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TITLE: Development of a Lifespan-Based Novel Composite Person-Reported Outcome Measure Using Data From the CINRG Duchenne Natural History Study

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Development of a Lifespan-Based Novel Composite Person-Reported Outcome Measure Using Data From the CINRG Duchenne Natural History Study

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Our proposed project will use quality of life questionnaire data from the first 4-7 years of ongoing Cooperative International Neuromuscular Research Group (CINRG) Duchenne Natural History Study. Using that data, we will identify questions that show differences between people with different levels of abilities (such as those who can walk or just raise a hand to the mouth), or that show changes over one year that might be seen by researchers during drug clinical trials. Those questions will then be combined and built into a computerized adaptive testing (CAT) system that will produce short, individualized surveys for clinical practice and clinical trial use that are tailored to a patients’ level of functional ability.
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1. INTRODUCTION:

**Background:** Development of novel technologies and therapeutic agents to treat Duchenne muscular dystrophy (DMD) have increased interest by regulatory bodies such as the Food and Drug Administration in the development of “clinically-meaningful” study endpoints for clinical trials. There is a need for the development of person-reported outcome (PRO) instruments that target a broad range of developmental and functional ability while effectively evaluating treatment effects in clinical trials.

**Objective:** Our proposed project will use quality of life questionnaire data from the first 4-7 years of ongoing Cooperative International Neuromuscular Research Group (CINRG) Duchenne Natural History Study. Using that data, we will identify questions that show differences between people with different levels of abilities (such as those who can walk or just raise a hand to the mouth), or that show changes over one year that might be seen by researchers during drug clinical trials. Those questions will then be combined and built into a computerized adaptive testing (CAT) system that will produce short, individualized surveys for clinical practice and clinical trial use that are tailored to a patients’ level of functional ability.

**Applicability:** Well-designed CAT-PRO questionnaires can be used in both clinical trials and day-to-day clinical practice. For clinical trials, they provide researchers with the ability to put all patients, regardless of their functional abilities, together on the same scale. That means that one tool can be used to evaluate quality of life across many types of studies and many groups of patients, but that the results can still be compared. Those results can then also be compared to other clinical trial measures such as strength tests, timed function tests, or pulmonary function tests to help teach researchers and regulatory authorities about how “in clinic” tests commonly used in clinical trials relate to a persons’ quality of life, and whether those tests are “clinically meaningful”. In day-to-day clinical practice, it means that doctors can have a single tool that can give feedback on a patient’s quality of life, even as their levels of ability change over time. Within 3 years, this project will be able to produce such a useful tool because much of the data has already been collected from the CINRG study and because the rest of the data will be from the large group of over 3000 volunteers who are already part of the Parent Project Muscular Dystrophy DuchenneConnect Registry.

**Impact and Contributions:** Data from the CINRG DMD natural history study cohort and the DuchenneConnect Registry will provide the basis for development of a “clinical trial-ready” novel CAT-based PRO measure that has been constructed against a background of comprehensive clinical assessments of strength and function across the DMD lifespan. This PRO measure will be rapidly usable as a sensitive measure for use in the growing field of DMD clinical trials, and will help to demonstrate “clinically meaningful” results to regulatory agencies in charge of new drug approval.

2. KEYWORDS:

Duchenne muscular dystrophy  
Person-reported outcomes  
Health-related quality of life  
Functional health assessment  
UC Davis / CINRG Duchenne Natural History Study
3. ACCOMPLISHMENTS: The PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency grants official whenever there are significant changes in the project or its direction.

What were the major goals of the project?
List the major goals of the project as stated in the approved SOW. If the application listed milestones/target dates for important activities or phases of the project, identify these dates and show actual completion dates or the percentage of completion.

Aim 1: Development of ICF-based Item Banks from CINRG DNHS PRO Data (Year 1, Months 1-6) - We will evaluate item responses across domains to develop domain-specific item banks for a composite PRO measure. We will evaluate responsiveness of PRO subscales and items at differing levels of function that represent functionally-meaningful activities of standing from supine, climbing stairs, rising from a chair, ambulating independently, reaching overhead, raising a hand to the mouth for feeding, and the need for mechanical cough assistance for airway clearance (defined as having a forced vital capacity >50% of predicted values for age). Data will include all available completed PRO form sets for all participants from the baseline visit up to at least the month 48 visit, and will an age range of 5-32+ years, which will represent approximately 1200+ 12-month intervals. Clinical data will include steroid treatment status, anthropometrics, timed motor performance testing (time to stand from supine, time to climb 4 stairs, time to run/walk 10 meters), Brooke and Vignos scales, and forced vital capacity pulmonary function. Some data from the cohort will be available out to 7 years of participation. At each visit time point, participants will be classified into a functional milestone group as previously described. Using that milestone grouping, we will evaluate 12-month change for each year of study participation. Those who increase in milestone scale score will be classified as having lost a functional milestone during that period. Participants will also be classified by steroid-user status as glucocorticoid naïve, previously-treated or currently-treated. Their questionnaire responses will be scored into instrument total and subscale scores per standard guidelines. Responses on all individual items will also be evaluated independently. Each instrument subscale and item will be classified according to ICF domain and subdomain for inclusion in domain-based item banks. Level of significance will be set at p<0.05.

Aim 1.1: Selection of Initial Item Bank Content (Year 1, Month 1-3) – Using all available PRO data, we will evaluate item responses across domains to develop domain-specific item banks for a composite PRO measure. We will evaluate responsiveness of PRO subscales and items at differing levels of function that represent functionally-meaningful activities of standing from supine, climbing stairs, rising from a chair, ambulating independently, reaching overhead, raising a hand to the mouth for feeding, and the need for mechanical cough assistance for airway clearance (defined as having a forced vital capacity >50% of predicted values for age).

