9%	8%
Moderately Satisfied	9%	-	18%	5%	17%	9%
Slightly Satisfied	6%	-	6%	6%	9%	5%
Not at all Satisfied	20%	30%	24%	24%	17%	17%
No response	52%	50%	47%	53%	43%	57%

**TABLE S-55d:** If a breathing device was recommended (e.g., CPAP or BiPAP) and you DO NOT use it, please tell us why:

	Overall (n=225)	cDM1-71 (n=10)	cDM1-94 (n=17)	DM1 (n=93)	DM2 (n=35)	U/U (n=65)
Tolerance	52%	50%	53%	56%	49%	49%
Awaiting sleep study results/not yet	4%	-	12%	3%	3%	3%
No benefit/no need	4%	-	6%	5%	-	5%
Side effects/adverse effects	4%	-	6%	4%	6%	3%
Financial/insurance/affordability	3%	-	-	1%	3%	8%
Use alternative (O2)	1%	10%	-	-	-	3%
Other	2%	10%	-	2%	-	2%
No response	30%	30%	24%	28%	40%	28%

**TABLE S-56a:** Have you ever had cataracts?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	54%	8%	45%	56%	66%	56%
No	43%	87%	53%	42%	33%	39%
Unknown	2%	1%	2%	1%	1%	4%
No response	1%	3%	-	1%	1%	1%

**TABLE S-56b:** If YES, did you have surgery?

	Overall (n=640)	cDM1-71 (n=6)	cDM1-94 (n=42)	DM1 (n=255)	DM2 (n=131)	U/U (n=185)
Yes	66%	50%	57%	64%	69%	68%
No	21%	33%	19%	27%	13%	18%
No response	13%	17%	24%	9%	18%	14%

**TABLE S-56c:** If you had surgery, at what age?

	Overall (n=424)	cDM1-71 (n=3)	cDM1-94 (n=24)	DM1 (n=162)	DM2 (n=91)	U/U (n=125)
<18	1%	33%	-	1%	-	2%
18 thru 24	5%	67%	21%	4%	3%	2%
25 thru 34	12%	-	8%	15%	9%	10%
35 thru 44	25%	-	38%	28%	13%	28%
45 thru 54	31%	-	21%	31%	37%	29%
55 thru 64	16%	-	8%	12%	29%	15%
65+	5%	-	-	4%	8%	6%
No response	4%	-	4%	4%	1%	8%
<b>Average age of first cataract surgery (calculated mean)</b>	<b>44.4</b>	<b>14.7</b>	<b>37.5</b>	<b>43.3</b>	<b>49.6</b>	<b>45.0</b>

**TABLE S-57a:** How HELPFUL have LEG OR ANKLE BRACES been for you?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	15%	58%	23%	11%	6%	13%
Somewhat Helpful	11%	20%	15%	10%	10%	11%
Not at all Helpful	5%	4%	6%	5%	5%	5%
Never Used	62%	13%	46%	70%	70%	60%
No response	8%	6%	10%	4%	10%	11%

**TABLE S-57b:** How HELPFUL has a CANE, CRUTCHES, WALKER been for you?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	23%	34%	18%	18%	30%	25%
Somewhat Helpful	18%	10%	22%	16%	20%	19%
Not at all Helpful	2%	-	3%	2%	4%	3%
Never Used	50%	39%	50%	59%	39%	45%
No response	7%	17%	6%	5%	7%	8%

**TABLE S-57c:** How HELPFUL has a MANUAL WHEELCHAIR been for you?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	13%	30%	19%	11%	9%	14%
Somewhat Helpful	9%	7%	6%	10%	8%	9%
Not at all Helpful	3%	1%	1%	2%	5%	3%
Never Used	66%	42%	62%	73%	70%	61%
No response	9%	20%	12%	5%	9%	13%

**TABLE S-57d:** How HELPFUL has an ELECTRIC WHEELCHAIR been for you?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Very Helpful	12%	4%	13%	11%	11%	15%
Somewhat Helpful	3%	-	2%	4%	3%	2%
Not at all Helpful	1%	-	1%	1%	1%	1%
Never Used	74%	72%	70%	79%	75%	70%
No response	11%	24%	14%	5%	11%	13%

**TABLE S-58a:** How often you do follow your doctors' advice (i.e., follow-up on referrals, take prescribed medications)?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Always	54%	72%	56%	49%	59%	52%
Often	31%	25%	34%	37%	26%	25%
Sometimes	8%	-	5%	8%	7%	12%
Rarely	2%	-	2%	2%	2%	3%
Never	1%	1%	-	1%	1%	2%
No response	4%	1%	2%	2%	6%	5%

**TABLE S-58b:** If you do NOT consistently follow your doctors' advice, please tell us why:

	Overall (n=200)	cDM1-71 (n=4)	cDM1-94 (n=8)	DM1 (n=91)	DM2 (n=37)	U/U (n=54)
Lack of medical expertise/lack of advice given	16%	-	50%	7%	22%	22%
No need/no benefit/lack of effect	15%	-	-	18%	14%	13%
Side effects/adverse effects/tolerance (esp. CPAP/BiPAP n=7)	15%	25%	13%	13%	14%	19%
Patient attitude/behaviour	14%	-	25%	20%	8%	7%
Financial/insurance/affordability	10%	-	-	11%	16%	7%
Lack of agreement	8%	75%	-	8%	-	7%
Lifestyle/diet/exercise	6%	-	-	9%	5%	4%
Lack of transportation/limited mobility	4%	-	-	1%	8%	7%
Psychological/emotional/overwhelming	3%	-	-	4%	3%	2%
Other	10%	-	13%	10%	11%	11%

## Section 9: Managing Daily Life

### MOBILITY Activities

**TABLE S-59a:** Rate how much of a challenge WALKING OUTSIDE OR INSIDE is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	6%	14%	12%	4%	5%	7%
Major Challenge	24%	24%	20%	20%	25%	29%
Moderate Challenge	27%	23%	21%	27%	29%	27%
Minor Challenge	18%	20%	19%	19%	16%	18%
Not a Challenge	25%	18%	28%	30%	25%	19%
No response	<1%	1%	-	-	1%	<1%

**TABLE S-59b:** Rate how much of a challenge STANDING UP, SITTING DOWN, BENDING DOWN is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	5%	8%	9%	2%	6%	6%
Major Challenge	26%	18%	24%	21%	30%	31%
Moderate Challenge	25%	31%	20%	23%	30%	25%
Minor Challenge	21%	18%	17%	24%	18%	18%
Not a Challenge	22%	21%	27%	28%	14%	17%
No response	2%	3%	3%	2%	4%	2%

**TABLE S-59c:** Rate how much of a challenge GOING UP AND DOWN STAIRS is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	20%	20%	26%	12%	24%	28%
Major Challenge	31%	27%	22%	30%	38%	30%
Moderate Challenge	18%	24%	17%	19%	16%	16%
Minor Challenge	15%	17%	18%	18%	11%	12%
Not a Challenge	14%	11%	16%	19%	10%	12%
No response	2%	1%	1%	2%	2%	2%

**TABLE S-59d:** Rate how much of a challenge STANDING (FOR ANY LENGTH OF TIME) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	12%	11%	19%	9%	11%	17%
Major Challenge	31%	27%	24%	30%	37%	34%
Moderate Challenge	23%	23%	18%	22%	25%	23%
Minor Challenge	16%	17%	19%	19%	16%	12%
Not a Challenge	15%	18%	18%	18%	11%	12%
No response	2%	4%	1%	2%	2%	3%

**TABLE S-59e:** Rate how much of a challenge MAINTAINING YOUR BALANCE is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	10%	8%	15%	8%	8%	14%
Major Challenge	31%	35%	36%	26%	33%	34%
Moderate Challenge	21%	15%	16%	21%	25%	22%
Minor Challenge	19%	21%	12%	19%	23%	18%
Not a Challenge	17%	17%	19%	25%	10%	12%
No response	1%	3%	2%	1%	2%	1%

**TABLE S-59f:** Rate how much of a challenge DRIVING A CAR is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	23%	65%	40%	16%	15%	25%
Major Challenge	3%	-	3%	3%	4%	3%
Moderate Challenge	6%	-	3%	6%	5%	8%
Minor Challenge	12%	-	7%	12%	20%	12%
Not a Challenge	49%	14%	29%	59%	53%	47%
No response	7%	21%	17%	5%	4%	5%

**HOUSEHOLD and PERSONAL NEEDS Activities****TABLE S-60a:** Rate how much of a challenge PREPARING MEALS is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	11%	55%	15%	6%	5%	12%
Major Challenge	11%	11%	11%	12%	11%	11%
Moderate Challenge	15%	6%	20%	15%	17%	16%
Minor Challenge	22%	4%	14%	23%	27%	22%
Not a Challenge	41%	23%	40%	44%	42%	39%
No response	<1%	1%	-	-	-	-

**TABLE S-60b:** Rate how much of a challenge HOUSEKEEPING (CLEANING, LAUNDRY) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	16%	44%	16%	10%	12%	21%
Major Challenge	17%	15%	16%	16%	19%	18%
Moderate Challenge	20%	6%	20%	20%	26%	19%
Minor Challenge	20%	13%	20%	24%	18%	18%
Not a Challenge	24%	7%	20%	29%	23%	22%
No response	3%	15%	7%	1%	4%	2%

