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| **Data dictionary for DMDQoLPsychometric2020.csv as of 07.09.2020** | | |
| **Variable** | **Type** | **Description (levels)** |
| ID | Nominal | Chronological participant ID |
| RecordedDate | Mixed | Date participant completed survey (Date, time) |
| Progress | Numeric | % survey completed |
| Finished | Nominal | Binary variable indicating whether the survey was completed (TRUE; FALSE) |
| DurationSecs | Numeric | Time taken to complete the survey in seconds |
| ReportMethod | Nominal | Method of survey completion (Assisted; Proxy; Self-report) |
| AgeGroup | Nominal | Age of person with DMD the response refers to (Under 16 years old; 16 years and over) |
| Consent | Nominal | Record of consent |
| **Background questions** (either the proxy or self-report version, indicated by *ReportMethod*, only self-report variants provided in the description for illustration) | | |
| RiseFromFloor | Ordinal | Response to “*Which of the following can you do independently (without any help)? Rise from lying on the floor to stand?*”  (1 = Yes, without using my hands; 2 = Yes, using my hands on the floor or on my legs to stand up; 3 = No, I can’t get up or need to use furniture to help; 999 = I would prefer not to say) |
| StandFromChair | Ordinal | Response to “*Which of the following can you do independently (without any help)? Stand up from a chair?*”  (1 = Yes, without using my arms; 2 = Yes, with help from my arms (e.g. pushing on the chair); 3 = No; 999 = I would prefer not to say) |
| StayStanding | Ordinal | Response to “*Which of the following can you do independently (without any help)? Stay standing for 3 seconds?*”  (1 = Yes, standing straight upright with my heels flat on the floor; 2 = Yes, but not straight upright or without my heels flat on the floor; 3 = No; 999 = I would prefer not to say) |
| WalkRun10Ms | Ordinal | Response to “*Which of the following can you do independently (without any help)? Walk/run for 10 metres?*”  (1 = Yes, I can run 10 metres; 2 = Yes, I can walk/run 10 metres, slower than a run but faster than a walk; 3 = Yes, I can walk 10 metres; 4 = No; 999 = I would prefer not to say) |
| Climb4Stairs | Ordinal | Response to “*Which of the following can you do independently (without any help)? Climb 4 stairs?*”  (1 = Yes, by directly facing the steps and without any support; 2 = Yes, by going sideways or with some support (e.g. using a handrail); 3 = No; 999 = I would prefer not to say) |
| TransferBedChair | Ordinal | Response to “*Which of the following can you do independently (without any help)? Transfer from a bed to a chair?*”  (1 = Yes, I can transfer myself from a bed to a chair on my own without any help; 2 = Yes, I can transfer from a bed to a chair, but need help with some parts of the movement; 3 = No, I need another person and/or lifting device to transfer me from a bed to a chair; 999 = I would prefer not to say) |
| HoldPenPickUpCoins | Nominal | Response to “*Can you hold a pen or pick up coins from a table?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| HandsToMouth | Nominal | Response to “*Can you raise your hands to your mouth?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| GlassToMouth | Nominal | Response to “*Can you lift a glass of water to your mouth?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| ForkToMouth | Nominal | Response to “*Can you lift a fork full of food to your mouth?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| ArmsAboveHead | Nominal | Response to “*Can you raise your arms above your head by bending your elbow?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| ArmsFullCircle | Nominal | Response to “*Can you move your arms in a full circle until they touch above your head?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| Steroids | Nominal | Response to “*Do you take steroid medication?*” (1 = Yes; 2 = No, but I used to take steroid medication; 3 = No, I have never taken steroid medication; 999 = I would prefer not to say) |
| HeartMeds | Nominal | Response to “*Do you take heart medication?*” (1 = Yes; 2 = No, but I used to take heart medication; 3 = No, I have never taken heart medication; 999 = I would prefer not to say) |
| BoneTreatment | Nominal | Response to “*Have you had any treatment for weaker bones?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| SpinalFusion | Nominal | Response to “*Have you had spinal fusion surgery?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| ElectricWheelchair | Nominal | Response to “*Do you use an electric wheelchair?*” (1 = Yes, all of the time; 2 = Yes, some of the time; 3 = No; 999 = I would prefer not to say) |