Task 1 (COMPLETE) – Human Subject Protection Approval Submission to DoD: In collaboration with data management staff at the Cooperative International Neuromuscular Research Group, we will submit IRB approvals from sites engaged in the CINRG Duchenne Natural History Study (DNHS). The project is currently funded by DoD and site approvals have been obtained previously. As this portion of the project involves data analysis only, no additional research aims require addition to the original study protocol. Participants have already consented to collection and analysis of PRO data by the project PI and CINRG collaborators. DoD-specific consent language has been added as required and consent for project participation has been collected from participants. This subtask will be conducted by Dr. Henricson and Mr. de Bie.

Task 2 (COMPLETE) - Dataset curation and formatting: In collaboration with data management staff at the Cooperative International Neuromuscular Research Group, we will reference the full-scale dataset from the CINRG Duchenne Natural History Study (DNHS) to construct an analysis-ready dataset including the functional milestone and PRO item responses required in the Aim 1 analysis. This subtask will be conducted by Dr. Henricson and Mr. de Bie.

Task 3 (COMPLETE) - PRO data analysis and WHO-ICF domain-based item bank construction: PRO instrument items will be evaluated to construct item banks based on the WHO-ICF domain structure. This subtask will be conducted by Dr. Henricson.

Aim 1.2 (Year 1, Month 4-5): To refine the item banks and ensure coverage across the entire spectrum of disease, we will identify ranges of function where overlapping PRO items or gaps in item content exist against a backdrop of the entire range of meaningful functional abilities demonstrated by the DMD population across all age groups.
Task 1 (COMPLETE) – Factor analysis and Rasch analysis to identify item bank performance (Months 4-5). Analysis for this aim will be conducted by Dr. Bagley, with the input and assistance of Dr. Henricson, Dr. McDonald and Dr. Joyce.

Aim 1.3: Focus Groups to Develop Supplemental Domain Items (Year 3) – To address areas of overlap and gaps in item content, we will conduct focus group discussions with an expert advisory group of DMD clinical research professionals, health care providers, parent caregivers, and patients with DMD to identify relevant items for inclusion in a composite PRO measure, and to develop new items where suitable ones do not exist.

Task 1 (COMPLETE) – Human Subject Protection Approval Submission to DoD: The project PI and co-investigators will develop a human subjects protocol and consent documentation for key informant interviews and focus groups, and will obtain IRB approval from UC Davis. UC Davis IRB approvals will be submitted to DoD HRPO for revision and approval. DoD revisions will be reviewed and approved by the UC Davis IRB. This task will be completed by Dr. McDonald, Dr. Henricson, Dr. Joyce and Mr. Owens.

Task 2 (COMPLETE) – Clinical expert key informant interviews: Areas of overlap and gaps in item content will be discussed via teleconference with a group of DMD clinical experts to identify possible question content to supplement the existing item banks. This task will be conducted by Dr. Joyce and Dr. Henricson with the assistance of outreach coordinator Erica Goude.

Task 3 (COMPLETE) – Patient and Caregiver focus groups: Areas of overlap and gaps in item content will be discussed in small focus groups of DMD patients and parents/guardians in face-to-face meetings at the UC Davis Center for Neuromuscular Disease Research. This task will be conducted by Dr. Joyce and Dr. Henricson with the assistance of outreach coordinator Erica Goude.

Task 4 (COMPLETE) – Existing PRO item review and new item generation: The frequently mentioned and most relevant items will be compared to existing PRO tools to determine whether there are pre-existing question items that can be included in the item banks. Where none exist, new items will be developed and reviewed with focus group participants from Task 2 prior to inclusion. This task will be conducted by Dr. Joyce, Dr. McDonald, Dr. Mulcahey and Dr. Henricson.

AIM 2: Pilot Testing of WHO-ICF Domain Item Banks using DuchenneConnect (Year 4)
DuchenneConnect is a web-based DMD patient data registry and epidemiology research tool hosted by Parent Project Muscular Dystrophy that is used by more than 3000 families worldwide to track important clinical data related to the health, function and health services utilization of their family member(s) with DMD. We will work with DuchenneConnect administrators to publish an online version of the full PRO banks including all final items across domains. We will ask DuchenneConnect participants to enroll in the study and complete question sets at baseline. One year later participants will be contacted by email and reminded to complete a follow-up set of assessments after 1 year of follow-up. Data will be combined with registry self-report glucocorticoid use and measures of functional “milestone” ability data.

Task 1 (COMPLETE) – Development of web-based item bank questionnaires: Using final pilot item banks developed in Aim 1, Dr. Henricson and Mr. Owens will work with PPMD DuchenneConnect representatives to construct a web-based version of item bank questionnaires and the related back-end database and accompanying data dictionary.

Task 2 – (COMPLETE) IRB review and approval of web-based DuchenneConnect item bank questionnaires: Dr. Henricson and Mr. Owens will coordinate IRB submission and review of web-based questionnaires and recruiting materials. This is a minimal risk study and can be processed at UC Davis via expedited IRB review.

Task 3 – (COMPLETE) Human Subject Protection Approval Submission to DoD: UC Davis IRB approvals will be submitted to DoD HRPO for revision and approval. DoD revisions will be reviewed and approved by the UC Davis IRB. This task will be completed by Dr. McDonald, Dr. Henricson, and Mr. Owens
Task 4 – (COMPLETE) Recruiting and launch of web-based forms in collaboration with DuchenneConnect: UC Davis outreach coordinator Erica Goude will collaborate with DuchenneConnect staff to provide email outreach and study recruiting to all participating DuchenneConnect members. This activity will continue until the end of Year 2.

Aim 2.1: Validation of New Domain-Based Item Banks (In progress) – Prospective 1-year data from the DuchenneConnect registry application of newly-derived item banks will be evaluated using techniques described in Aim 1 to confirm that items are responsive to self-reported changes in milestone ability over a time period consistent with design of contemporary clinical trials. Rasch analysis will be repeated to confirm item fit and performance for retained and newly-developed items.

Task 1 – Confirmatory Rasch Analysis: Item response data collected via DuchenneConnect will be tested to confirm responsiveness to changes in self-reported functional milestone abilities. Item responses for the draft item banks including new items directed to fill “gaps” will be re-analyzed by RASCH to confirm their item fit and performance. Dr. Bagley will conduct this activity, with input and data review by Dr. McDonald, Dr. Mulcahey, Dr. Joyce, and Dr. Henricson.

