

Contextual observations	
One-time entry	Demographics Comorbidities Milestones <i>First symptoms</i> <i>Refferal</i> <i>Genetic diagnosis</i> <i>Walk independently</i> <i>Loss of ambulation</i> <i>Scoliosis surgery</i> <i>Wheelchair</i> <i>Airstacking</i> <i>Cough machine</i> <i>(Non-)invasive ventilation</i> <i>Cardiac devices</i> Diagnosis Genetics
Multiple measurements during outpatient visits	Work, education, social and familial anamnesis Clinical- and general assessment Ventilation <i>Lung volume recruitment techniques</i> <i>Non-invasive ventilation</i> <i>Invasive ventilation</i> Cardiac assessment <i>Cardiac MRI</i> <i>Cardiac Echo</i> Respiratory assessment, CO2-and oxygen assessment <i>Spirometry</i> <i>Transcutaneous carbon dioxide monitoring</i> <i>Transcutaneous oxygen monitoring</i> Spinal assessment <i>X-ray</i> <i>VFA</i> Bone assessment <i>Dexa</i> Lab blood and urine tests Fysiotherapy <i>Ambulatory status en treatment diagnosis</i> <i>Motor Function Measure Domein D2</i> <i>Goniometry</i> <i>Hand Held Dynamometry</i> <i>NorthStar Ambulatory Assessment</i> <i>Rise from floor</i> <i>10 Meter run test</i> <i>4-Stairs climb</i> <i>6 Minutes walking test</i> <i>Performance Of Upper Limb Measure 2.0</i> <i>Brooke & Vignos</i>
Continuously over time	Complications Interventions Medications Participation in trials and studies