Clinical Data

Record ID: _____

Physician Name: _____

Clinic Name: _____

Region Name: _____

Last Exam Date: _____

Weight (kg): _____

Height (cm): _____

Diagnosis

Clinical Diagnosis:
- ◯ Congenital
- ◯ DM1
- ◯ DM2
- ◯ DM1 asymptomatic mutation
- ◯ DM2 asymptomatic mutation

Age at symptom onset:
- ◯ Asymptomatic
- ◯ Congenital (neonatal)
- ◯ Onset before age 20
- ◯ Onset after age 20

Positive Family History:
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, select inheritance:
- ☐ Maternal
- ☐ Paternal

Genetics

Genetic Test Result:
- ◯ DM1 repeat expansion
- ◯ DM2 repeat expansion
- ◯ Other

Other, please specify: _____

Repeat Size/Test result: _____

Method of Testing:
- ◯ PCR & Southern Blot
- ◯ QP-PCR
- ◯ DNA
- ◯ PCR
- ◯ Other

If OTHER, please specify: _____

Date of test: _____

Laboratory: _____

Neuromuscular

Myotonia:
- ◯ No clinical myotonia
- ◯ Mild (little to no impact on daily living)
- ◯ Severe (significant impact on daily living)

Myotonia Medication Use:
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, please specify: _____

Motor Function

Ambulation:
- ◯ Ambulatory (unassisted)
- ◯ Ambulatory (assisted)
- ◯ Non ambulatory

Able to walk for 6 minutes?
- ◯ Yes
- ◯ No
- ◯ Unknown

Motor Assistance (check all that apply):
- ☐ AFO
- ☐ Cane
- ☐ Walker
- ☐ Scooter

Wheelchair use:
- ◯ Yes, full-time
- ◯ Yes, part-time
- ◯ No
- ◯ Unknown

If YES, at age (years): _____

Cardiac

ECG:
- ◯ Yes
- ◯ No

Date of last test: _____

QRS Duration: _____

PR Interval: _____

Sinus Rhythym:
- ◯ Yes
- ◯ No

If sinus rhythm is not present, select rhythm:
- ◯ Atrial fibrillation
- ◯ Bradycardia
- ◯ Tachycardia
- ◯ Unknown
- ◯ Other

If other, please specify: _____

Echocardiogram:
- ◯ Yes
- ◯ No
- ◯ Unknown

Date of last exam: _____

LVEF (%): _____

Heart Condition:
- ◯ Yes, cardiomyopathy
- ◯ Yes, arrythmia or conduction block
- ◯ Yes, but not specified
- ◯ No
- ◯ Unknown

If YES, specify age at dignosis (years): _____

Cardiac Implant:
- ◯ Yes, pacemaker
- ◯ Yes, ICD
- ◯ Yes, but not specified
- ◯ No
- ◯ Unknown

If YES, specify age at implant (years): _____

Cardiac Medication Use:
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, please specify: _____

Respiratory

Pulmonary Function Test:
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, year of test: _____

Sitting FVC (%): _____

Suppine FVC (%): _____

Peak Cough Flow: _____

Are airway interventions in use?
- ◯ Yes
- ◯ No
- ◯ Not available
- ◯ Unknown

If YES above, check all that apply:
- ☐ Manual breath stacking — Date: _____
- ☐ Suction — Date: _____
- ☐ Cough assist with in/exsufflator — Date: _____

Hospitalized for pneumonia since last visit?
- ◯ Yes
- ◯ No
- ◯ Unknown

Date of last hospitalization: _____

Ventilation

Non-invasive ventilation:
- ◯ Pre-existing (other diagnosis)
- ◯ Recommended
- ◯ Recommended & used
- ◯ Recommended & not used
- ◯ Recommended & declined
- ◯ Recommended & not tolerated
- ◯ Not yet indicated
- ◯ Not available
- ◯ Unknown

If YES/RECOMMENDED, enter the date first used/recommended: _____

If YES, check ventilation type:
- ☐ CPAP
- ☐ BiPAP
- ☐ Sip & puff

Non-invasive: check duration of all:
- ◯ Full-time
- ◯ Part-time - nocturnal only
- ◯ Part-time - nocturnal and periodic daytime