Aim 2.2: Identification of Item Responsiveness to Group Differences Due to Glucocorticoid Therapy (In progress) Evaluate the responsiveness of the composite PRO item banks to differences in milestone scores. We will test the hypothesis that functionally-specific mobility and ADL PRO items will be differentially responsive functional “milestone” abilities.

Task 1 – Evaluation of responsiveness to differences functional “milestone” ability: Dr. Bagley and Dr. Henricson will conduct this activity, with input and data review by Dr. McDonald, Dr. Mulcahey, and Dr. Joyce.

AIM 3: Development of a Computerized Adaptive Testing PRO instrument for use in clinical trials (In progress) In the third year of the project, we will use Year 2 pilot data to develop a brief computerized adaptive testing (CAT) version of the new composite PRO instrument, and we will make it available to the clinical research community for inclusion in natural history studies and clinical trials for persons with DMD.

Aim 3.1: Perform a CAT simulation from data obtained from the comprehensive PRO item banks A real data simulation approach will be used to investigate the accuracy of each CAT generated from the full-item banks.

Task 1: Dr. Mulcahey will lead the group in developing CAT simulations for 5-, 10- and 15-item computer adaptive tests.

Aim 3.2: Establish discriminant and concurrent validity of the CAT version of the composite PRO in parents/caregivers of DMD subjects Evaluation of the ability of the mobility and daily routines full-item banks and the 5-, 10-, and 15-item simulated CATs to discriminate between and among groups of DMD subjects.

Task 1 – IRB review and approval of CAT PRO simulations: Dr. Henricson and Mr. Owens will coordinate IRB submission and review of CAT simulation protocols and recruiting materials to enroll 80 DNHS participants at UC Davis. This is a minimal risk study and can be processed at UC Davis via expedited IRB review.

Task 2 – Human Subject Protection Approval Submission to DoD: UC Davis IRB approvals will be submitted to DoD HRPO for revision and approval. DoD revisions will be reviewed and approved by the UC Davis IRB. This task will be completed by Dr. McDonald, Dr. Henricson, and Mr. Owens.

Task 3 – Dr. Mulcahey will lead the group in comparing results of newly-developed CAT evaluations to functional performance data collected on 80 DNHS participants enrolled at UC Davis in conjunction with their regularly scheduled study visits.
What was accomplished under these goals?

**Aim 1: Development of ICF-based Item Banks from CINRG DNHS PRO Data (Completed)**

**Aim 1.1: Selection of Initial Item Bank Content (Completed)** – Using all available PRO data, we will evaluate item responses across domains to develop domain-specific item banks for a composite PRO measure. We will evaluate responsiveness of PRO subscales and items at differing levels of function that represent functionally-meaningful activities of standing from supine, climbing stairs, rising from a chair, ambulating independently, reaching overhead, raising a hand to the mouth for feeding, and the need for mechanical cough assistance for airway clearance (defined as having a forced vital capacity >50% of predicted values for age).

**Aim 1.2 (Completed):** To refine the item banks and ensure coverage across the entire spectrum of disease, we will identify ranges of function where overlapping PRO items or gaps in item content exist against a backdrop of the entire range of meaningful functional abilities demonstrated by the DMD population across all age groups.

**Aim 1.3: Focus Groups to Develop Supplemental Domain Items (Completed)** – To address areas of overlap and gaps in item content, we will conduct focus group discussions with an expert advisory group of DMD clinical research professionals, health care providers, parent caregivers, and patients with DMD to identify relevant items for inclusion in a composite PRO measure, and to develop new items where suitable ones do not exist.

**AIM 2: Pilot Testing of WHO-ICF Domain Item Banks using DuchenneConnect (In progress)** – DuchenneConnect is a web-based DMD patient data registry and epidemiology research tool hosted by Parent Project Muscular Dystrophy (PPMD) that is used by more than 3000 families worldwide to track important clinical data related to the health, function and health services utilization of their family member(s) with DMD. We will work with DuchenneConnect administrators to publish an online version of the full PRO banks including all final items across domains. We will ask DuchenneConnect participants to enroll in the study and complete question sets at baseline. One year later participants will be contacted by email and reminded to complete a follow-up set of assessments after 1 year of follow-up. Data will be combined with registry self-report glucocorticoid use and measures of functional “milestone” ability data.

**Accomplishments and Results:** Full PRO online question bank shared with PPMD DuchenneConnect registry team and the muscular dystrophy association. See Appendix 1 for details about study enrollment to date.

**Aim 2.1: Validation of New Domain-Based Item Banks (In Progress)** – Prospective 1-year data from the DuchenneConnect registry application of newly-derived item banks will be evaluated using techniques described in Aim 1 to confirm that items are responsive to self-reported changes in milestone ability over a time period consistent with design of contemporary clinical trials. Rasch analysis will be repeated to confirm item fit and performance for retained and newly-developed items.

**Aim 2.2: Identification of Item Responsiveness to Group Differences Due to Glucocorticoid Therapy (In Progress)**
Evaluate the responsiveness of the composite PRO item banks to differences in milestone scores. We will test the hypothesis that functionally-specific mobility and ADL PRO items will be differentially responsive functional “milestone” abilities.

**AIM 3: Development of a Computerized Adaptive Testing PRO instrument for use in clinical trials (In progress)**
In the fourth year of the project, we will use Aim 2 pilot data to develop a brief computerized adaptive testing (CAT) version of the new composite PRO instrument, and we will make it available to the clinical research community for inclusion in natural history studies and clinical trials for persons with DMD.

**Aim 3.1: Perform a CAT simulation from data obtained from the comprehensive PRO item banks (In progress)** A real data simulation approach will be used to investigate the accuracy of each CAT generated from the full-item banks.

