# UK FSHD 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) ℹ
- EQ-5D-5L ℹ
- Fatigue Severity Scale (FSS) ℹ
- Visual Analogue Fatigue Scale (VAFS) ℹ
- Patient Global Impression (PGI) ℹ
- Patient Global Impression of Change (PGI-C) ℹ
- Facial Function Scale (FFS) ℹ
- Visual Analogue Scale – Pain (VAS)
- QOL-NMD ℹ

### Mobility

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

### Symptoms

- Symptom Onset
- Muscle Weakness
- Grip Strength
- Retinal Vascular Disease
- Hearing impairment

### 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