| Ventilation | Nominal | Response to “*Do you use a ventilator?*” (1 = Yes, during the day and night; 2 = Yes, during the night; 3 = No; 999 = I would prefer not to say) |
| FeedingTube | Nominal | Response to “*Do you use a feeding tube?*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| ASD | Nominal | Response to “*Have you ever been diagnosed with any of the following conditions? Autistic spectrum disorder (ASD)*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| AD(H)D | Nominal | Response to “*Have you ever been diagnosed with any of the following conditions? Attention deficit hyperactivity disorder (ADHD or ADD)*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| OCD | Nominal | Response to “*Have you ever been diagnosed with any of the following conditions? Obsessive compulsive disorder (OCD)*” (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| LearningDisability | Nominal | Response to “*Have you ever been diagnosed with any of the following conditions? Learning disability/cognitive impairment”* (1 = Yes; 2 = No; 999 = I would prefer not to say) |
| Age | Numeric | Age of the respondent with DMD (in years) |
| **DMDQoL** (either the proxy or self-report version, indicated by *ReportMethod*, only self-report variants provided in the description for illustration) | | |
| DMDQoL1 | Ordinal | Response to “*I found it hard to get around*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL2 | Ordinal | Response to “*I found it hard to use my arms*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL3 | Ordinal | Response to “*I found it hard to use my hands*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL4 | Ordinal | Response to “*I found it hard to use my fingers*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL5 | Ordinal | Response to “*I found it hard to eat*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL6 | Ordinal | Response to “*I found it hard to breathe*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL7 | Ordinal | Response to “*I was in pain*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL8 | Ordinal | Response to “*I felt tired*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL9 | Ordinal | Response to “*I found it hard to talk to people*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL10 | Ordinal | Response to “*I could take part in the things I wanted to*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL11 | Ordinal | Response to “*I did the things I enjoyed*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL12 | Ordinal | Response to “*I could do the things I wanted to by myself*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL13 | Ordinal | Response to “*I was happy with the people around me*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL14 | Ordinal | Response to “*I was happy with the people I had to help me*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL15 | Ordinal | Response to “*I could take part in things with my friends*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL16 | Ordinal | Response to “*I felt left out*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL17 | Ordinal | Response to “*I felt lonely*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL18 | Ordinal | Response to “*I liked the way I was treated by people*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL19 | Ordinal | Response to “*I felt good about myself*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL20 | Ordinal | Response to “*I felt good about my appearance*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL21 | Ordinal | Response to “*I felt worried*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL22 | Ordinal | Response to “*I felt embarrassed*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL23 | Ordinal | Response to “*I felt unhappy*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL24 | Ordinal | Response to “*I felt annoyed*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL25 | Ordinal | Response to “*I felt angry*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL26 | Ordinal | Response to “*I was worried about the future*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| DMDQoL27 | Ordinal | Response to “*I felt I could cope with things*“ (1 = Never; 2 = Sometimes; 3 = A lot of the time; 4 = All of the time; 999 = N/A) |
| **EQ-5D** (either EQ-5D-5L or EQ-5D-Y, indicated by *AgeGroup*; either proxy or self-report, indicated by *ReportMethod,* only EQ-5D-5L self-report variants provided in the description for illustration) | | |
