

DMD Registry	
Clinical Module	
Data field	Entry guidelines and help tool
Diagnosis	Choose the clinical diagnosis if known.
Previous muscle biopsy	If the individual has had a muscle biopsy performed.
Currently able to walk	Is the individual able to walk with or without help (orthoses, assistive device or human assistance) inside or outdoors? Tick box if the individual is able to walk; leave blank if not able to walk.
Currently able to sit without support	Is the individual able to maintain a sitting position on a chair or wheelchair without using their upper limbs for support or leaning against the back of the chair? Tick box if individual is able to sit without support; leave blank if not able to sit without support.
Wheelchair use (over 3 years of age)	If the individual needs to use a wheelchair permanently (because they are not able to walk at all) or if they need to use a wheelchair intermittently (because they are still able to walk sometimes).
Wheelchair usage age	Age in years when the individual started using a wheelchair.
Current steroid therapy	Choose from the drop down list if the individual is currently taking steroid therapy.
Previous steroid therapy	The number of years an individual, who is not currently taking steroids, has been on steroid therapy. Include periods of time separated by a break in therapy irrespective of whether a change in therapy occurred. Enter 0 to indicate that no previous steroid therapy has occurred.
Scoliosis surgery	Indicate if the individual has had any type of surgical procedure for lateral curvature of the spine in the coronal plane with a Cobb angle of greater than 10 degrees.
Current cardiac medication	Is the individual currently taking heart medication?
Heart failure/Cardiomyopathy	Has the individual had heart failure or cardiomyopathy (a disease of the heart muscle)?
LVEF score	Indicate the person's last Left Ventricular Ejection Fraction expressed as a percentage. $[LVEF\% = (\text{End diastolic volume} - \text{End systolic volume}) / [\text{End diastolic volume}]]$.
LVEF date	Enter the date of the last LVEF examination.
Heart medication table	Identify all known heart medication and indicate if the individual is currently taking it or if it was taken previously. Specify each drug with its International Nonproprietary Name (INN) to catch use of CoQ10 etc.
Non-invasive ventilation	If the individual uses a nasal or bucal mask for ventilation. Also indicate if the ventilation is used usually at night (Part-time) OR during day time and at night.

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Invasive ventilation	If the individual has a tracheostomy for ventilation. Also indicate if the ventilation is used usually at night (Part-time) OR during day time and at night.
FVC score	The individual's last Forced Vital Capacity expressed as a % predicted for height (not in mL). This is a pulmonary function test performed with spirometry.
FVC date	The date of the last FVC test (DD-MM-YYYY).
Family Members Table	The details of family members with a history of DMD.
Clinical Trials Table	The trial and drug details of any current and previous trials the individual has participated in.
Other registries	Other registries the individual is registered in.
Notes	Include any relevant details not covered in the previous sections here.
Genetic Module	
Gene	Enter gene (HGNC Approved symbol)
Exon	Enter transcript reference sequence ID
DNA variation	Enter DNA change (HGVS nomenclature) or use the wizard (+) to create the HGVS nomenclature.
RNA variation	Enter RNA change (HGVS nomenclature) or use the wizard (+) to create the HGVS nomenclature.
Protein variation	Enter protein variation.
Technique	Select as appropriate.
All Exons Tested	Select as appropriate.
All Exons Tested	Select as appropriate.
Exon boundaries known	Select as appropriate.
All exons sequenced point mutations	Select as appropriate.
All exons tested in male relative	Select as appropriate.