

UK FSHD Registry Medical Questionnaire & Clinical Assessment Overview

For patient and/or clinician data entry

The new Medical Questionnaire covers the following topics:

Clinical Symptoms and Other Conditions

- Cataracts onset & surgery
- Ptosis onset & surgery
- Gastrointestinal Issues
- Urinary Issues
- Psychological Issues
- Neurodiversity
- Other Medical Conditions

Assistive Devices

- Non-Invasive / Invasive Ventilation Use (*status, access, compliance, device types, usage frequency & quantity*)
- Feeding Devices (*status, type, usage*)

Medication and Medical Interventions

- Prescription / OTC Meds (*type, reason*)
- Orthopaedic Surgery
- Heart rhythm devices
- Broken bones
- Scapular fixation surgery

The following Clinical Assessments can also be reported:

Clinical Assessment Information

- Electrocardiogram (ECG)
 - Date, sinus, PR, QRS
- Echocardiogram (Echo)
 - Date, LVEF
- Pulmonary Function Tests (PFT)
 - Date, FVC%, FVC Absolute