**Aim 3.2: Establish discriminant and concurrent validity of the CAT version of the composite PRO in parents/ caregivers of DMD subjects (In progress).** Evaluation of the ability of the mobility and daily routines full-item banks and the 5-, 10-, and 15-item simulated CATs to discriminate between and among groups of DMD subjects.
What opportunities for training and professional development has the project provided?
Nothing to Report

How were the results disseminated to communities of interest?
If there is nothing significant to report during this reporting period, state “Nothing to Report.”

Describe how the results were disseminated to communities of interest. Include any outreach activities that were undertaken to reach members of communities who are not usually aware of these project activities, for the purpose of enhancing public understanding and increasing interest in learning and careers in science, technology, and the humanities.

Members of MDA and PPMD communities received two (2) email messages with direct links to the full online version of the DMD-LMS PRO instrument. These direct calls for participation in this project raised awareness of the pressing need for new tools to provide additional person reported outcomes to DMD-related research.

What do you plan to do during the next reporting period to accomplish the goals?
We will continue our outreach efforts and work in tandem with PPMD and the MDA to raise awareness and recruit participants for this research.

4. IMPACT: Describe distinctive contributions, major accomplishments, innovations, successes, or any change in practice or behavior that has come about as a result of the project relative to:

What was the impact on the development of the principal discipline(s) of the project?
Nothing to Report

What was the impact on other disciplines?
Nothing to Report

What was the impact on technology transfer?
Nothing to Report

What was the impact on society beyond science and technology?
Nothing to Report

5. CHANGES/PROBLEMS: The PD/PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency grants official whenever there are significant changes in the project or its direction. If not previously reported in writing, provide the following additional information or state, “Nothing to Report,” if applicable:

Changes in approach and reasons for change
Actual or anticipated problems or delays and actions or plans to resolve them

The full version of the DMD-LMS has only been live for a short time period. Although there has been a good initial response and high level of participation from our outreach efforts to date, our specific aims for this research that require participant data for analysis will be delayed until an sufficient preliminary data set is established.

Changes that had a significant impact on expenditures

Nothing to Report

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents

Nothing to Report

Significant changes in use or care of human subjects

Nothing to Report

Significant changes in use or care of vertebrate animals

Nothing to Report

Significant changes in use of biohazards and/or select agents

Nothing to Report

6. PRODUCTS: List any products resulting from the project during the reporting period. If there is nothing to report under a particular item, state “Nothing to Report.”

Publications, conference papers, and presentations

Nothing to Report

Journal publications

Nothing to Report

Books or other non-periodical, one-time publications.

Nothing to Report

Other publications, conference papers and presentations.

Nothing to Report

- Website(s) or other Internet site(s)

The production version of the DMD-LMS can be accessed via the following link: https://is.gd/ucdavis_dmdlms

- Technologies or techniques

Nothing to Report
7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Name: Craig McDonald, MD (PI) - No Change
Name: Erik Henricson, MPH (Co-Investigator) - No Change
Name: Nanette Joyce, DO (Co-Investigator) - No Change
Name: Anita Bagley, PhD, MPH (Co-Investigator) - No Change
Name: Corey Owens, MS (Data Manager) – No Change
Name: Erica Goude, MS (Outreach Coordinator) - No Change
Name: Mary Jane Mulcahey, PhD (Co-Investigator) – No Change

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Nothing to Report

What other organizations were involved as partners?

Parent Project Muscular Dystrophy and the Muscular Dystrophy Association

8. SPECIAL REPORTING REQUIREMENTS

COLLABORATIVE AWARDS:

QUAD CHARTS:

9. APPENDICES:

1. Enrollment Details and Composite Results to Date for DMD-LMS
## CTSC# 4262: Validity and Field Testing of the Duchenne Muscular Dystrophy Lifetime Mobility Scale (DMD-LMS)

### Data Exports, Reports, and Stats

#### Selected instruments and/or events (all records)

Enter the birth date of the person with DMD:

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<thead>
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</thead>
<tbody>
<tr>
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</table>

#### Today's Date

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<tr>
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<td>0 (0.0%)</td>
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</tbody>
</table>

#### Age in Days

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<th>Unique</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>StDev</th>
<th>Sum</th>
<th>Percentile</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>0 (0.0%)</td>
<td>191</td>
<td>0.00</td>
<td>18,629.00</td>
<td>5,464.37</td>
<td>2,871.52</td>
<td>1,092,873.00</td>
<td>0.05</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2,401.85</td>
<td>2,955.00</td>
<td>3,510.50</td>
<td>4,426.00</td>
<td>6,256.50</td>
</tr>
</tbody>
</table>

Lowest values: 0, 2130, 2184, 2217, 2217  
Highest values: 12451, 12730, 12760, 15516, 18629

![Scatter plot](download-image)

#### Age in Years

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<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
<th>Unique</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>StDev</th>
<th>Sum</th>
<th>Percentile</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>0 (0.0%)</td>
<td>186</td>
<td>0.00</td>
<td>51.00</td>
<td>14.96</td>
<td>7.86</td>
<td>2,992.14</td>
<td>0.05</td>
</tr>
</tbody>
</table>

Lowest values: 0, 5.83, 5.98, 6.07, 6.07  
Highest values: 34.09, 34.85, 34.94, 42.48, 51
Has your child recently turned age 18?

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>200 (100.0%)</td>
</tr>
</tbody>
</table>

Are you / your son with DMD taking steroids for strength maintenance?

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
<th>Unique</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>0 (0.0%)</td>
<td>2</td>
</tr>
</tbody>
</table>

Counts/frequency: Yes (149, 74.5%), No (51, 25.5%)

Stand up from lying on the floor without help?

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
<th>Unique</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>0 (0.0%)</td>
<td>2</td>
</tr>
</tbody>
</table>

Counts/frequency: Yes (70, 35.0%), No (130, 65.0%)
Climb at least 4 stairs without help?

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
<th>Unique</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>0 (0.0%)</td>
<td>2</td>
</tr>
</tbody>
</table>

Counts/frequency: Yes (74, 37.0%), No (126, 63.0%)

Stand up from a chair without help?

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
<th>Unique</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>0 (0.0%)</td>
<td>2</td>
</tr>
</tbody>
</table>

Counts/frequency: Yes (85, 42.5%), No (115, 57.5%)

Walk at least 10 meters (about 30 feet) without help?