**TABLE S-60c:** Rate how much of a challenge HANDLING OBJECTS (OPENING JARS, TURNING KNOBS) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	14%	32%	18%	10%	8%	18%
Major Challenge	29%	23%	30%	33%	23%	29%
Moderate Challenge	23%	20%	27%	25%	24%	20%
Minor Challenge	20%	8%	14%	21%	26%	19%
Not a Challenge	13%	10%	10%	11%	19%	12%
No response	2%	7%	2%	1%	2%	2%

**TABLE S-60d:** Rate how much of a challenge USING CUTLERY AND KITCHEN UTENSILS is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	6%	25%	12%	4%	3%	6%
Major Challenge	10%	15%	11%	10%	8%	11%
Moderate Challenge	18%	21%	22%	19%	13%	18%
Minor Challenge	23%	17%	21%	22%	27%	23%
Not a Challenge	41%	17%	31%	44%	50%	41%
No response	2%	4%	3%	1%	2%	2%

**TABLE S-60e:** Rate how much of a challenge SWALLOWING, EATING, DRINKING is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	3%	8%	6%	2%	2%	4%
Major Challenge	10%	15%	9%	11%	6%	10%
Moderate Challenge	18%	10%	16%	20%	15%	20%
Minor Challenge	27%	24%	33%	31%	24%	25%
Not a Challenge	39%	37%	32%	35%	52%	39%
No response	2%	6%	4%	1%	2%	2%

**TABLE S-60f:** Rate how much of a challenge WASHING (SHOWERING, BATHING) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	7%	24%	12%	4%	5%	7%
Major Challenge	9%	18%	11%	6%	5%	13%
Moderate Challenge	16%	21%	17%	15%	14%	18%
Minor Challenge	21%	17%	27%	20%	28%	19%
Not a Challenge	46%	17%	33%	54%	48%	41%
No response	1%	3%	1%	1%	2%	2%

**TABLE S-60g:** Rate how much of a challenge DRESSING (DOING UP BUTTONS, ZIPPERS) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	8%	32%	15%	5%	4%	7%
Major Challenge	12%	23%	11%	9%	6%	15%
Moderate Challenge	16%	20%	21%	16%	12%	14%
Minor Challenge	22%	11%	26%	26%	22%	17%
Not a Challenge	42%	13%	26%	42%	56%	44%
No response	1%	1%	2%	1%	1%	2%

**COMMUNICATION Activities****TABLE S-61a:** Rate how much of a challenge SPEAKING (PRONOUNCING WORDS) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	2%	20%	1%	1%	1%	1%
Major Challenge	13%	32%	21%	10%	6%	15%
Moderate Challenge	21%	28%	28%	22%	14%	22%
Minor Challenge	27%	10%	21%	32%	24%	28%
Not a Challenge	36%	6%	29%	36%	54%	34%
No response	1%	4%	-	<1%	2%	1%

**TABLE S-61b:** Rate how much of a challenge WRITING (HOLDING A PEN) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	3%	20%	3%	1%	1%	2%
Major Challenge	14%	38%	20%	11%	9%	16%
Moderate Challenge	16%	20%	20%	16%	19%	14%
Minor Challenge	21%	8%	18%	25%	22%	19%
Not a Challenge	44%	11%	37%	47%	48%	46%
No response	2%	1%	1%	1%	3%	2%

**PSYCHOLOGICAL Activities****TABLE S-62a:** Rate how much of a challenge CONCENTRATING is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	1%	1%	2%	<1%	1%	1%
Major Challenge	12%	32%	20%	10%	10%	9%
Moderate Challenge	22%	34%	26%	19%	27%	19%
Minor Challenge	26%	14%	19%	31%	24%	27%
Not a Challenge	37%	14%	32%	37%	38%	42%
No response	2%	4%	1%	1%	2%	2%

**TABLE S-62b:** Rate how much of a challenge ALERTNESS (STAYING AWAKE) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	2%	1%	1%	2%	2%	2%
Major Challenge	18%	10%	12%	23%	16%	16%
Moderate Challenge	20%	17%	23%	22%	13%	23%
Minor Challenge	29%	27%	30%	31%	27%	28%
Not a Challenge	28%	39%	32%	21%	40%	28%
No response	2%	6%	2%	1%	3%	3%

**TABLE S-62c:** Rate how much of a challenge PUTTING THOUGHTS INTO WORDS is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	2%	23%	3%	<1%	1%	1%
Major Challenge	10%	21%	12%	9%	10%	8%
Moderate Challenge	19%	23%	20%	18%	22%	18%
Minor Challenge	24%	20%	26%	24%	26%	25%
Not a Challenge	43%	7%	38%	49%	40%	45%
No response	2%	7%	1%	<1%	2%	4%

**TABLE S-62d:** Rate how much of a challenge PLANNING DAILY ACTIVITIES is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	4%	34%	5%	2%	1%	2%
Major Challenge	7%	15%	6%	6%	6%	8%
Moderate Challenge	13%	14%	14%	11%	14%	15%
Minor Challenge	20%	10%	20%	23%	19%	20%
Not a Challenge	54%	21%	52%	57%	58%	52%
No response	2%	6%	2%	2%	2%	3%

**TABLE S-62e:** Rate how much of a challenge REMEMBERING THINGS is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	2%	8%	4%	1%	1%	1%
Major Challenge	13%	11%	15%	11%	15%	15%
Moderate Challenge	20%	21%	15%	21%	22%	18%
Minor Challenge	30%	23%	28%	31%	34%	30%
Not a Challenge	35%	34%	38%	35%	29%	36%
No response	<1%	3%	-	<1%	-	-

## SOCIAL Activities

**TABLE S-63a:** Rate how much of a challenge ROMANTIC, EMOTIONAL, INTIMATE LIFE is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	11%	35%	19%	6%	8%	11%
Major Challenge	12%	7%	10%	14%	14%	13%
Moderate Challenge	13%	6%	18%	12%	16%	11%
Minor Challenge	15%	-	7%	18%	16%	17%
Not a Challenge	42%	30%	37%	45%	41%	43%
No response	7%	23%	9%	5%	7%	6%

**TABLE S-63b:** Rate how much of a challenge RELATIONSHIPS/INTERACTIONS WITH OTHERS are for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	1%	6%	2%	1%	1%	1%
Major Challenge	9%	15%	16%	8%	9%	8%
Moderate Challenge	16%	24%	15%	18%	14%	15%
Minor Challenge	21%	15%	14%	22%	24%	20%
Not a Challenge	50%	32%	52%	47%	52%	53%
No response	3%	7%	1%	3%	2%	3%

**TABLE S-63c:** Rate how much of a challenge DISCLOSURE (TALKING ABOUT YOUR DISEASE) is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	6%	39%	14%	4%	3%	2%
Major Challenge	8%	3%	9%	8%	10%	8%
Moderate Challenge	12%	4%	10%	13%	10%	13%
Minor Challenge	16%	11%	10%	16%	18%	17%
Not a Challenge	55%	27%	52%	56%	60%	56%
No response	4%	15%	6%	2%	2%	3%

## DOCTORS' OFFICE Activities

**TABLE S-64a:** Rate how much of a challenge PREPARING FOR A VISIT TO THE DOCTOR is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	3%	15%	9%	3%	1%	2%
Major Challenge	7%	7%	6%	6%	6%	9%
Moderate Challenge	8%	13%	10%	6%	10%	8%
Minor Challenge	16%	11%	14%	19%	16%	14%
Not a Challenge	62%	44%	54%	65%	64%	63%
No response	3%	10%	7%	2%	3%	3%

**TABLE S-64b:** Rate how much of a challenge **ADVOCATING FOR APPROPRIATE CARE** is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	7%	37%	13%	5%	3%	4%
Major Challenge	10%	10%	14%	9%	10%	12%
Moderate Challenge	10%	6%	6%	10%	13%	12%
Minor Challenge	14%	6%	6%	15%	16%	15%
Not a Challenge	52%	28%	48%	57%	52%	49%
No response	7%	14%	13%	3%	7%	8%

**TABLE S-64c:** Rate how much of a challenge **BOOKING/TRACKING APPOINTMENTS** is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	7%	44%	11%	4%	4%	5%
Major Challenge	6%	4%	12%	6%	5%	7%
Moderate Challenge	<1%	-	1%	-	1%	-
Minor Challenge	22%	7%	16%	21%	28%	24%
Not a Challenge	59%	28%	50%	65%	60%	60%
No response	5%	17%	11%	3%	5%	5%

**WORK/SCHOOL Activities****TABLE S-65a:** Rate how much of a challenge **COMPLETING YOUR EDUCATION/SCHOOLING** is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	9%	20%	13%	7%	5%	10%
Major Challenge	9%	17%	15%	9%	5%	8%
Moderate Challenge	8%	21%	17%	6%	5%	6%
Minor Challenge	7%	14%	2%	8%	7%	7%
Not a Challenge	47%	17%	38%	54%	54%	44%
No response	20%	11%	15%	16%	24%	25%

**TABLE S-65b:** Rate how much of a challenge **EMPLOYMENT (OBTAINING/RETAINING WORK)** is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	26%	46%	29%	20%	23%	31%
Major Challenge	10%	13%	12%	12%	5%	9%
Moderate Challenge	7%	1%	11%	9%	4%	6%
Minor Challenge	6%	-	3%	7%	8%	6%
Not a Challenge	31%	14%	21%	37%	36%	25%
No response	21%	25%	24%	15%	25%	22%

