

The digital DDD questionnaires *Baseline and yearly follow-ups*

The areas covered include initial complaints, symptoms, diagnoses, significant disease milestones, and the usage of medication.

The digital questionnaires are designed prioritizing user-friendliness and minimizing the burden. This involves incorporating dependencies and shorted annual follow-up questionnaire, which contain fewer questions compared to the baseline questionnaire. The follow-up omits initial inquiries about complaints at the start and age of diagnosis and answers regarding daily life activities and medications are only necessary if changes have taken place within the past 12 months.

Overview of the items captured with tailored questioning for patients with Duchenne

Age first experienced complaints or symptoms

Manifestation of first experienced complaints or symptoms

Age of diagnosis (as assessed by specialist)

Genetic confirmation

Family members with similar genetic DMD mutation

Performance of muscle biopsy

Ability to climb stairs without aid, including date of loss of ability

Ability to walk 5 meters indoors without assistance, including date of loss of ability

Ability to stand with support, including date of loss of ability

Ability to bring a full glass to the mouth with one arm/hand, including date of loss of ability

Use of breathing mask, mouthpiece and/or other breathing aids, including date of start

Wheelchair presence, type, distance, use of arm support

Scoliosis surgery

Corticosteroid use, type, scheme, dosage, reason to stop or switch

Heart medication

Use, reason of use, type of anticoagulants

Overview of content for patients with Becker

Age first experienced complaints or symptoms

Manifestation of first experienced complaints or symptoms

Age of diagnosis (as assessed by specialist)

Genetic confirmation

Family members with similar genetic DMD mutation

Performance of muscle biopsy

Ability to climb stairs without aid, including date of loss of ability

Ability to stand up from seated, including date of loss of ability

Ability to walk 5 meters indoors without assistance, including date of loss of ability

Ability to bring a full glass to the mouth with one arm/hand, including date of loss of ability

Use, type of walking aids

Wheelchair presence, type, distance, use of arm support

Corticosteroid use, type, scheme, dosage

Heart medication

Use, reason of use, type of anticoagulants

Use of cardiac devices