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
<th>Unique</th>
</tr>
</thead>
<tbody>
<tr>
<td>200</td>
<td>0 (0.0%)</td>
<td>2</td>
</tr>
</tbody>
</table>

Counts/frequency: Yes (87, 43.5%), No (113, 56.5%)
Reach your arms all the way over your head without help?

Counts/frequency: Yes (121, 60.5%), No (79, 39.5%)

Breathe OK during the day without some type of ventilator or bi-pap machine?

Counts/frequency: Yes (173, 86.5%), No (27, 13.5%)

Complete?

Counts/frequency: Incomplete (0, 0.0%), Unverified (0, 0.0%), Complete (200, 100.0%)
With no difficulty
With some difficulty
With a lot of difficulty
Could not do it

Counts/frequency: With no difficulty (83, 43.9%), With some difficulty (12, 6.3%), With a lot of difficulty (7, 3.7%), Could not do it (87, 46.0%)

I could sit down on a chair without help.

Counts/frequency: With no difficulty (83, 43.9%), With some difficulty (12, 6.3%), With a lot of difficulty (7, 3.7%), Could not do it (87, 46.0%)

I could stand up from a chair without help.

Counts/frequency: With no difficulty (66, 34.7%), With some difficulty (17, 8.9%), With a lot of difficulty (4, 2.1%), Could not do it (103, 54.2%)
With no difficulty

With some difficulty

With a lot of difficulty

Could not do it

I could bend over from a seated position and pick up something off the floor without help.

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<td>189</td>
<td>2 (1.0%)</td>
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</table>

Counts/frequency: With no difficulty (39, 20.6%), With some difficulty (41, 21.7%), With a lot of difficulty (26, 13.8%), Could not do it (83, 43.9%)

I could get down on my knees without holding on to something.
Counts/frequency: With no difficulty (20, 10.6%), With some difficulty (38, 20.1%), With a lot of difficulty (18, 9.5%), Could not do it (113, 59.8%)

I could bend over from a standing position and pick up something off the floor.

Counts/frequency: With no difficulty (29, 15.4%), With some difficulty (34, 18.1%), With a lot of difficulty (13, 6.9%), Could not do it (112, 59.6%)
With no difficulty

With some difficulty

With a lot of difficulty

Could not do it

I could get into bed without help.

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Counts/frequency: With no difficulty (64, 33.9%), With some difficulty (22, 11.6%), With a lot of difficulty (9, 4.8%), Could not do it (94, 49.7%)

I could get out of bed without help.
Counts/frequency: With no difficulty (66, 34.9%), With some difficulty (22, 11.6%), With a lot of difficulty (7, 3.7%), Could not do it (94, 49.7%)

I could change positions/reposition myself in my bed without help.

Counts/frequency: With no difficulty (76, 40.6%), With some difficulty (31, 16.6%), With a lot of difficulty (18, 9.6%), Could not do it (62, 33.2%)
I could get up from the floor without help.

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Counts/frequency: With no difficulty (23, 12.2%), With some difficulty (40, 21.3%), With a lot of difficulty (13, 6.9%), Could not do it (112, 59.6%)

I could get in and out of an adult sized chair without help.
Counts/frequency: With no difficulty (59, 31.4%), With some difficulty (21, 11.2%), With a lot of difficulty (8, 4.3%), Could not do it (100, 53.2%)

I could get on and off a chair without help and without using my arms.

Counts/frequency: With no difficulty (26, 13.9%), With some difficulty (36, 19.3%), With a lot of difficulty (9, 4.8%), Could not do it (116, 62.0%)
I could get on and off a low chair without help.

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<tr>
<td>186</td>
<td>5 (2.6%)</td>
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</table>

Counts/frequency: With no difficulty (42, 22.6%), With some difficulty (26, 14.0%), With a lot of difficulty (14, 7.5%), Could not do it (104, 55.9%)

I could get on and off a toilet without help.
Counts/frequency: With no difficulty (66, 35.1%), With some difficulty (14, 7.4%), With a lot of difficulty (5, 2.7%), Could not do it (103, 54.8%)

I could climb into a bathtub without a tub bench without help.

Counts/frequency: With no difficulty (44, 23.7%), With some difficulty (22, 11.8%), With a lot of difficulty (9, 4.8%), Could not do it (111, 59.7%)
With no difficulty
With some difficulty
With a lot of difficulty
Could not do it

I could climb out of a bathtub without a tub bench without help.

Count/frequency: With no difficulty (35, 18.9%), With some difficulty (28, 15.1%), With a lot of difficulty (12, 6.5%), Could not do it (110, 59.5%)

I could transfer to a tub bench without help.
With no difficulty (58, 31.2%), With some difficulty (21, 11.3%), With a lot of difficulty (7, 3.8%), Could not do it (100, 53.8%)

Counts/frequency: With no difficulty (58, 31.2%), With some difficulty (21, 11.3%), With a lot of difficulty (7, 3.8%), Could not do it (100, 53.8%)

I could transfer from a tub bench without help.

Counts/frequency: With no difficulty (55, 29.7%), With some difficulty (20, 10.8%), With a lot of difficulty (5, 2.7%), Could not do it (105, 56.8%)
I could sit on a bench without back support for 15 minutes without help.

**Counts/frequency:** With no difficulty (68, 37.0%), With some difficulty (44, 23.9%), With a lot of difficulty (11, 6.0%), Could not do it (61, 33.2%)

---

I could sit on a bench without back support for 30 minutes without help.
With no difficulty (47, 25.8%), With some difficulty (45, 24.7%), With a lot of difficulty (21, 11.5%), Could not do it (69, 37.9%)

I could sit in a regular chair without help and without holding on.

Counts/frequency: With no difficulty (83, 44.9%), With some difficulty (32, 17.3%), With a lot of difficulty (14, 7.6%), Could not do it (56, 30.3%)
I could stand on my tiptoes to reach for something without help.