**TABLE S-65c:** Rate how much of a challenge PERFORMING YOUR TASKS AT WORK/SCHOOL is for you:

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Unable to Perform	16%	11%	16%	14%	16%	22%
Major Challenge	11%	27%	15%	11%	6%	11%
Moderate Challenge	11%	27%	17%	11%	10%	8%
Minor Challenge	12%	14%	11%	14%	12%	7%
Not a Challenge	29%	11%	26%	34%	28%	27%
No response	21%	10%	16%	16%	28%	26%

**TABLE S-66:** Which of these challenges impact your daily life the MOST?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Mobility	34%	37%	23%	35%	36%	34%
Work/school	21%	25%	27%	18%	20%	22%
Household and personal needs	20%	27%	17%	26%	15%	16%
Psychological	18%	25%	24%	24%	13%	11%
Social	16%	7%	21%	19%	11%	16%
Communication	9%	28%	9%	9%	4%	7%
Doctors' office	5%	1%	6%	5%	6%	5%
No response	26%	18%	20%	23%	28%	32%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because multiple responses were permitted (up to three)

**TABLE S-67:** What is your biggest obstacle in managing myotonic dystrophy in your daily life?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Mobility/Balance/Accessibility	26%	15%	33%	22%	30%	29%
Other Physical Challenges/Symptoms	21%	18%	23%	21%	23%	20%
Household Chores/Daily Activities	17%	23%	9%	18%	18%	17%
Sleep and Fatigue	16%	7%	13%	24%	15%	10%
Emotional—Psychological	7%	4%	6%	9%	10%	5%
Cognitive—Psychological	6%	11%	3%	9%	4%	4%
Access to Care and Information	3%	-	2%	3%	4%	4%
Dependency/Reliance on Others	3%	4%	4%	2%	3%	3%
Other	2%	4%	1%	2%	2%	2%
No response	23%	25%	27%	21%	20%	28%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because multiple responses were received

## Section 10: Your Insurance

### USA Respondents Only

**TABLE S-68a:** What is your level of health insurance coverage? (USA)

	Overall (n=944)	cDM1-71 (n=51)	cDM1-94 (n=67)	DM1 (n=403)	DM2 (n=173)	U/U (n=228)
I do not have health insurance coverage	5%	-	3%	4%	6%	6%
I have partial coverage	11%	8%	9%	11%	10%	14%
I have full coverage	81%	90%	84%	83%	80%	75%
No response	4%	2%	4%	2%	3%	5%

**TABLE S-68b:** If you do not have full health insurance coverage, please tell us why: (USA)

	Overall (n=184)	cDM1-71 (n=5)	cDM1-94 (n=11)	DM1 (n=70)	DM2 (n=34)	U/U (n=58)
Medicaid/Medicare/State-sponsored	26%	20%	18%	30%	24%	24%
Financial/affordability	24%	20%	36%	23%	26%	24%
Employer-sponsored/other copay	9%	20%	9%	9%	9%	9%
Other	8%	40%	-	6%	9%	9%
No response	33%	-	36%	33%	32%	34%

**TABLE S-68c:** Do you feel you have adequate insurance to meet the costs associated with your myotonic dystrophy? (USA)

	Overall (n=944)	cDM1-71 (n=51)	cDM1-94 (n=67)	DM1 (n=403)	DM2 (n=173)	U/U (n=228)
Yes	58%	82%	61%	60%	52%	53%
No	25%	12%	22%	24%	29%	28%
Unknown	15%	6%	13%	15%	16%	18%
No response	2%	-	3%	2%	3%	2%

**TABLE S-68d:** Have you ever had difficulty meeting the costs associated with managing your myotonic dystrophy? (USA)

	Overall (n=944)	cDM1-71 (n=51)	cDM1-94 (n=67)	DM1 (n=403)	DM2 (n=173)	U/U (n=228)
Yes	33%	37%	33%	33%	38%	29%
No	57%	55%	60%	59%	56%	55%
Unknown	7%	6%	4%	6%	4%	14%
No response	2%	2%	3%	1%	2%	2%

### Canadian Respondents Only

**TABLE S-69a:** What is your level of health insurance coverage (over and above universal health care)? (Canada)

	Overall (n=236)	cDM1-71 (n=20)	cDM1-94 (n=27)	DM1 (n=54)	DM2 (n=27)	U/U (n=102)
I do not have additional/supplemental health insurance coverage	50%	40%	59%	39%	48%	54%
I have additional/supplemental health insurance coverage	46%	60%	37%	61%	44%	39%
No response	4%	-	4%	-	7%	7%

**TABLE S-69b:** Do you feel you have adequate insurance to meet the costs associated with your myotonic dystrophy? (Canada)

	Overall (n=236)	cDM1-71 (n=20)	cDM1-94 (n=27)	DM1 (n=54)	DM2 (n=27)	U/U (n=102)
Yes	42%	55%	41%	44%	33%	40%
No	30%	10%	30%	30%	37%	32%
Unknown	24%	35%	22%	24%	19%	24%
No response	4%	-	7%	2%	11%	4%

**TABLE S-69c:** Have you ever had difficulty meeting the costs associated with managing your myotonic dystrophy? (Canada)

	Overall (n=236)	cDM1-71 (n=20)	cDM1-94 (n=27)	DM1 (n=54)	DM2 (n=27)	U/U (n=102)
Yes	32%	30%	41%	26%	37%	31%
No	58%	55%	52%	63%	52%	59%
Unknown	7%	15%	-	9%	4%	6%
No response	4%	-	7%	2%	7%	4%

## Section 11: End of Survey

**TABLE S-70a:** Did anyone help you fill out the survey?

	Overall (n=1,180)	cDM1-71 (n=71)	cDM1-94 (n=94)	DM1 (n=457)	DM2 (n=200)	U/U (n=330)
Yes	39%	89%	49%	35%	20%	42%
No	56%	7%	46%	61%	73%	53%
No response	5%	4%	5%	4%	7%	6%

**TABLE S-70b:** If YES, who helped you?

	Overall (n=520)	cDM1-71 (n=66)	cDM1-94 (n=51)	DM1 (n=179)	DM2 (n=54)	U/U (n=156)
Parent/guardian	50%	86%	78%	46%	20%	41%
Spouse	25%	2%	8%	32%	39%	26%
Other family member or caregiver	11%	8%	4%	9%	13%	16%
Study coordinator	2%	-	-	2%	2%	4%
Other	<1%	-	-	-	-	1%
No response	12%	5%	10%	11%	26%	12%

**TABLE S-70c:** If YES, how much assistance did you receive?

	Overall (n=459)	cDM1-71 (n=63)	cDM1-94 (n=46)	DM1 (n=162)	DM2 (n=40)	U/U (n=137)
Minor	37%	5%	20%	47%	38%	43%
Moderate	23%	6%	20%	27%	35%	26%
Major	37%	86%	54%	23%	28%	28%
No response	3%	3%	7%	2%	-	3%

# Family Member/Caregiver Survey Data Tables

## Section 12: About Family Members/Caregivers

**TABLE S-71:** What country do you live in?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
USA	77%	72%	58%	91%	78%	78%
Canada	23%	28%	42%	9%	22%	22%

**TABLE S-72:** What state or province do you live in? (reported by region)

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
USA: New England	4%	-	-	4%	8%	5%
USA: Middle Atlantic	11%	22%	13%	13%	14%	3%
USA: East North Central	14%	11%	6%	14%	18%	11%
USA: West North Central	9%	11%	3%	12%	11%	3%
USA: South Atlantic	14%	17%	10%	16%	11%	16%
USA: East South Central	1%	-	3%	1%	-	1%
USA: West South Central	4%	-	6%	5%	3%	3%
USA: Mountain	6%	-	6%	10%	3%	3%
USA: Pacific	12%	11%	10%	15%	9%	9%
Canada: Atlantic	1%	-	-	1%	-	2%
Canada: Quebec	<1%	-	-	-	-	2%
Canada: Ontario	14%	22%	32%	4%	18%	23%
Canada: Prairies	5%	6%	3%	3%	3%	11%
Canada: British Columbia	3%	-	6%	2%	-	5%
No response	1%	-	-	1%	2%	2%

**TABLE S-73:** What is your date of birth (D.O.B.)? (reported as age in years at time of survey completion)

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
10 thru 19	<1%	-	-	1%	2%	-
20 thru 29	2%	22%	-	2%	-	-
30 thru 39	7%	11%	-	8%	3%	10%
40 thru 49	16%	17%	6%	17%	18%	15%
50 thru 59	32%	44%	45%	34%	20%	29%
60+	40%	6%	45%	35%	55%	41%
No response	3%	-	3%	4%	2%	5%
<b>Average age of family member/caregiver (calculated mean)</b>	<b>57.1</b>	<b>45.8</b>	<b>60.6</b>	<b>55.5</b>	<b>61.1</b>	<b>58.3</b>

**TABLE S-74:** What is your gender?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Female	51%	72%	48%	52%	42%	56%
Male	47%	28%	48%	46%	57%	43%
No response	2%	-	3%	2%	2%	1%

**TABLE S-75:** Do you have myotonic dystrophy yourself?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Yes	18%	28%	23%	19%	11%	19%
No	79%	72%	77%	79%	83%	77%
Unknown	1%	-	-	1%	3%	1%
No response	2%	-	-	2%	3%	3%

**TABLE S-76:** What is your relationship to the person who filled out the original patient survey (the subject)?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
I am their parent/guardian	35%	83%	48%	34%	15%	39%
I am their spouse/partner	52%	6%	35%	56%	69%	45%
I am their sibling (brother or sister)	2%	-	3%	2%	3%	4%
I am their child	4%	-	6%	4%	3%	6%
I am their friend	2%	-	3%	2%	3%	1%
I am their professional caregiver	3%	6%	3%	2%	5%	2%
Other relative/ extended family	1%	6%	-	1%	-	1%
No response	1%	-	-	1%	2%	1%