Invasive ventilation:
- ◯ Yes, part-time
- ◯ Yes, full-time
- ◯ No
- ◯ Unknown

If YES, enter date first used: _____

Digestive/Endocrine

Dysphagia:
- ◯ Yes
- ◯ No
- ◯ Unknown

Diet modifications:
- ◯ Recommended & followed
- ◯ Recommended & not followed
- ◯ Unknown

Gastric tube:
- ◯ Yes
- ◯ No
- ◯ Unknown

Nasogastric tube:
- ◯ Yes
- ◯ No
- ◯ Unknown

Diabetes:
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES, at age (years): _____

Diabetes Medication Use:
- ◯ Yes
- ◯ No
- ◯ Unknown

If YES above, please specify: _____

Other Comorbidities

Does the patient have incontinence?
- ◯ Yes
- ◯ No
- ◯ Unknown

If yes, check incontinence type:
- ◯ Urinary
- ◯ Fecal
- ◯ Urinary & fecal

Age at incontinence onset: _____

Does this individual display cognitive impairment?
◯ Yes
◯ No
◯ Unknown

Which screening test was used? _____

Fatigue/Sleepiness:
◯ Yes
◯ No
◯ Unknown

Fatigue/Sleepiness medication use:
◯ Yes
◯ No
◯ Unknown

If YES above, please specify: _____

Does the patient have cataracts?
◯ Yes
◯ No
◯ Unknown

Cataract surgery:
◯ Yes
◯ No
◯ Unknown

If YES above, date of surgery: _____

Social Data

Does the patient participate in any other registries?
◯ Yes
◯ No
◯ Unknown

If YES, please specify: _____

To which population group does the patient belong? (check all that apply)

☐ White
☐ Chinese
☐ South Asian
☐ Black
☐ Filipino
☐ Latin American
☐ Arab
☐ Southeast Asian
☐ Korean
☐ West Asian
☐ Japanese
☐ Aboriginal/First Nations
☐ Unknown
☐ Visible minority
☐ Declined
☐ Not available
☐ Other

If OTHER, please specify: _____

What is the patient's highest level of education?
◯ Elementary
◯ High School
◯ Post-secondary
◯ Some post-secondary
◯ Declined

Which occupations have you held?
☐ Management
☐ Natural and Applied Sciences
☐ Sales and Service
☐ Trades, Transport, Equipment Operator
☐ Art, Culture, Recreation and Sport
☐ Processing, Manufacturing, Utilities
☐ Business, Finance or Administration
☐ Primary Industry (Agriculture, Mining, Oil & Gas, Exploration, Fishing)
☐ Health
☐ Social Science, Education, Gov't Service, or Religion
☐ Patient has never worked
☐ Unknown
☐ Other

If OTHER, please specify: _____

What is the patient's total household income before taxes?

◯ Less than $5,000
◯ $5,000 - $9,999
◯ $10,000-$14,999
◯ $15,000-$19,999
◯ $20,000-$24,999
◯ $25,000-$29,999
◯ $30,000-$34,999
◯ $35,000-$39,999
◯ $40,000-$44,999
◯ $45,000-$49,999
◯ $50,000-$59,999
◯ $60,000-$69,999
◯ $70,000-$79,999
◯ $80,000-$89,999
◯ $90,000-$99,999
◯ $100,000-$124,999
◯ $125,000-$149,999
◯ $150,000 or more
◯ Declined
◯ Unknown

How many hours of paid home care per day does the patient receive? _____

From:
- ◯ Government
- ◯ Private
- ◯ Unknown

Are home care costs covered or paid for personnally?
- ◯ Covered
- ◯ Paid for personnally
- ◯ Unknown

Is the amount of home care available/received adequate?
- ◯ Yes
- ◯ No
- ◯ Unknown

Is necessary transportation available?
- ◯ Yes
- ◯ No
- ◯ Unknown
- ◯ Not feasible

Living Status:
- ◯ Independent
- ◯ With spouse/partner
- ◯ With roommmate
- ◯ With caregiver that is not spouse/rommate
- ◯ Group home
- ◯ Long-term care facility
- ◯ Unknown/Declined

Family data:
- ◯ Single
- ◯ Common-law
- ◯ Married
- ◯ Divorced
- ◯ Widowed
- ◯ Unknown/Declined

Is the patient in a same-sex relationship?
- ◯ Yes
- ◯ No
- ◯ Unknown/Declined

Dependents:
- ◯ Yes, unaffected
- ◯ Yes, affected
- ◯ No
- ◯ Unknown

Notes

Notes: _____