**File C – Copy of the psychometric survey (self-report version)**

Thank you for your interest in this survey on quality of life in Duchenne Muscular Dystrophy (DMD).

So we can get you to the correct information, can you please tell us how you would be completing this survey, should you agree to take part.  If you decide not to take part and exit the survey, this data will be deleted.  
   
**Please note that only one response (and response type) is allowed for each person with DMD that takes part in the survey.  You (the person with DMD), or the person you are completing this survey on behalf of (who has DMD), must be at least seven years old and live in the UK.  If this is not true, please exit this survey now.**

* **Self-report** (I have a diagnosis of DMD and I would be completing the survey and answering the questions myself)
* **Assisted self-report** (I would be helping someone with a diagnosis of DMD complete the survey, they would be giving me the answers)
* **Proxy report** (I would be completing this survey on behalf of someone with a diagnosis of DMD, I would be answering the questions)

*Please note that any information you enter will be stored and processed using services provided by Qualtrics. These services have been the subject of independent assessment to ensure compliance with applicable data security standards. Further information can be found on the Qualtrics website (*<https://www.qualtrics.com/security-statement/>*).*

Thank you. And now, which age category do you, or the person you are completing this survey on behalf of, fit into?

* Under 16 years old
* 16 years old and over

Display This Question:

If Thank you. And now, which age category do you, or the person you are completing this survey on be... = Under 16 years old

**Thank you, please note that there is a minimum age for participation in this survey of seven years’ old. If you are completing this survey and you are under 16 years old, then you need parental/guardian consent to do so.  In continuing with this survey you confirm that you have a parent or guardian with you available to read the study information and provide consent on the next few pages.  If you do not have a parent or guardian with you, please do not complete this survey until they are available.**

**<INFORMATION SHEET AND INFORMED CONSENT PROCEDURES GO HERE>**

Thank you for agreeing to take part in this survey.  In order for us to ensure we hear a range of people’s experiences of quality of life in DMD, it is important we take some brief aggregate background details about you.  Please answer the following questions by selecting the box that best describes you.

Which of the following can you do independently (without any help)?  
   
Rise from lying on the floor to stand?

* Yes, without using my hands
* Yes, using my hands on the floor or on my legs to stand up
* No, I can't get up or need to use furniture to help
* I would prefer not to say

Stand up from a chair?

* Yes, without using my arms
* Yes, with help from my arms (e.g. pushing on the chair)
* No
* I would prefer not to say

Stay standing for 3 seconds?

* Yes, standing straight upright with my heels flat on the floor
* Yes, but not straight upright or without my heels flat on the floor
* No
* I would prefer not to say

Walk/run for 10 metres?

* Yes, I can run 10 metres
* Yes, I can walk/run 10 metres, slower than a run but faster than a walk
* Yes, I can walk 10 metres
* No
* I would prefer not to say

Climb 4 stairs?

* Yes, by directly facing the steps and without any support
* Yes, by going sideways or with some support (e.g. using a handrail)
* No
* I would prefer not to say

Transfer from a bed to a chair?

* Yes, I can transfer myself from a bed to a chair on my own without any help
* Yes, I can transfer from a bed to a chair, but need help with some parts of the movement
* No, I need another person and/or lifting device to transfer me from a bed to a chair
* I would prefer not to say

Can you hold a pen or pick up coins from a table?

* Yes
* No
* I would prefer not to say

Display This Question:

If Can you hold a pen or pick up coins from a table? = Yes

Can you raise your hands to your mouth?

* Yes
* No
* I would prefer not to say

Display This Question:

If Can you raise your hands to your mouth? = Yes

Can you lift a glass of water to your mouth?

* Yes
* No
* I would prefer not to say

Display This Question:

If Can you raise your hands to your mouth? = Yes

Can you lift a fork full of food to your mouth?

* Yes
* No
* I would prefer not to say

Display This Question:

If Can you lift a glass of water to your mouth? = Yes

Can you raise your arms above your head by bending your elbow?

* Yes
* No
* I would prefer not to say

Display This Question:

If Can you raise your arms above your head by bending your elbow? = Yes

Can you move your arms in a full circle until they touch above your head?

* Yes
* No
* I would prefer not to say

Do you take steroid medication?

* Yes
* No, but I used to take steroid medication
* No, I have never taken steroid medication
* I would prefer not to say

Do you take heart medication?

* Yes
* No, but I used to take heart medication
* No, I have never taken heart medication
* I would prefer not to say

Have you had any treatment for weaker bones?

* Yes
* No
* I would prefer not to say

Have you had spinal fusion surgery?

* Yes
* No
* I would prefer not to say

Do you use an electric wheelchair?

* Yes, all of the time
* Yes, some of the time
* No
* I would prefer not to say

Do you use a ventilator?

* Yes, during the day and night
* Yes, during the night
* No
* I would prefer not to say

Do you use a feeding tube?

* Yes
* No
* I would prefer not to say

Have you ever been diagnosed with any of the following conditions? (Please tick all that apply)

* Autistic spectrum disorder (ASD)
* Attention deficit hyperactivity disorder (ADHD or ADD)
* Obsessive compulsive disorder (OCD)
* Learning disability/cognitive impairment
* None of the above
* I would prefer not to say

Finally, how old are you?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Thank you. Now please answer the following questions that ask about different areas of your quality of life.

**<DMD-QoL QUESTIONNAIRE GOES HERE>**

**<EQ-5D-5L or EQ-5D-Y GOES HERE>**

**<PedsQL Generic Core Scales (age-variant) GOES HERE>**

Thank you for taking part in this survey.  In reimbursement for your time, you are entitled to receive a £5 eGift Voucher for Amazon.co.uk.  If you would like to receive the voucher, please enter your email address below.  We will then email the voucher to you within one week.  Your email will be stored securetly and confidentially, and deleted after we have sent the voucher to your address.

* Yes, I would like to receive the voucher and my email address is:

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* No, I would not like to receive the voucher