**TABLE S-77:** How much assistance did you provide the subject in completing the original patient survey?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
ALL: I completed the entire patient survey	17%	67%	35%	14%	5%	18%
MAJOR: I provided SUBSTANTIAL help	6%	11%	6%	5%	5%	7%
MODERATE: I provided some help	9%	6%	13%	9%	8%	11%
MINOR: I only helped with reading/filling in questions	15%	-	13%	18%	9%	18%
NONE: I did not provide any assistance	50%	17%	29%	52%	71%	44%
No response	2%	-	3%	2%	3%	2%

## Section 13: The Family Member/Caregiver Role

**TABLE S-78:** How much time do you spend with the subject?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
I live with the subject full-time	85%	94%	81%	88%	85%	81%
I see the subject each day	2%	-	3%	2%	2%	3%
I see the subject several times a week	8%	6%	10%	9%	9%	7%
I see the subject once a week or less	4%	-	6%	2%	3%	9%
No response	0%	-	-	-	2%	-

**TABLE S-79:** How much assistance do you provide the subject in managing their daily life?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
MAJOR ASSISTANCE: constantly; work together all the time	23%	67%	32%	21%	12%	23%
MODERATE ASSISTANCE: frequently; work together often	32%	17%	42%	32%	25%	40%
MINOR ASSISTANCE: occasionally; normally independent	42%	11%	19%	46%	60%	33%
No response	2%	6%	6%	1%	3%	3%

**TABLE S-80a:** In what ways do you help the subject?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
I provide financial support	56%	78%	71%	58%	46%	53%
I provide emotional support	87%	89%	84%	92%	83%	81%
I help them with their household tasks and chores	74%	61%	71%	75%	75%	76%
I help them with their personal needs	37%	94%	52%	32%	23%	41%
I help them with their schoolwork	11%	50%	19%	11%	-	6%
I help them with their healthcare	55%	94%	65%	56%	37%	55%
I attend clinical visits with them	68%	94%	74%	68%	60%	67%
Transportation	5%	-	3%	5%	5%	4%
Mobility/ balance/ getting around	2%	-	-	2%	5%	1%
Coaching/ encouragement	2%	6%	-	3%	2%	2%
Daily life support (comprehensive)	1%	6%	-	2%	-	1%
Other	1%	6%	-	-	2%	2%
No response	1%	-	-	1%	2%	2%

**TABLE S-80b:** Considering all the things you do to help the subject, what do you think is the MOST important?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Financial support	12%	11%	13%	13%	8%	15%
Emotional support	51%	28%	65%	53%	51%	47%
Household tasks and chores	22%	-	16%	24%	25%	21%
Personal needs	11%	11%	23%	11%	5%	9%
Schoolwork	2%	6%	3%	2%	2%	2%
Healthcare	14%	22%	16%	15%	8%	14%
Attend clinical visits with them	5%	-	6%	4%	11%	3%
Transportation	4%	-	10%	3%	3%	4%
Mobility/balance/getting around	7%	6%	6%	7%	8%	4%
Coaching/encouragement	5%	11%	3%	5%	3%	6%
Daily life support (comprehensive)	7%	33%	6%	5%	5%	5%
Other	2%	-	-	2%	2%	3%
No response	9%	17%	3%	6%	11%	13%

**TABLE S-81a:** Do you help other people manage their myotonic dystrophy?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Yes	27%	33%	39%	30%	14%	27%
No	72%	67%	61%	70%	85%	73%
No response	<1%	-	-	-	2%	-

**TABLE S-81b:** If YES, how many? (total number including the subject)

	Overall (n=110)	cDM1-71 (n=6)	cDM1-94 (n=12)	DM1 (n=56)	DM2 (n=9)	U/U (n=25)
One person	11%	17%	-	16%	-	8%
Two people	57%	50%	83%	52%	67%	56%
Three people	23%	33%	17%	25%	11%	24%
Four people	6%	-	-	2%	22%	12%
Five people	3%	-	-	5%	-	-
More than five people	<1%	<1%	<1%	<1%	<1%	<1%

## Section 14: Information and Resources and Family Members/Caregivers

**TABLE S-82a:** How HELPFUL has a GENERAL PRACTITIONER/FAMILY DOCTOR been for you as a source of information?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Helpful	12%	33%	13%	12%	5%	13%
Somewhat Helpful	33%	28%	48%	32%	37%	33%
Not Very Helpful	34%	28%	26%	34%	32%	40%
Never Used	17%	11%	10%	19%	20%	12%
No response	3%	-	3%	3%	6%	2%

**TABLE S-82b:** How HELPFUL have OTHER MEDICAL SPECIALISTS been for you as a source of information?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Helpful	37%	56%	39%	41%	29%	29%
Somewhat Helpful	35%	22%	39%	34%	42%	37%
Not Very Helpful	13%	6%	19%	11%	14%	18%
Never Used	11%	11%	3%	12%	6%	14%
No response	4%	6%	-	3%	9%	2%

**TABLE S-82c:** How HELPFUL have FAMILY/FRIENDS been for you as a source of information?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Helpful	17%	22%	16%	13%	20%	22%
Somewhat Helpful	30%	17%	29%	36%	25%	23%
Not Very Helpful	27%	50%	29%	25%	20%	30%
Never Used	23%	11%	23%	22%	26%	22%
No response	4%	-	3%	3%	9%	2%

**TABLE S-82d:** How HELPFUL have PATIENT ORGANIZATIONS been for you as a source of information?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Helpful	29%	33%	29%	37%	20%	18%
Somewhat Helpful	35%	50%	29%	33%	37%	41%
Not Very Helpful	14%	-	19%	13%	15%	15%
Never Used	17%	11%	19%	15%	17%	21%
No response	5%	6%	3%	2%	11%	4%

**TABLE S-82e:** How HELPFUL have GENERAL HEALTH-RELATED WEBSITES been for you as a source of information?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Helpful	9%	11%	6%	10%	9%	10%
Somewhat Helpful	37%	44%	26%	40%	37%	31%
Not Very Helpful	22%	22%	26%	21%	23%	21%
Never Used	28%	22%	35%	26%	22%	35%
No response	4%	-	6%	3%	9%	3%

**TABLE S-82f:** How HELPFUL have PRINTED MATERIALS/BOOKS been for you as a source of information?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Helpful	14%	11%	10%	16%	12%	14%
Somewhat Helpful	49%	56%	61%	52%	48%	39%
Not Very Helpful	15%	17%	13%	13%	8%	23%
Never Used	19%	17%	16%	17%	26%	20%
No response	3%	-	-	3%	6%	3%

**TABLE S-83:** Who or what has been the MOST helpful source of information for YOU?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Medical specialists	32%	39%	42%	35%	29%	22%
Patient organizations	25%	17%	19%	30%	18%	23%
Printed materials/books	14%	22%	23%	13%	8%	14%
Websites/Internet	13%	6%	6%	14%	14%	14%
Personal experience	11%	6%	13%	11%	14%	9%
Family/friends	10%	11%	3%	9%	8%	15%
General practitioner/family doctor	6%	22%	3%	5%	3%	9%
Not specified	8%	-	6%	6%	12%	11%

NOTE: Grouped accordingly from written responses provided; percentages can add up to more than 100% because multiple responses were received

**TABLE S-84:** What is the NUMBER ONE best way for YOU to receive information about myotonic dystrophy?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Receiving information by LETTERMAIL (printed)	26%	22%	29%	19%	35%	31%
Receiving information by EMAIL (electronically)	18%	28%	10%	22%	12%	14%
Visiting other health-related websites (internet/online)	10%	17%	10%	10%	12%	9%
Talking with health care providers	10%	6%	16%	10%	6%	11%
Visiting patient organization websites/patient organization materials	9%	11%	16%	14%	3%	4%
Reading books and other printed material	8%	11%	3%	9%	8%	9%
Talking with friends/family	6%	-	6%	7%	12%	2%
Other	3%	6%	3%	3%	2%	2%
No response	9%	-	6%	5%	9%	18%

NOTE: Percentages can add up to more than 100% because multiple responses were permitted

**TABLE S-85:** Which areas would you like to get more information about?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Available treatments/ medications	72%	72%	58%	75%	68%	74%
Clinical trials	55%	61%	61%	61%	54%	43%
Scientific research	52%	44%	52%	59%	48%	45%
Exercise	49%	28%	42%	51%	57%	47%
Cardiac implications	46%	44%	32%	48%	43%	51%
Nutrition	44%	44%	39%	47%	34%	47%
Anesthesia risks	38%	39%	39%	41%	26%	40%
Caregiver support/ training	38%	39%	39%	36%	31%	47%
Where to find specialists/ disease experts	37%	39%	26%	37%	34%	44%
Financial assistance	37%	39%	26%	34%	37%	47%
Patient organizations (i.e., MDA, MDF, MDC)	29%	17%	26%	31%	25%	34%
Technical aids	29%	17%	26%	29%	31%	32%
Disclosure (talking with others about my disease)	26%	17%	29%	27%	23%	27%
Psychological supports	25%	44%	23%	28%	17%	21%
Community supports	25%	44%	32%	25%	17%	23%
Health insurance	22%	11%	13%	24%	17%	29%
Genetic counseling/ family planning	14%	11%	13%	12%	20%	15%
Workplace accommodations	11%	6%	-	14%	5%	11%
School accommodations/ assistance	9%	44%	3%	11%	-	5%
Other	3%	-	-	3%	4%	5%
No response	4%	-	3%	3%	9%	1%

