DM1 Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Ethnic origins	How does the patient describe their ethnic origin? Select from the drop-down list.
Condition	What type of myotonic dystrophy has the patient been diagnosed with? Choose the condition if known.
Affected status	Select from drop-down list if known.
First symptom	What was the first symptom that prompted the diagnosis? Choose from the drop-down list if known.
First suspected by	Who first suspected the patient to have myotonic dystrophy? Select from the drop-down list.
Diagnosed	Does the patient have a confirmed clinical or molecular diagnosis?
Age in years at clinical diagnosis	What was the patient's age at the time of clinical diagnosis?
Age in years at molecular diagnosis	What was the patient's age at the time of molecular diagnosis?
Are details of genetic testing available?	Select answer (Yes/No/Unknown)
Genetic test date	Enter the date of the genetic test if known (DD-MM-YYYY)
Has the patient received genetic counselling?	Select answer (Yes/No/Unknown)
Has anyone in the patient's family received genetic counselling?	Select answer (Yes/No/Unknown)
Currently able to walk	Is the individual able to walk with or without help (orthoses, assistive device or human assistance) inside or outdoors? Select yes if the individual is able to walk; select no if not able to walk.
Current use of devices to assist with walking	If the patient is currently able to walk, does the patient use a device to assist with walking? Select the device from the list, or select 'No device required' if the patient does not use a device to assist with walking.
At what age did the patient commence using devices to assist with walking?	Enter the patient's age (years) at which they first used any device for walking.
Current best motor function	Select the option that describes the patient's current best level of motor function. Walking refers to walking with or without help (orthoses or assistive device or human assistance), inside or outdoors.
Wheel chair use	Select from drop-down list if known.
Wheelchair use age	If using wheelchair specify age at start of wheelchair use.

DM1 Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Dysarthria	Does the patient have problems with their speech? Select the option that best describes the patient's speech ability.
Myotonia	Does myotonia currently have a negative effect on the patient's daily activities? Select the option that best describes the effect of myotonia.
Facial weakness	Does the patient experience any facial weakness?
Was there any evidence of hypotonia or weakness within the first four weeks?	Did the patient have evidence of muscle weakness in the first 4 weeks following birth?
Flexor digitorum profundis	
Tibialis Anterior	Enter the last MRC scale of muscle grading. Grading: 5 = normal to 1 = extreme weakness.
Neck Flexion	
Iliopsoas	
Muscle Strength Score	Automatically calculates based on previous answers.
Muscle medication table	Identify all known medication prescribed or complementary that is used to improve muscle function and indicate if the individual is currently taking it or if it was taken previously. Specify each drug with its International Nonproprietary Name (INN).
Cardiac implant	Does the patient have a device implanted on the heart?
Age cardiac implant received	Enter the age of the patient at the time cardiac implant was received.
Cataract diagnosis	Has the patient been diagnosed with cataract?
Cataract surgery	Has the patient received cataract surgery?
Age at cataract surgery	Enter the patient's age at which cataract surgery was performed.
Heart condition	Has the patient been diagnosed with a heart condition? Select from drop-down list.
At what age was the patient diagnosed with a heart condition?	Enter the patient's age at the time of diagnosis.