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</table>

Counts/frequency: With no difficulty (52, 28.1%), With some difficulty (25, 13.5%), With a lot of difficulty (4, 2.2%), Could not do it (104, 56.2%)

I could turn my head all the way to the side to look at someone or something without help.
Counts/frequency: With no difficulty (128, 69.2%), With some difficulty (20, 10.8%), With a lot of difficulty (11, 5.9%), Could not do it (26, 14.1%)

I could turn myself during the night without help.

Counts/frequency: With no difficulty (81, 44.3%), With some difficulty (22, 12.0%), With a lot of difficulty (16, 8.7%), Could not do it (64, 35.0%)
I could stand while washing my hands and face at a sink without help.

<table>
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<td>182</td>
<td>9 (4.7%)</td>
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</table>

Counts/frequency: With no difficulty (77, 42.3%), With some difficulty (12, 6.6%), With a lot of difficulty (5, 2.7%), Could not do it (88, 48.4%)

I could get in and out of a low vehicle (car) without help.
With no difficulty (43, 23.4%), With some difficulty (30, 16.3%), With a lot of difficulty (7, 3.8%), Could not do it (104, 56.5%)

Counts/frequency: With no difficulty (43, 23.4%), With some difficulty (30, 16.3%), With a lot of difficulty (7, 3.8%), Could not do it (104, 56.5%)

I could get in and out of a high-clearance vehicle (SUV or truck ) without help.

Counts/frequency: With no difficulty (6, 3.3%), With some difficulty (48, 26.2%), With a lot of difficulty (18, 9.8%), Could not do it (111, 60.7%)

Counts/frequency: With no difficulty (6, 3.3%), With some difficulty (48, 26.2%), With a lot of difficulty (18, 9.8%), Could not do it (111, 60.7%)
I could nod my head "yes" without help.

Counts/frequency: With no difficulty (161, 87.5%), With some difficulty (17, 9.2%), With a lot of difficulty (2, 1.1%), Could not do it (4, 2.2%)
With no difficulty (78, 42.6%), With some difficulty (41, 22.4%), With a lot of difficulty (22, 12.0%), Could not do it (42, 23.0%)

Counts/frequency:

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</thead>
<tbody>
<tr>
<td>183</td>
<td>8 (4.2%)</td>
<td>4</td>
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</table>

I could balance while sitting on the toilet without help.

Counts/frequency: With no difficulty (106, 58.2%), With some difficulty (30, 16.5%), With a lot of difficulty (8, 4.4%), Could not do it (38, 20.9%)

<table>
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<td>9 (4.7%)</td>
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</table>
I could wipe/clean myself after using the toilet without help.

<table>
<thead>
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<tr>
<td>180</td>
<td>11 (5.8%)</td>
<td>4</td>
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</table>

Counts/frequency: With no difficulty (58, 32.2%), With some difficulty (31, 17.2%), With a lot of difficulty (11, 6.1%), Could not do it (80, 44.4%)
Counts/frequency: Incomplete (7, 3.7%), Unverified (0, 0.0%), Complete (184, 96.3%)

<table>
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<td>191</td>
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</table>
CTSC# 4262: Validity and Field Testing of the Duchenne Muscular Dystrophy Lifetime Mobility Scale (DMD-LMS)

Data Exports, Reports, and Stats

Selected instruments and/or events (all records)

I could sit down on a chair without help.

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Counts/frequency: With no difficulty (83, 43.9%), With some difficulty (12, 6.3%), With a lot of difficulty (7, 3.7%), Could not do it (87, 46.0%)

I could stand up from a chair without help.

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<tbody>
<tr>
<td>190</td>
<td>1 (0.5%)</td>
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</table>

Counts/frequency: With no difficulty (66, 34.7%), With some difficulty (17, 8.9%), With a lot of difficulty (4, 2.1%), Could not do it (103, 54.2%)
I could bend over from a seated position and pick up something off the floor without help.

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Counts/frequency: With no difficulty (39, 20.6%), With some difficulty (41, 21.7%), With a lot of difficulty (26, 13.8%), Could not do it (83, 43.9%)

I could get down on my knees without holding on to something.
Counts/frequency: With no difficulty (20, 10.6%), With some difficulty (38, 20.1%), With a lot of difficulty (18, 9.5%), Could not do it (113, 59.8%)

I could bend over from a standing position and pick up something off the floor.

Counts/frequency: With no difficulty (29, 15.4%), With some difficulty (34, 18.1%), With a lot of difficulty (13, 6.9%), Could not do it (112, 59.6%)
I could get into bed without help.

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Counts/frequency: With no difficulty (64, 33.9%), With some difficulty (22, 11.6%), With a lot of difficulty (9, 4.8%), Could not do it (94, 49.7%)

I could get out of bed without help.
Counts/frequency: With no difficulty (66, 34.9%), With some difficulty (22, 11.6%), With a lot of difficulty (7, 3.7%), Could not do it (94, 49.7%)

I could change positions/reposition myself in my bed without help.

Counts/frequency: With no difficulty (76, 40.6%), With some difficulty (31, 16.6%), With a lot of difficulty (18, 9.6%), Could not do it (62, 33.2%)
I could get up from the floor without help.

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Counts/frequency: With no difficulty (23, 12.2%), With some difficulty (40, 21.3%), With a lot of difficulty (13, 6.9%), Could not do it (112, 59.6%)

I could get in and out of an adult sized chair without help.
With no difficulty (59, 31.4%), With some difficulty (21, 11.2%), With a lot of difficulty (8, 4.3%), Could not do it (100, 53.2%)

Counts/frequency: With no difficulty (59, 31.4%), With some difficulty (21, 11.2%), With a lot of difficulty (8, 4.3%), Could not do it (116, 62.0%)

I could get on and off a chair without help and without using my arms.

Counts/frequency: With no difficulty (26, 13.9%), With some difficulty (36, 19.3%), With a lot of difficulty (9, 4.8%), Could not do it (116, 62.0%)
I could get on and off a low chair without help.