## Section 15: Additional Insights from Family Members/Caregivers

**TABLE S-86:** How satisfied are YOU with the overall medical care the subject receives?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Satisfied	19%	33%	13%	20%	20%	15%
Satisfied	40%	39%	45%	44%	31%	35%
Neutral	26%	17%	29%	24%	31%	30%
Dissatisfied	10%	6%	10%	9%	11%	16%
Very Dissatisfied	2%	-	-	2%	3%	3%
No response	2%	6%	3%	2%	5%	1%

**TABLE S-87:** What is YOUR biggest challenge in helping the subject manage their myotonic dystrophy?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Managing the Complexity of the Disease	43%	17%	55%	42%	40%	46%
Caregiver Burden	33%	50%	39%	35%	29%	26%
Coaching & Advocacy	21%	22%	13%	20%	26%	21%
Other	<1%	-	3%	1%	-	-
No response	16%	17%	6%	15%	20%	17%

## Section 16: The Subject's Symptoms

**TABLE S-88a:** What type of myotonic dystrophy does the subject have?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Congenital myotonic dystrophy type 1 (CDM1)	19%	94%	58%	13%	3%	16%
Myotonic dystrophy type 1 (DM1)	43%	6%	19%	74%	11%	18%
Myotonic dystrophy type 2 (DM2)	16%	-	3%	6%	74%	4%
Unknown/unsure (U/U)	21%	-	19%	6%	12%	57%
No response	1%	-	-	1%	-	4%

**TABLE S-88b:** What type of myotonic dystrophy does the subject have? (reclassified\*)

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
*Congenital myotonic dystrophy type 1 with age of onset at birth and diagnosis less than or equal to two years of age (cDM1-71)	10%	89%	23%	5%	-	6%
*Congenital myotonic dystrophy type 1 with age of onset older than birth and diagnosis greater than two years of age (cDM1-94)	10%	6%	35%	7%	3%	10%
Myotonic dystrophy type 1 (DM1)	43%	6%	19%	74%	11%	18%
Myotonic dystrophy type 2 (DM2)	16%	-	3%	6%	74%	4%
Unknown/unsure (U/U)	21%	-	19%	6%	12%	57%
No response	1%	-	-	1%	-	4%

**TABLE S-89:** In general, would you say the subject's current health is:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Excellent	3%	6%	-	5%	3%	-
Very good	15%	33%	23%	12%	17%	11%
Good	35%	39%	29%	37%	37%	31%
Fair	37%	17%	29%	36%	31%	49%
Poor	8%	-	16%	7%	8%	9%
No response	2%	6%	3%	2%	5%	1%

**TABLE S-90a:** About how old was the subject when the first significant symptoms were noticed?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
0	13%	89%	32%	9%	-	12%
1 thru 9	9%	6%	23%	7%	2%	16%
10 thru 19	19%	-	13%	25%	14%	19%
20 thru 29	14%	-	13%	16%	8%	17%
30 thru 39	18%	-	10%	18%	28%	17%
40 thru 49	13%	6%	3%	13%	15%	14%
50 thru 59	9%	-	3%	8%	22%	3%
60+	3%	-	-	3%	9%	-
No response	2%	-	3%	2%	3%	2%
<b>Average age at onset (calculated mean)</b>	<b>25.4</b>	<b>2.3</b>	<b>12.8</b>	<b>26.1</b>	<b>38.4</b>	<b>21.6</b>

**TABLE S-90b:** What was the first symptom noticed?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Muscle Weakness	32%	-	26%	34%	35%	35%
Myotonia	21%	11%	16%	25%	23%	17%
Balance, Mobility Issues	19%	-	6%	15%	38%	21%
Neonatal Problems	9%	67%	29%	5%	-	5%
Sleep, Fatigue, Energy	7%	-	6%	10%	-	9%
Cognitive, Developmental Delays	5%	-	6%	7%	2%	6%
Cataracts, Eyes	4%	-	6%	5%	5%	2%
Pain	4%	-	-	4%	11%	1%
Speech, Swallowing	3%	-	6%	3%	-	6%
Cardiac	3%	-	-	3%	6%	2%
Gastrointestinal Problems	2%	-	3%	3%	-	1%
Other	2%	-	3%	2%	-	1%
Does not experience symptoms	<1%	-	-	1%	-	-
No response	10%	22%	10%	7%	9%	12%

NOTE: Grouped accordingly from first written response provided

**MUSCLE Symptoms****TABLE S-91a:** Rate how much MYOTONIA (DIFFICULTY RELAXING MUSCLE) impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	17%	11%	26%	15%	17%	22%
Has Symptom with MODERATE Impact	30%	22%	29%	30%	38%	23%
Has Symptom with MINOR Impact	26%	11%	26%	27%	23%	30%
Has Symptom but NO Impact	8%	11%	-	10%	9%	3%
Does Not Experience Symptom	14%	44%	13%	12%	11%	15%
No response	5%	-	6%	5%	2%	6%

**TABLE S-91b:** Rate how much MUSCLE WEAKNESS impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	50%	50%	65%	48%	52%	48%
Has Symptom with MODERATE Impact	33%	39%	13%	33%	35%	35%
Has Symptom with MINOR Impact	10%	11%	6%	12%	8%	10%
Has Symptom but NO Impact	3%	-	6%	4%	-	2%
Does Not Experience Symptom	2%	-	-	2%	2%	2%
No response	3%	-	10%	2%	3%	3%

**TABLE S-91c:** Rate how much MUSCLE ACHES, CRAMPS impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	19%	-	16%	18%	29%	21%
Has Symptom with MODERATE Impact	28%	33%	29%	28%	25%	32%
Has Symptom with MINOR Impact	23%	28%	29%	22%	23%	19%
Has Symptom but NO Impact	8%	11%	6%	8%	8%	6%
Does Not Experience Symptom	17%	28%	16%	19%	14%	14%
No response	4%	-	3%	4%	2%	7%

**TABLE S-91d:** Rate how much MUSCLE PAIN impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	21%	6%	26%	18%	32%	20%
Has Symptom with MODERATE Impact	23%	22%	23%	22%	22%	26%
Has Symptom with MINOR Impact	21%	22%	26%	20%	15%	23%
Has Symptom but NO Impact	10%	11%	3%	13%	9%	6%
Does Not Experience Symptom	22%	39%	19%	24%	20%	17%
No response	4%	-	3%	3%	2%	7%

**GASTROINTESTINAL Symptoms****TABLE S-92a:** Rate how much DIFFICULTY SWALLOWING (DYSPHAGIA) impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	15%	39%	10%	12%	14%	19%
Has Symptom with MODERATE Impact	23%	-	45%	23%	20%	21%
Has Symptom with MINOR Impact	25%	39%	16%	28%	25%	20%
Has Symptom but NO Impact	11%	11%	13%	14%	8%	6%
Does Not Experience Symptom	23%	11%	16%	20%	31%	28%
No response	3%	-	-	3%	3%	5%

**TABLE S-92b:** Rate how much DIARRHEA impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	12%	-	13%	13%	11%	11%
Has Symptom with MODERATE Impact	20%	11%	16%	22%	17%	23%
Has Symptom with MINOR Impact	20%	-	19%	20%	20%	21%
Has Symptom but NO Impact	14%	22%	19%	14%	12%	10%
Does Not Experience Symptom	31%	61%	29%	27%	37%	32%
No response	3%	6%	3%	3%	3%	3%

**TABLE S-92c:** Rate how much CONSTIPATION impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	15%	22%	19%	13%	22%	12%
Has Symptom with MODERATE Impact	23%	17%	19%	24%	18%	28%
Has Symptom with MINOR Impact	22%	11%	23%	22%	23%	23%
Has Symptom but NO Impact	10%	6%	13%	12%	3%	9%
Does Not Experience Symptom	27%	44%	19%	26%	31%	26%
No response	3%	-	6%	3%	3%	3%

**TABLE S-92d:** Rate how much FREQUENT HICCUPS impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	5%	6%	3%	4%	5%	6%
Has Symptom with MODERATE Impact	10%	17%	16%	12%	3%	9%
Has Symptom with MINOR Impact	19%	17%	13%	22%	17%	14%
Has Symptom but NO Impact	16%	22%	23%	19%	9%	13%
Does Not Experience Symptom	47%	39%	39%	40%	60%	53%
No response	4%	-	6%	3%	6%	5%

**TABLE S-92e:** Rate how much ABDOMINAL PAIN impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	8%	-	13%	9%	9%	6%
Has Symptom with MODERATE Impact	17%	17%	19%	19%	12%	17%
Has Symptom with MINOR Impact	21%	17%	26%	20%	17%	24%
Has Symptom but NO Impact	10%	11%	13%	10%	6%	12%
Does Not Experience Symptom	40%	56%	23%	37%	51%	37%
No response	4%	-	6%	4%	5%	3%

**CARDIORESPIRATORY Symptoms****TABLE S-93a:** Rate how much ABDOMINAL PAIN impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	11%	-	13%	12%	11%	12%
Has Symptom with MODERATE Impact	15%	6%	19%	13%	11%	21%
Has Symptom with MINOR Impact	15%	17%	16%	12%	25%	14%
Has Symptom but NO Impact	15%	17%	10%	19%	14%	11%
Does Not Experience Symptom	42%	61%	42%	42%	38%	39%
No response	2%	-	-	2%	2%	3%