DM1 Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Does the patient experience heart racing or beating irregularly?	Select answer (Yes/No/Unknown)
Heart palpitations	Has the patient experienced heart palpitations or been found to have a cardiac arrhythmia?
Blackouts or fainting	Has the patient experienced blackouts or fainting?
ECG	Has the patient had an electrocardiogram?
ECG Sinus Rhythym	Enter the results from the ECG.
ECG PR Interval	
ECG QRS Duration	
ECG Examination Date	Enter the date of the ECG.
Echocardiogram	Has the patient had an echocardiogram?
LVEF Score (%)	Left Ventricular Ejection Fraction (LVEF) determined by ultrasound examination of the heart; expressed in % [%=(End disatolic volume - End systolic volume) ÷ End diastolic volume] to specify last LVEF(%) and date of examination
LVEF date	Enter the date of the last Echocardiogram (DD-MM-YYYY).
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	Does the patient regularly use a non-invasive ventilation device?
Age ventilation device use commenced	Enter the age of the patient at the time any ventilation device use commenced.
Non-invasive ventilation type	Select the non-invasive ventilation device the patient is currently using if known.
Invasive ventilation	Does the patient use invasive ventilation? (mechanical ventilation with tracheostomy)
Measured FVC	Enter the measured FVC. Using spirometer measures of total volume of air exhaled from a full lung (total lung capacity) to an empty lung (residual volume).
Date of last spirometer reading of FVC	Enter the date of the last spirometer reading of FVC (DD-MM-YYYY).

DM1 Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Calculated FVC	Enter the calculated FVC in percentage (%).
Dysphagia	Does the patient have difficulty swallowing?
Gastric nasal tube	Does the patient need nutritional supplementation via a nasogastric or nasojejunal tube or gastrostomy?
Fatigue	Does fatigue or daytime sleepiness currently have a negative effect on the patient's normal daily activities? Select the option that best describes the effect of sleepiness.
Sitting and reading	Select the option that best describes the patient's chance of dozing in each situation.
Watching TV	
Sitting, inactive, in a public place	
As a passenger in a car for an hour without a break	
Lying down to rest in the afternoon when circumstances permit	
Sitting and talking to someone	
Sitting quietly after lunch without alcohol	
In a car, while stopped for a few minutes in traffic	
Fatigue medication table	Identify all known fatigue medication and indicate if the individual is currently taking it or if it was taken previously.
Education	Select the patient's highest level of education.
Occupation	Select the employment status of the patient.
Has myotonic dystrophy affected the patient's employment?	Select from drop-down list.
Comment	Enter any other comments about socioeconomic factors.

DM1 Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Diabetes	Has the patient been diagnosed with diabetes?
Age at diagnosis	What was the patient's age at the time of diagnosis of diabetes?
Pneumonia	Has the patient had pneumonia?
Pneumonia age	What was the patient's age at the first episode of pneumonia? Leave blank if the patient has never suffered from pneumonia.
Number of chest infections in the last 12 months	Enter the number of chest infections the patient has had in the last 12 months.
Has the patient been diagnosed with cancer or a tumour?	Select answer (Yes/No).
If yes please choose from the following options	Select any relevant cancers or tumours.
Others	Enter any other cancers/tumours not listed.
If the patient was diagnosed with cancer please indicate the body organ it was diagnosed in	Enter the primary body organ.
General medical factors II	Tick any that apply.
Cognitive impairment	Does the patient have any cognitive impairment?
Body weight	Enter the patient's body weight in kilograms.
Height	Enter the patient's height in centimetres.
Does the patient wear a Medicalert bracelet?	Select answer (Yes/No).
Physiotherapy	Has the patient received physiotherapy?
Emotional & psychological counselling	Has the patient received emotional and psychological counselling?
Speech therapy	Has the patient received speech therapy?
Occupational therapy	Has the patient received occupational therapy?
Vocational rehabilitation	Has the patient received vocational rehabilitation?

DM1 Registry	
Clinical Module	
Data field	**Entry guidelines and help tool**
Family Members Table	The details of family members with a history of DM1.
Clinical Trials Table	The trial and drug details of any current and previous trials the individual has participated in.
Other registry	Other registries the individual is registered in.
Genetic Module	
Disease type	Enter the disease type as appropriate.
Genetic variant	Enter the genetic variant as appropriate.
DNA repeat sequence	Enter the DNA repeat sequence as appropriate.
Sequence repeat number	Enter the sequence repeat number as appropriate.
Chromosome region targeted	Enter the chromosome region targeted as appropriate.
Typing method	Enter the typing method.
Testing laboratory	This is a lookup field - type some characters within the laboratory name.