**Counts/frequency:** With no difficulty (42, 22.6%), With some difficulty (26, 14.0%), With a lot of difficulty (14, 7.5%), Could not do it (104, 55.9%)

---

**Counts/frequency:** With no difficulty (32, 33%), With some difficulty (30, 31%), With a lot of difficulty (12, 12%), Could not do it (58, 60%)

---

I could get on and off a toilet without help.
Counts/frequency: With no difficulty (66, 35.1%), With some difficulty (14, 7.4%), With a lot of difficulty (5, 2.7%), Could not do it (103, 54.8%)

Counts/frequency: With no difficulty (44, 23.7%), With some difficulty (22, 11.8%), With a lot of difficulty (9, 4.8%), Could not do it (111, 59.7%)
I could climb out of a bathtub without a tub bench without help.

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Counts/frequency: With no difficulty (35, 18.9%), With some difficulty (28, 15.1%), With a lot of difficulty (12, 6.5%), Could not do it (110, 59.5%)

I could transfer to a tub bench without help.
With no difficulty (58, 31.2%), With some difficulty (21, 11.3%), With a lot of difficulty (7, 3.8%), Could not do it (100, 53.8%)

I could transfer from a tub bench without help.

Counts/frequency: With no difficulty (55, 29.7%), With some difficulty (20, 10.8%), With a lot of difficulty (5, 2.7%), Could not do it (105, 56.8%)
With no difficulty
With some difficulty
With a lot of difficulty
Could not do it

I could sit on a bench without back support for 15 minutes without help.

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Counts/frequency: With no difficulty (68, 37.0%), With some difficulty (44, 23.9%), With a lot of difficulty (11, 6.0%), Could not do it (61, 33.2%)

With no difficulty
With some difficulty
With a lot of difficulty
Could not do it

I could sit on a bench without back support for 30 minutes without help.
With no difficulty (47, 25.8%), With some difficulty (45, 24.7%), With a lot of difficulty (21, 11.5%), Could not do it (69, 37.9%)

Counts/frequency: With no difficulty (47, 25.8%), With some difficulty (45, 24.7%), With a lot of difficulty (21, 11.5%), Could not do it (69, 37.9%)

I could sit in a regular chair without help and without holding on.

Counts/frequency: With no difficulty (83, 44.9%), With some difficulty (32, 17.3%), With a lot of difficulty (14, 7.6%), Could not do it (56, 30.3%)
I could stand on my tiptoes to reach for something without help.

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Counts/frequency: With no difficulty (52, 28.1%), With some difficulty (25, 13.5%), With a lot of difficulty (4, 2.2%), Could not do it (104, 56.2%)

I could turn my head all the way to the side to look at someone or something without help.
Counts/frequency: With no difficulty (128, 69.2%), With some difficulty (20, 10.8%), With a lot of difficulty (11, 5.9%), Could not do it (26, 14.1%)

I could turn myself during the night without help.

Counts/frequency: With no difficulty (81, 44.3%), With some difficulty (22, 12.0%), With a lot of difficulty (16, 8.7%), Could not do it (64, 35.0%)

I could stand while washing my hands and face at a sink without help.

Counts/frequency: With no difficulty (77, 42.3%), With some difficulty (12, 6.6%), With a lot of difficulty (5, 2.7%), Could not do it (88, 48.4%)
I could get in and out of a low vehicle (car) without help.

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**Counts/frequency:** With no difficulty (43, 23.4%), With some difficulty (30, 16.3%), With a lot of difficulty (7, 3.8%), Could not do it (104, 56.5%)

I could get in and out of a high-clearance vehicle (SUV or truck) without help.

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**Counts/frequency:** With no difficulty (6, 3.3%), With some difficulty (48, 26.2%), With a lot of difficulty (18, 9.8%), Could not do it (111, 60.7%)

I could nod my head "yes" without help.

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**Counts/frequency:** With no difficulty (161, 87.5%), With some difficulty (17, 9.2%), With a lot of difficulty (2, 1.1%), Could not do it (4, 2.2%)
I could lift my head up when I lay on my back without help.

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*Counts/frequency:* With no difficulty (78, 42.6%), With some difficulty (41, 22.4%), With a lot of difficulty (22, 12.0%), Could not do it (42, 23.0%)

I could balance while sitting on the toilet without help.

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*Counts/frequency:* With no difficulty (106, 58.2%), With some difficulty (30, 16.5%), With a lot of difficulty (8, 4.4%), Could not do it (38, 20.9%)

I could wipe/clean myself after using the toilet without help.

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Counts/frequency: With no difficulty (58, 32.2%), With some difficulty (31, 17.2%), With a lot of difficulty (11, 6.1%), Could not do it (80, 44.4%)

Complete?

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Counts/frequency: Incomplete (7, 3.7%), Unverified (0, 0.0%), Complete (184, 96.3%)
CTSC# 4262: Validity and Field Testing of the Duchenne Muscular Dystrophy Lifetime Mobility Scale (DMD-LMS)

Data Exports, Reports, and Stats

Selected instruments and/or events (all records)

I could run short distances without help.

<table>
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<tbody>
<tr>
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<td>0 (0.0%)</td>
<td>4</td>
</tr>
</tbody>
</table>

Counts/frequency: With No Difficulty (22, 11.2%), With Some Difficulty (42, 21.3%), With a Lot of Difficulty (6, 3.0%), Could Not Do It (127, 64.5%)

![Bar chart showing responses to running short distances](chart.png)

I could walk for 30 minutes without help.

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<tbody>
<tr>
<td>195</td>
<td>2 (1.0%)</td>
<td>4</td>
</tr>
</tbody>
</table>

Counts/frequency: With No Difficulty (23, 11.8%), With Some Difficulty (32, 16.4%), With a Lot of Difficulty (27, 13.8%), Could Not Do It (113, 57.9%)
With No Difficulty

With Some Difficulty

With a Lot of Difficulty

Could Not Do It

I could walk for 15 minutes without help.