**TABLE S-93b:** Rate how much RECURRENT LUNG INFECTIONS/PNEUMONIA impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	4%	-	-	4%	5%	5%
Has Symptom with MODERATE Impact	7%	11%	16%	5%	8%	5%
Has Symptom with MINOR Impact	10%	17%	-	8%	9%	17%
Has Symptom but NO Impact	9%	22%	10%	7%	8%	12%
Does Not Experience Symptom	66%	50%	65%	72%	68%	56%
No response	4%	-	10%	3%	3%	4%

**TABLE S-93c:** Rate how much SHORTNESS OF BREATH impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	9%	6%	3%	7%	17%	11%
Has Symptom with MODERATE Impact	14%	-	19%	12%	20%	14%
Has Symptom with MINOR Impact	20%	11%	19%	20%	12%	27%
Has Symptom but NO Impact	12%	6%	19%	11%	5%	17%
Does Not Experience Symptom	43%	78%	29%	48%	43%	32%
No response	2%	-	10%	2%	3%	-

**TABLE S-93d:** Rate how much DIZZINESS/FAINTING impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	2%	-	-	1%	3%	2%
Has Symptom with MODERATE Impact	8%	-	13%	7%	14%	7%
Has Symptom with MINOR Impact	17%	6%	13%	20%	18%	17%
Has Symptom but NO Impact	14%	11%	13%	12%	14%	15%
Does Not Experience Symptom	55%	83%	52%	57%	48%	54%
No response	3%	-	10%	3%	3%	4%

**SLEEP and FATIGUE Symptoms****TABLE S-94a:** Rate how much DAYTIME SLEEPINESS impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	35%	6%	26%	40%	38%	32%
Has Symptom with MODERATE Impact	24%	22%	23%	27%	17%	24%
Has Symptom with MINOR Impact	19%	28%	23%	16%	17%	21%
Has Symptom but NO Impact	11%	22%	19%	9%	12%	12%
Does Not Experience Symptom	10%	22%	6%	7%	12%	10%
No response	1%	-	3%	1%	3%	1%

**TABLE S-94b:** Rate how much FATIGUE impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	36%	17%	32%	39%	35%	36%
Has Symptom with MODERATE Impact	29%	17%	32%	29%	37%	24%
Has Symptom with MINOR Impact	20%	17%	16%	20%	17%	22%
Has Symptom but NO Impact	9%	39%	13%	7%	3%	9%
Does Not Experience Symptom	6%	11%	6%	5%	5%	6%
No response	1%	-	-	1%	3%	2%

**TABLE S-94c:** Rate how much DIFFICULTY FALLING ASLEEP impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	13%	6%	26%	12%	12%	14%
Has Symptom with MODERATE Impact	16%	6%	10%	15%	26%	15%
Has Symptom with MINOR Impact	17%	-	13%	20%	14%	18%
Has Symptom but NO Impact	10%	11%	10%	11%	12%	9%
Does Not Experience Symptom	42%	78%	42%	40%	32%	43%
No response	2%	-	-	2%	3%	2%

**TABLE S-94d:** Rate how much TROUBLE BREATHING DURING SLEEP (APNEA) impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	19%	22%	19%	21%	17%	16%
Has Symptom with MODERATE Impact	15%	6%	19%	14%	15%	18%
Has Symptom with MINOR Impact	13%	11%	13%	12%	20%	14%
Has Symptom but NO Impact	10%	17%	10%	9%	6%	12%
Does Not Experience Symptom	40%	44%	35%	42%	38%	36%
No response	2%	-	3%	2%	3%	4%

**PSYCHOLOGICAL Symptoms****TABLE S-95a:** Rate how much LEARNING DIFFICULTIES/CHALLENGES impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	18%	61%	29%	17%	5%	17%
Has Symptom with MODERATE Impact	16%	28%	23%	13%	15%	17%
Has Symptom with MINOR Impact	15%	-	16%	16%	20%	12%
Has Symptom but NO Impact	11%	6%	6%	9%	12%	18%
Does Not Experience Symptom	39%	6%	26%	44%	45%	34%
No response	1%	-	-	1%	3%	2%

**TABLE S-95b:** Rate how much DIFFICULTY CONCENTRATING impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	13%	39%	16%	14%	8%	11%
Has Symptom with MODERATE Impact	20%	22%	29%	19%	17%	21%
Has Symptom with MINOR Impact	19%	17%	13%	19%	26%	18%
Has Symptom but NO Impact	13%	11%	10%	14%	14%	14%
Does Not Experience Symptom	32%	11%	32%	33%	31%	32%
No response	2%	-	-	2%	5%	4%

**TABLE S-95c:** Rate how much DEPRESSION impacts the subject's daily life:

	Total (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	10%	11%	6%	11%	6%	11%
Has Symptom with MODERATE Impact	17%	6%	29%	14%	28%	16%
Has Symptom with MINOR Impact	20%	6%	16%	20%	29%	17%
Has Symptom but NO Impact	10%	11%	6%	12%	11%	10%
Does Not Experience Symptom	39%	67%	42%	40%	23%	40%
No response	3%	-	-	2%	3%	6%

**TABLE S-95d:** Rate how much ANXIETY impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	11%	22%	16%	11%	8%	7%
Has Symptom with MODERATE Impact	18%	22%	19%	18%	20%	16%
Has Symptom with MINOR Impact	20%	6%	19%	20%	23%	23%
Has Symptom but NO Impact	13%	11%	3%	14%	14%	14%
Does Not Experience Symptom	36%	39%	39%	35%	32%	35%
No response	2%	-	3%	2%	3%	4%

**HORMONAL and ENDOCRINE Symptoms****TABLE S-96a:** Rate how much DIABETES impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	4%	-	6%	1%	11%	4%
Has Symptom with MODERATE Impact	4%	-	-	4%	8%	3%
Has Symptom with MINOR Impact	4%	6%	6%	3%	5%	5%
Has Symptom but NO Impact	2%	-	3%	2%	2%	3%
Does Not Experience Symptom	85%	94%	84%	89%	74%	81%
No response	2%	-	-	2%	2%	3%

**TABLE S-96b:** Rate how much SEXUAL/INTIMACY PROBLEMS impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	12%	-	3%	9%	14%	22%
Has Symptom with MODERATE Impact	8%	6%	6%	11%	9%	5%
Has Symptom with MINOR Impact	8%	-	16%	10%	8%	5%
Has Symptom but NO Impact	6%	-	3%	5%	12%	5%
Does Not Experience Symptom	58%	83%	68%	58%	52%	52%
No response	7%	11%	3%	7%	5%	10%

**TABLE S-96c:** Rate how much FERTILITY PROBLEMS impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	11%	6%	10%	11%	9%	15%
Has Symptom with MODERATE Impact	2%	-	-	3%	2%	1%
Has Symptom with MINOR Impact	2%	-	-	3%	2%	1%
Has Symptom but NO Impact	4%	-	6%	4%	5%	5%
Does Not Experience Symptom	70%	83%	81%	66%	75%	68%
No response	10%	11%	3%	13%	8%	10%

**TABLE S-96d:** Rate how much BALDING/THINNING HAIR impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	21%	6%	23%	21%	17%	27%
Has Symptom with MODERATE Impact	14%	6%	19%	14%	8%	15%
Has Symptom with MINOR Impact	9%	-	6%	9%	12%	11%
Has Symptom but NO Impact	11%	11%	16%	11%	14%	11%
Does Not Experience Symptom	43%	78%	35%	42%	48%	37%
No response	1%	-	-	3%	2%	-

**OTHER Symptoms****TABLE S-97a:** Rate how much HEADACHES, MIGRAINES impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	5%	6%	-	4%	6%	9%
Has Symptom with MODERATE Impact	10%	6%	10%	9%	14%	12%
Has Symptom with MINOR Impact	17%	6%	26%	17%	22%	14%
Has Symptom but NO Impact	12%	22%	10%	12%	11%	13%
Does Not Experience Symptom	53%	61%	55%	57%	46%	49%
No response	2%	-	-	3%	2%	4%

**TABLE S-97b:** Rate how much DROOPING EYELIDS (PTOSIS) impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	15%	6%	32%	13%	14%	19%
Has Symptom with MODERATE Impact	17%	11%	19%	17%	12%	20%
Has Symptom with MINOR Impact	18%	17%	6%	18%	18%	19%
Has Symptom but NO Impact	13%	17%	13%	18%	5%	11%
Does Not Experience Symptom	35%	50%	29%	31%	49%	31%
No response	1%	-	-	3%	2%	-

**TABLE S-97c:** Rate how much HEARING LOSS impacts the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	12%	6%	10%	11%	15%	12%
Has Symptom with MODERATE Impact	11%	-	13%	8%	14%	15%
Has Symptom with MINOR Impact	13%	17%	16%	10%	26%	9%
Has Symptom but NO Impact	4%	-	6%	5%	3%	4%
Does Not Experience Symptom	57%	78%	52%	64%	37%	57%
No response	3%	-	3%	2%	5%	3%

**TABLE S-97d:** Rate how much BALANCE ISSUES impact the subject's daily life:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Has Symptom with MAJOR Impact	44%	28%	58%	41%	43%	47%
Has Symptom with MODERATE Impact	22%	17%	13%	21%	25%	26%
Has Symptom with MINOR Impact	13%	33%	10%	12%	12%	15%
Has Symptom but NO Impact	6%	6%	6%	7%	2%	4%
Does Not Experience Symptom	15%	17%	13%	17%	17%	9%
No response	1%	-	-	2%	2%	-

