

# UK DM Registry Patient Questionnaire Overview

*For patient/caregiver data entry only*

The new Patient Registry Questionnaire covers the following topics:

## **Diagnosis & Demographics**

- Clinical diagnosis
- Genetic report status
- Affected family
- Ethnicity

## **Access to Care**

- NMD specialists last seen
- NMD care site
- Dates, frequency & appointment type
- Access to counselling
- Care funding & management
- Social care child & adult
- Care comments

## **Access to Research**

- Current & previous trial participation
- Trial preferences
- Type, interventions, rating

## **Patient Reported Outcome Measures (PROMs)**

- Summary of Observed Function Test (SOFT) <sup>i</sup>
- EQ-5D-5L <sup>i</sup>
- Myotonia Behaviour Scale Score <sup>i</sup>
- Epworth Sleep Scale Score <sup>i</sup>
- Fatigue Severity Scale Score <sup>i</sup>
- Visual Analogue Fatigue Scale (VAFS) <sup>i</sup>
- Patient Global Impression (PGI) <sup>i</sup>
- Patient Global Impression of Change (PGI-C) <sup>i</sup>
- DM1-ACTIVc Score <sup>i</sup>

## **Mobility**

- WC Use
- Status, dates, type
- Additional Aids

## **Symptoms**

- Symptoms & Onset
- Dysphagia & Onset
- Grip Strength

## **Fertility and Family Planning**

- Family planning
- Fertility Issues
- Pregnancies & outcomes

## **Physiotherapy**

- Status, access, dates
- Main symptoms and benefits

## **Speech & Language Therapy**

- Status, access, dates
- Main symptoms and benefits

## **Occupational Therapy**

- Status, access, dates
- Main symptoms and benefits