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Counts/frequency: With No Difficulty (37, 19.1%), With Some Difficulty (35, 18.0%), With a Lot of Difficulty (11, 5.7%), Could Not Do It (111, 57.2%)

I could walk more than a mile without help.
Counts/frequency: With No Difficulty (7, 3.6%), With Some Difficulty (23, 11.8%), With a Lot of Difficulty (30, 15.4%), Could Not Do It (135, 69.2%)

I could walk three blocks without help.

Counts/frequency: With No Difficulty (23, 11.8%), With Some Difficulty (38, 19.5%), With a Lot of Difficulty (18, 9.2%), Could Not Do It (116, 59.5%)
With No Difficulty

With Some Difficulty

With a Lot of Difficulty

Could Not Do It

I could walk one block without help.

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<td>3 (1.5%)</td>
<td>4</td>
</tr>
</tbody>
</table>

Counts/frequency: With No Difficulty (59, 30.4%), With Some Difficulty (18, 9.3%), With a Lot of Difficulty (8, 4.1%), Could Not Do It (109, 56.2%)

I could walk between rooms without help.
**Counts/frequency:** With No Difficulty (85, 43.8%), With Some Difficulty (6, 3.1%), With a Lot of Difficulty (5, 2.6%), Could Not Do It (98, 50.5%)

---

**I could walk up three flights of stairs without help.**

**Counts/frequency:** With No Difficulty (5, 2.6%), With Some Difficulty (28, 14.5%), With a Lot of Difficulty (27, 14.0%), Could Not Do It (133, 68.9%)
I could walk up one flight of stairs without help.

<table>
<thead>
<tr>
<th>Total Count (N)</th>
<th>Missing</th>
<th>Unique</th>
</tr>
</thead>
<tbody>
<tr>
<td>192</td>
<td>5 (2.5%)</td>
<td>4</td>
</tr>
</tbody>
</table>

Counts/frequency: With No Difficulty (21, 10.9%), With Some Difficulty (40, 20.8%), With a Lot of Difficulty (14, 7.3%), Could Not Do It (117, 60.9%)

I could walk up 2-3 stairs without help.
Counts/frequency: With No Difficulty (45, 23.3%), With Some Difficulty (30, 15.5%), With a Lot of Difficulty (4, 2.1%), Could Not Do It (114, 59.1%)

I could walk up and down ramps or hills without help.

Counts/frequency: With No Difficulty (34, 17.7%), With Some Difficulty (42, 21.9%), With a Lot of Difficulty (10, 5.2%), Could Not Do It (106, 55.2%)
I could walk up and down curbs without help.

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<td>5 (2.5%)</td>
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</table>

Counts/frequency: With No Difficulty (45, 23.4%), With Some Difficulty (24, 12.5%), With a Lot of Difficulty (10, 5.2%), Could Not Do It (113, 58.9%)

I could jump with both feet off the ground without help.
With No Difficulty
With Some Difficulty
With a Lot of Difficulty
Could Not Do It

Counts/frequency: With No Difficulty (15, 7.8%), With Some Difficulty (21, 10.9%), With a Lot of Difficulty (16, 8.3%), Could Not Do It (140, 72.9%)

I could hop on one foot without help.

Counts/frequency: With No Difficulty (6, 3.1%), With Some Difficulty (24, 12.6%), With a Lot of Difficulty (22, 11.5%), Could Not Do It (139, 72.8%)
I could walk on rough, uneven surfaces (such as lawns, gravel driveway) without help.

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<tr>
<td>192</td>
<td>5 (2.5%)</td>
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</tr>
</tbody>
</table>

Counts/frequency: With No Difficulty (45, 23.4%), With Some Difficulty (34, 17.7%), With a Lot of Difficulty (6, 3.1%), Could Not Do It (107, 55.7%)

I could walk on slightly uneven surfaces (such as cracked pavement) without help.
Counts/frequency: With No Difficulty (59, 30.9%), With Some Difficulty (23, 12.0%), With a Lot of Difficulty (7, 3.7%), Could Not Do It (102, 53.4%)

I could crawl across a room without help.

Counts/frequency: With No Difficulty (69, 36.1%), With Some Difficulty (22, 11.5%), With a Lot of Difficulty (10, 5.2%), Could Not Do It (90, 47.1%)
I could keep my balance while walking for 30 minutes without help.

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</thead>
<tbody>
<tr>
<td>189</td>
<td>8 (4.1%)</td>
<td>4</td>
</tr>
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</table>

Counts/frequency: With No Difficulty (39, 20.6%), With Some Difficulty (25, 13.2%), With a Lot of Difficulty (12, 6.3%), Could Not Do It (113, 59.8%)

I could keep my balance while walking for 15 minutes without help.
With No Difficulty (46, 24.3%), With Some Difficulty (27, 14.3%), With a Lot of Difficulty (10, 5.3%), Could Not Do It (106, 56.1%)

Counts/frequency: With No Difficulty (46, 24.6%), With some difficulty (25, 13.1%), With a lot of difficulty (13, 6.8%), Could not do it (106, 55.5%)

I could crawl up a flight of stairs without help.

Counts/frequency: With no difficulty (47, 24.6%), With some difficulty (25, 13.1%), With a lot of difficulty (13, 6.8%), Could not do it (106, 55.5%)
I could scoot down a flight of stairs without help.

<table>
<thead>
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</thead>
<tbody>
<tr>
<td>191</td>
<td>6 (3.0%)</td>
<td>4</td>
</tr>
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</table>

Counts/frequency: With no difficulty (73, 38.2%), With some difficulty (17, 8.9%), With a lot of difficulty (14, 7.3%), Could not do it (87, 45.5%)
CTSC# 4262: Validity and Field Testing of the Duchenne Muscular Dystrophy... https://redcap.ucdmc.ucdavis.edu/redcap/redcap_v7.4.10/DataExport/ind...

<table>
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<th>Missing</th>
<th>Unique</th>
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</thead>
<tbody>
<tr>
<td>197</td>
<td>0 (0.0%)</td>
<td>2</td>
</tr>
</tbody>
</table>

**Counts/frequency:** Incomplete (4, 2.0%), Unverified (0, 0.0%), Complete (193, 98.0%)

![Graph showing counts/frequency]

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10/24/2018, 8:14 AM