**TABLE S-98:** Of all the problems/symptoms the subject experiences, which ones IMPACT THEIR LIFE THE MOST?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Muscle symptoms	49%	33%	52%	51%	60%	40%
Other physical problems/symptoms (including balance)	44%	17%	42%	42%	46%	52%
Sleep and fatigue symptoms	38%	33%	29%	44%	40%	31%
Psychological symptoms	29%	56%	52%	31%	18%	21%
Gastrointestinal symptoms	26%	17%	29%	27%	22%	28%
Cardiorespiratory symptoms	13%	11%	10%	13%	14%	14%
Biological, hormonal, endocrine symptoms	6%	-	6%	5%	5%	7%
No response	6%	11%	3%	5%	5%	11%

## Section 17: The Subject's Medical Care

**TABLE S-99a:** Does the subject take medication for daytime sleepiness (DTS) and/or fatigue?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Yes	17%	-	26%	27%	6%	5%
No	81%	94%	71%	71%	89%	94%
Unknown	1%	-	-	1%	2%	1%
No response	2%	6%	3%	2%	3%	-

**TABLE S-99b:** If YES, which medication(s) does the subject take for DTS and/or fatigue?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
1. Modafinil	50%	-	75%	47%	50%	40%
2. Methylphenidate	22%	-	13%	24%	25%	20%
3. Adderall	7%	-	-	8%	-	20%

NOTE: a total of 12 medications were reported; only the top three are presented in rank order above

**TABLE S-99c:** If the subject takes medication for DTS and/or fatigue, how satisfied are you with its effect?

	Overall (n=68)	cDM1-71 (n=0)	cDM1-94 (n=8)	DM1 (n=51)	DM2 (n=4)	U/U (n=5)
Extremely satisfied	4%	-	13%	4%	-	-
Very satisfied	31%	-	38%	33%	25%	-
Moderately satisfied	47%	-	38%	45%	50%	80%
Slightly satisfied	13%	-	-	14%	25%	20%
Not at all satisfied	4%	-	13%	4%	-	-

**TABLE S-100a:** How often does the subject follow their doctors' advice?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Always	59%	83%	74%	55%	63%	56%
Often	27%	11%	16%	32%	25%	24%
Sometimes	7%	-	-	8%	6%	12%
Rarely	1%	-	6%	1%	-	3%
Never	1%	-	-	1%	-	2%
No response	4%	6%	3%	4%	6%	2%

**TABLE S-100b:** If the subject does NOT follow their doctors' advice, please tell us why you think that's the case:

	Overall (n=93)	cDM1-71 (n=1)	cDM1-94 (n=6)	DM1 (n=50)	DM2 (n=9)	U/U (n=24)
Patient attitude/behaviour	48%	-	50%	50%	11%	58%
Lack of medical expertise/lack of advice given	12%	-	-	10%	33%	8%
Side effects/adverse effects/tolerance	9%	-	17%	8%	-	13%
Lack of agreement	8%	-	17%	8%	11%	4%
Financial/insurance/affordability	6%	-	-	10%	11%	-
Lifestyle/diet/exercise	6%	-	-	4%	11%	13%
Psychological/emotional	6%	100%	17%	6%	11%	-
No need/no benefit/lack of effect	2%	-	-	4%	-	-
Lack of transportation/limited mobility	2%	-	-	-	11%	4%

**TABLE S-101:** How satisfied do you think the subject is with the overall medical care they receive?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Very Satisfied	17%	28%	10%	18%	12%	18%
Satisfied	46%	44%	55%	48%	46%	40%
Neutral	22%	22%	23%	21%	26%	22%
Dissatisfied	9%	-	3%	7%	9%	17%
Very Dissatisfied	1%	-	3%	2%	2%	1%
No response	4%	6%	6%	5%	5%	1%

## Section 18: The Subject's Daily Life

### MOBILITY Activities

**TABLE S-102a:** Rate how much of a challenge WALKING OUTSIDE OR INSIDE is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	11%	17%	26%	7%	9%	14%
Major Challenge	34%	28%	16%	33%	38%	36%
Moderate Challenge	22%	22%	19%	21%	26%	24%
Minor Challenge	17%	22%	19%	17%	15%	17%
Not a Challenge	14%	11%	13%	19%	9%	9%
No response	2%	-	6%	3%	2%	-

**TABLE S-102b:** Rate how much of a challenge STANDING UP, SITTING DOWN, BENDING DOWN is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	6%	17%	13%	3%	5%	9%
Major Challenge	34%	22%	29%	30%	40%	40%
Moderate Challenge	26%	33%	23%	22%	37%	23%
Minor Challenge	18%	11%	19%	23%	8%	15%
Not a Challenge	14%	17%	13%	19%	8%	10%
No response	2%	-	3%	2%	3%	3%

**TABLE S-102c:** Rate how much of a challenge GOING UP AND DOWN STAIRS is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	28%	17%	55%	19%	35%	35%
Major Challenge	32%	33%	10%	34%	37%	31%
Moderate Challenge	17%	33%	6%	18%	11%	19%
Minor Challenge	9%	-	16%	11%	6%	9%
Not a Challenge	11%	17%	10%	16%	6%	6%
No response	2%	-	3%	3%	5%	-

**TABLE S-102d:** Rate how much of a challenge STANDING (FOR ANY LENGTH OF TIME) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	16%	17%	32%	12%	15%	20%
Major Challenge	38%	22%	29%	36%	37%	46%
Moderate Challenge	19%	11%	13%	20%	28%	16%
Minor Challenge	12%	39%	16%	12%	11%	9%
Not a Challenge	12%	11%	6%	16%	8%	7%
No response	2%	-	3%	3%	2%	2%

**TABLE S-102e:** Rate how much of a challenge MAINTAINING YOUR BALANCE is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	14%	6%	29%	10%	15%	17%
Major Challenge	35%	33%	23%	35%	37%	40%
Moderate Challenge	20%	22%	23%	20%	20%	18%
Minor Challenge	15%	28%	10%	13%	14%	17%
Not a Challenge	14%	11%	13%	19%	11%	6%
No response	2%	-	3%	3%	3%	1%

**TABLE S-102f:** Rate how much of a challenge DRIVING A CAR is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	32%	83%	52%	23%	18%	44%
Major Challenge	3%	-	-	3%	3%	4%
Moderate Challenge	8%	6%	3%	9%	8%	7%
Minor Challenge	18%	-	13%	22%	28%	10%
Not a Challenge	32%	6%	16%	34%	42%	31%
No response	7%	6%	16%	9%	2%	4%

**HOUSEHOLD and PERSONAL NEEDS Activities****TABLE S-103a:** Rate how much of a challenge PREPARING MEALS is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	17%	61%	23%	10%	11%	26%
Major Challenge	14%	17%	23%	14%	9%	13%
Moderate Challenge	21%	6%	29%	22%	17%	23%
Minor Challenge	19%	6%	6%	18%	32%	18%
Not a Challenge	25%	11%	16%	30%	29%	16%
No response	4%	-	3%	5%	2%	4%

**TABLE S-103b:** Rate how much of a challenge HOUSEKEEPING (CLEANING, LAUNDRY) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	22%	50%	32%	16%	18%	29%
Major Challenge	21%	33%	16%	19%	17%	29%
Moderate Challenge	21%	6%	26%	22%	25%	16%
Minor Challenge	14%	-	10%	14%	22%	14%
Not a Challenge	18%	11%	10%	24%	15%	11%
No response	3%	-	6%	4%	3%	2%

**TABLE S-103c:** Rate how much of a challenge HANDLING OBJECTS (OPENING JARS, TURNING KNOBS) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	20%	39%	32%	16%	11%	26%
Major Challenge	36%	44%	32%	37%	28%	39%
Moderate Challenge	18%	-	16%	22%	17%	16%
Minor Challenge	15%	6%	13%	14%	32%	11%
Not a Challenge	8%	11%	3%	7%	11%	6%
No response	3%	-	3%	3%	2%	2%

**TABLE S-103d:** Rate how much of a challenge USING CUTLERY AND KITCHEN UTENSILS is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	9%	22%	19%	6%	3%	12%
Major Challenge	17%	33%	13%	15%	22%	17%
Moderate Challenge	24%	17%	26%	25%	14%	30%
Minor Challenge	21%	17%	26%	22%	18%	17%
Not a Challenge	26%	11%	13%	27%	40%	21%
No response	3%	-	3%	4%	3%	3%

**TABLE S-103e:** Rate how much of a challenge SWALLOWING, EATING, DRINKING is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	5%	11%	6%	3%	5%	6%
Major Challenge	14%	33%	6%	12%	9%	19%
Moderate Challenge	20%	6%	29%	20%	17%	23%
Minor Challenge	28%	33%	23%	29%	29%	24%
Not a Challenge	31%	17%	29%	32%	37%	27%
No response	3%	-	6%	4%	3%	-

**TABLE S-103f:** Rate how much of a challenge WASHING (SHOWERING, BATHING) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	9%	44%	23%	3%	3%	14%
Major Challenge	14%	22%	23%	10%	14%	17%
Moderate Challenge	19%	17%	10%	17%	22%	23%
Minor Challenge	21%	6%	26%	26%	15%	15%
Not a Challenge	36%	11%	13%	41%	45%	30%
No response	2%	-	6%	3%	2%	1%