| EQ5DMobility | Ordinal | Response to “*I have \_\_\_ in walking about”* (5L: 1 = No problems; 2 = Slight problems; 3 = Moderate problems; 4 = Severe problems; 5 = Unable; Y: 1 = 1 = No problems; 2 = Some problems; 3 = A lot of problems) |
| EQ5DSelfCare | Ordinal | Response to “*I have \_\_\_ washing or dressing myself”* (5L: 1 = No problems; 2 = Slight problems; 3 = Moderate problems; 4 = Severe problems; 5 = Unable; Y: 1 = 1 = No problems; 2 = Some problems; 3 = A lot of problems) |
| EQ5DActivities | Ordinal | Response to “*I have \_\_\_ doing my usual activities”* (5L: 1 = No problems; 2 = Slight problems; 3 = Moderate problems; 4 = Severe problems; 5 = Unable; Y: 1 = 1 = No problems; 2 = Some problems; 3 = A lot of problems) |
| EQ5DPainDiscomfort | Ordinal | Response to “*I have \_\_\_ pain or discomfort”* (5L: 1 = No pain or discomfort; 2 = Slight pain or discomfort; 3 = Moderate pain or discomfort; 4 = Severe pain or discomfort; 5 = Extreme pain or discomfort; Y: 1 = 1 = No pain or discomfort; 2 = Some pain or discomfort; 3 = A lot of pain or discomfort) |
| EQ5DAnxietyDepression | Ordinal | Response to “*I am \_\_\_ anxious or depressed”* (5L: 1 = Not anxious or depressed; 2 = Slightly anxious or depressed; 3 = Moderately anxious or depressed; 4 = Severely anxious or depressed; 5 = Extremely anxious or depressed; Y: 1 = 1 = Not worried, sad or unhappy; 2 = A bit worried, sad or unhappy; 3 = Very worried, sad or unhappy) |
| EQ5DVAS | Numeric | VAS rating of health (0 = worst health you can imagine; 100 best health you can imagine) |
| **PEDSQL** (either young child, child, adolescent, young adult or adult versions, indicated by *Age*; either proxy or self-report, indicated by *ReportMethod*, only adolescent self-report variants provided in the description for illustration) | | |
| PEDSQL1 | Ordinal | Response to “*It is hard for me to walk more than a couple of streets (about 100 metres)*” (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL2 | Ordinal | Response to “*It is hard for me to run”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL3 | Ordinal | Response to “*It is hard for me to do sports activities or exercise”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL4 | Ordinal | Response to “*It is hard for me to lift heavy things”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL5 | Ordinal | Response to “*It is hard for me to have a bath or shower by myself”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL6 | Ordinal | Response to “*It is hard for me to do chores around the house”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL7 | Ordinal | Response to “*I have aches and pains”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL8 | Ordinal | Response to “*I feel tired”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL9 | Ordinal | Response to “*I feel afraid or scared”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL10 | Ordinal | Response to “*I feel sad”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL11 | Ordinal | Response to “*I feel angry”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL12 | Ordinal | Response to “*I have trouble sleeping”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL13 | Ordinal | Response to “*I worry about what will happen to me”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL14 | Ordinal | Response to “*I have trouble getting on with other teenagers”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL15 | Ordinal | Response to “*Other teenagers do not want to be my friend”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL16 | Ordinal | Response to “*Other teenagers tease me”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL17 | Ordinal | Response to “*I cannot do things that other teenagers my age can do”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL18 | Ordinal | Response to “*It is hard to keep up with other teenagers my age”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL19 | Ordinal | Response to “*It is hard to pay attention in class”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL20 | Ordinal | Response to “*I forget things”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL21 | Ordinal | Response to “*I have trouble keeping up with my school / college work”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL22 | Ordinal | Response to “*I miss school / college because of not feeling well”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| PEDSQL23 | Ordinal | Response to “*I miss school / college tio go to the doctor or hospital”* (0 = Never; 1 = Almost Never; 2 = Sometimes; 3 = Often; 4 = Almost Always) |
| ValidSample | Binary | Binary indicator of whether case features in the ‘valid sample’ used for analysis (0 = no, 1 = yes) |