**TABLE S-103g:** Rate how much of a challenge DRESSING (DOING UP BUTTONS, ZIPPERS) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	10%	33%	26%	6%	9%	10%
Major Challenge	17%	39%	19%	16%	8%	19%
Moderate Challenge	22%	11%	13%	23%	18%	30%
Minor Challenge	22%	6%	23%	26%	20%	20%
Not a Challenge	27%	11%	16%	27%	43%	20%
No response	2%	-	3%	2%	2%	1%

**COMMUNICATION Activities**

**TABLE S-104a:** Rate how much of a challenge SPEAKING (PRONOUNCING WORDS) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	3%	22%	3%	4%	2%	1%
Major Challenge	15%	33%	23%	11%	6%	21%
Moderate Challenge	23%	22%	19%	27%	14%	23%
Minor Challenge	24%	17%	16%	26%	22%	26%
Not a Challenge	33%	6%	35%	30%	55%	27%
No response	2%	-	3%	2%	2%	2%

**TABLE S-104b:** Rate how much of a challenge WRITING (HOLDING A PEN) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	5%	28%	10%	4%	5%	3%
Major Challenge	17%	33%	19%	14%	11%	22%
Moderate Challenge	18%	11%	6%	20%	8%	29%
Minor Challenge	22%	22%	35%	24%	18%	17%
Not a Challenge	35%	6%	23%	35%	57%	26%
No response	3%	-	6%	3%	2%	3%

**PSYCHOLOGICAL Activities**

**TABLE S-105a:** Rate how much of a challenge CONCENTRATING is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	1%	6%	3%	1%	2%	1%
Major Challenge	14%	22%	13%	15%	6%	15%
Moderate Challenge	25%	33%	32%	24%	26%	27%
Minor Challenge	25%	33%	16%	24%	29%	23%
Not a Challenge	32%	6%	29%	32%	34%	34%
No response	3%	-	6%	5%	3%	-

**TABLE S-105b:** Rate how much of a challenge ALERTNESS (STAYING AWAKE) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	2%	-	3%	2%	3%	1%
Major Challenge	18%	6%	13%	21%	18%	18%
Moderate Challenge	27%	22%	32%	26%	26%	30%
Minor Challenge	28%	39%	35%	28%	26%	24%
Not a Challenge	22%	33%	10%	19%	25%	26%
No response	3%	-	6%	4%	2%	1%

**TABLE S-105c:** Rate how much of a challenge PUTTING THOUGHTS INTO WORDS is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	3%	28%	3%	3%	-	3%
Major Challenge	11%	22%	10%	11%	11%	9%
Moderate Challenge	22%	28%	29%	20%	14%	27%
Minor Challenge	21%	11%	16%	21%	23%	19%
Not a Challenge	41%	11%	35%	41%	49%	43%
No response	2%	-	6%	3%	3%	-

**TABLE S-105d:** Rate how much of a challenge PLANNING DAILY ACTIVITIES is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	5%	44%	3%	4%	2%	5%
Major Challenge	10%	22%	16%	10%	3%	13%
Moderate Challenge	19%	17%	26%	19%	15%	20%
Minor Challenge	21%	6%	16%	22%	25%	21%
Not a Challenge	40%	11%	32%	41%	54%	38%
No response	3%	-	6%	5%	2%	2%

**TABLE S-105e:** Rate how much of a challenge REMEMBERING THINGS is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	2%	6%	6%	2%	2%	1%
Major Challenge	14%	28%	6%	12%	15%	17%
Moderate Challenge	22%	17%	26%	25%	20%	18%
Minor Challenge	25%	22%	29%	23%	31%	23%
Not a Challenge	35%	28%	29%	35%	29%	39%
No response	3%	-	3%	4%	3%	1%

**SOCIAL Activities****TABLE S-106a:** Rate how much of a challenge ROMANTIC, EMOTIONAL, INTIMATE LIFE is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	16%	67%	26%	9%	14%	19%
Major Challenge	15%	6%	10%	17%	11%	20%
Moderate Challenge	11%	-	13%	10%	15%	11%
Minor Challenge	17%	-	16%	19%	15%	16%
Not a Challenge	31%	22%	26%	34%	35%	22%
No response	10%	6%	10%	11%	9%	12%

**TABLE S-106b:** Rate how much of a challenge RELATIONSHIPS/INTERACTIONS WITH OTHERS are for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	2%	11%	-	2%	2%	2%
Major Challenge	13%	33%	26%	12%	6%	11%
Moderate Challenge	17%	17%	19%	17%	12%	22%
Minor Challenge	20%	11%	10%	20%	26%	19%
Not a Challenge	43%	22%	42%	43%	49%	40%
No response	5%	6%	3%	6%	5%	5%

**TABLE S-106c:** Rate how much of a challenge DISCLOSURE (TALKING ABOUT YOUR DISEASE) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	7%	61%	6%	4%	-	6%
Major Challenge	9%	6%	13%	9%	5%	11%
Moderate Challenge	11%	11%	10%	11%	9%	13%
Minor Challenge	18%	6%	13%	21%	15%	18%
Not a Challenge	49%	17%	48%	48%	66%	45%
No response	7%	-	10%	7%	5%	7%

**DOCTORS' OFFICE Activities****TABLE S-107a:** Rate how much of a challenge PREPARING FOR A VISIT TO THE DOCTOR is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	7%	50%	13%	5%	2%	4%
Major Challenge	7%	17%	13%	5%	8%	10%
Moderate Challenge	10%	6%	10%	12%	9%	10%
Minor Challenge	22%	22%	13%	18%	25%	33%
Not a Challenge	48%	6%	48%	53%	54%	37%
No response	5%	-	3%	7%	3%	6%

**TABLE S-107b:** Rate how much of a challenge ADVOCATING FOR APPROPRIATE CARE is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	9%	61%	6%	6%	3%	13%
Major Challenge	10%	11%	19%	11%	8%	10%
Moderate Challenge	14%	-	26%	12%	12%	17%
Minor Challenge	17%	11%	3%	17%	18%	21%
Not a Challenge	42%	17%	42%	44%	52%	32%
No response	7%	-	3%	10%	6%	7%

**TABLE S-107c:** Rate how much of a challenge BOOKING/TRACKING APPOINTMENTS is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	13%	78%	26%	8%	5%	13%
Major Challenge	7%	6%	16%	6%	2%	12%
Moderate Challenge	8%	-	3%	10%	8%	9%
Minor Challenge	14%	-	6%	13%	15%	19%
Not a Challenge	51%	17%	45%	55%	68%	41%
No response	6%	-	3%	8%	3%	6%

**WORK/SCHOOL Activities****TABLE S-108a:** Rate how much of a challenge COMPLETING YOUR EDUCATION/SCHOOLING is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	13%	28%	26%	10%	8%	17%
Major Challenge	8%	39%	19%	6%	2%	9%
Moderate Challenge	5%	11%	13%	4%	3%	5%
Minor Challenge	5%	-	3%	7%	-	9%
Not a Challenge	38%	22%	16%	44%	45%	31%
No response	30%	-	23%	28%	43%	30%

**TABLE S-108b:** Rate how much of a challenge EMPLOYMENT (OBTAINING/RETAINING WORK) is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	36%	72%	52%	29%	29%	43%
Major Challenge	8%	17%	-	12%	2%	7%
Moderate Challenge	4%	-	-	4%	6%	4%
Minor Challenge	5%	-	6%	8%	2%	4%
Not a Challenge	20%	11%	6%	21%	31%	14%
No response	26%	-	35%	25%	31%	28%

**TABLE S-108c:** Rate how much of a challenge PERFORMING YOUR TASKS AT WORK/SCHOOL is for the subject:

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Unable to Perform	22%	17%	29%	17%	22%	33%
Major Challenge	11%	39%	19%	12%	5%	5%
Moderate Challenge	10%	28%	3%	11%	9%	10%
Minor Challenge	8%	6%	6%	10%	3%	9%
Not a Challenge	22%	11%	10%	25%	28%	17%
No response	26%	18%	31%	22%	31%	34%

**TABLE S-109:** Which of these challenges do you think impacts the subject's daily life the MOST?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Mobility	39%	22%	45%	39%	43%	36%
Household and personal needs	23%	28%	16%	25%	22%	22%
Social	23%	11%	23%	27%	15%	26%
Work/school	21%	17%	26%	24%	12%	21%
Psychological	20%	22%	26%	24%	14%	16%
Communication	9%	44%	26%	9%	5%	3%
Doctors' office	7%	6%	10%	4%	5%	13%
No response	18%	17%	10%	16%	26%	21%

**TABLE S-110:** What do you think is the subject's biggest obstacles in managing their daily life?

	Overall (n=402)	cDM1-71 (n=18)	cDM1-94 (n=31)	DM1 (n=187)	DM2 (n=65)	U/U (n=94)
Mobility/ Balance/ Accessibility	22%	11%	29%	13%	37%	28%
Other Physical Challenges/ Symptoms	21%	33%	29%	20%	20%	19%
Sleep and Fatigue	14%	6%	6%	20%	11%	10%
Emotional-Psychological	13%	-	10%	13%	15%	14%
Cognitive-Psychological	13%	11%	16%	17%	3%	12%
Dependency/ Reliance on Others	5%	11%	6%	4%	6%	5%
Household Chores/ Daily Activities	5%	6%	6%	4%	6%	6%
Access to Care and Information	2%	-	-	3%	2%	1%
Other	2%	6%	-	3%	2%	2%
No response	21%	28%	23%	21%	22%	20%

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