MEASURE #6: Patient Referred for Physical, Occupational, or Speech/Swallowing Therapy

**MUSCULAR DYSTROPHY**

### Measure Description

All visits for patients diagnosed with a muscular dystrophy (MD) where the patient was referred for physical, occupational, or speech/swallowing therapy.

### Measure Components

<table>
<thead>
<tr>
<th>Numerator Statement</th>
<th>Denominator Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient visits where the patient was referred for physical, occupational, or speech/swallowing therapy.</td>
<td>All visits for patients diagnosed with a muscular dystrophy.</td>
</tr>
</tbody>
</table>

#### Exceptions:

- Medical exception for not referring for physical, occupational, or speech/swallowing therapy. (i.e., patient does not need therapy based upon MD phenotype; patient already currently being seen by physical therapy (PT), occupational therapy (OT), or speech/swallowing specialist)
- Patient exception for not referring for physical, occupational, or speech/swallowing therapy. (i.e., patient or family caregiver declines)
- System exception for not referring for physical, occupational, or speech/swallowing therapy. (i.e., patient does not have insurance to cover therapy, patient cannot travel to the therapy facility)

- L5. For patients with MD, clinicians should prescribe physical and occupational therapy, as well as bracing and assistive devices that are adapted specifically to the patient’s deficiencies and contractures, in order to preserve mobility and function and prevent contractures (Level B).¹
- L3. Clinicians should recommend that patients with MD have periodic assessments by a physical and occupational therapist for symptomatic and preventive screening (Level B)¹
- F1. Clinicians should refer MD patients with dysphagia, frequent aspiration or weight loss for speech therapy and/or gastroenterology evaluation to assess and manage swallowing function, aspiration risk, teach patients techniques for safe and effective swallowing (“chin tuck” maneuver, altered food consistencies, etc.) and to consider placement of gastrostomy/jejunostomy tube for nutritional support. (Level B)¹
- L1. Clinicians should refer patients with MD to a clinic that has access to multiple specialties (e.g., physical therapy, occupational therapy, respiratory therapy, speech and swallowing therapy, cardiology, pulmonology, orthopedics, and genetics) designed specifically to care for patients with muscular dystrophy and other neuromuscular disorders in order to provide efficient and effective long-term care (Level B)¹
- H1. Physicians should consider referrals to allied health professionals, including physical, occupational, and speech therapists, seating and mobility specialists, rehabilitation specialists, and orthopedic surgeons to help maximize function and potentially slow the progression of musculoskeletal complications in children with congenital muscular dystrophy (CMD). (Level TBD)²
- D3. Clinicians should encourage patients with facioscapulohumeral muscular dystrophy (FSHD) to engage in low intensity aerobic exercise. Clinician can use the practical physical activities guidelines for individuals with disabilities

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provided by the department of Health and Human Services (http://www.health.gov/paguidelines/guidelines/chapter7.aspx) to counsel patients about aerobic exercise.3

- D4. For patients interested in strength training, clinicians should refer patients to physical therapists to establish a safe exercise program using appropriate low/medium weights/resistance that takes into consideration the patient’s physical limitations.3

- Children with neuromuscular disease with a history of swallowing difficulties should have a feeding assessment by a speech and language therapist including a video fluoroscopy swallow assessment if the swallow is thought to be unsafe.4

Rationale for the Measure

Patients with MD may have difficulty receiving adequate oral intake due to dysphagia and/or inability to feed themselves due to excessive arm weakness. Maintaining adequate nutrition and body weight is important for optimizing strength, function, and quality of life. When oral intake is inadequate, other means of maintaining intake, such as gastrostomy or jejunostomy feeding tubes, may be needed to maintain optimal nutrition. There is evidence from related conditions (amyotrophic lateral sclerosis [ALS]) that maintenance of nutrition and body weight prolongs survival.1

The principles of the long-term management of patients with limb girdle muscular dystrophy (LGMD) must emphasize maintaining mobility and functional independence for as long as possible, with a focus on maximizing quality of life. The prevention and management of comorbidities, both expected and acquired, is a major part of such management. This would include joint contractures, scoliosis, osteoporosis, dysphagia, and restrictive lung disease (expected), as well as obesity, metabolic syndrome, and stress fractures (acquired).1

Despite inadequate research in this area, the available evidence suggests that this population would benefit from both strengthening and aerobic fitness training programs. Due to the muscle degeneration in muscular dystrophy, there may be some risk of exercise-induced muscle damage and subsequent overwork weakness following supramaximal, high-intensity exercise. Overwork weakness is defined as a prolonged decrease in absolute muscle strength and endurance following strenuous or excessive exercise. It is often accompanied by extreme delayed onset muscle soreness, peaking 1-5 days postexercise, and possibly inducing myoglobinuria. Clinicians need to be prudent in their recommendations, encouraging alternating periods of physical activity and scheduled rest. Clinicians should also be aware that true overwork weakness has not been demonstrated in any trial of exercise done in this population to date. All forms of physical exercise should therefore be prescribed cautiously, using a common sense approach. There have been several randomized or quasi-randomized controlled trials comparing strength training programs, aerobic exercise programs, or both to non-training controls in
patients with a variety of neuromuscular disorders. On the basis of this literature, both strength training and aerobic exercise programs appear to be safe, without any notable deleterious effects.1

**Gap in care**

Physical therapy should be started as early as possible. From the time of diagnosis, preventive therapy is an essential part of daily management. Referral to physical or occupational therapy is prompted by the diagnosis of MD, appearance of contractures, loss of motor function, decreased mobility, altered gait, abnormal positioning, muscle weakness, pain, scoliosis, problems with transfers, joint deformity, and loss of activities of daily living.2 Publications have emphasized the importance of rehabilitation in the management of pain.

Most medical centers do have physical, occupational, and speech/swallowing therapists. The percentage of patients that do not get the needed physical therapy, occupational therapy, or speech/swallowing therapy it is unclear as studies have not been conducted to look at this specific gap in care. However, anticipatory guidance is needed by all three services to avoid functional deterioration and malnutrition.

**Opportunity for Improvement**

PT should focus on the maintenance of function and mobility, prevention or treatment of joint contractures and spine deformities, training of patients to carry out activities that are safe. PT can also recommend transfer aids and adaptive equipment to ensure the highest degree of independence and safety.

OT should focus on encouraging patient to perform activities of daily living to the best ability. OT can also encourage patient to engage in activities such as singing or playing wind instruments, which may improve pulmonary function. OT also teaches the patient to maintain adequate seating position and wheelchair support. Such early and adequate posturing of feet and neck can effectively prevent foot deformities and hyperextension of the neck.

Speech and language pathologists assess MD patients for any swallowing difficulties, nutrition status, and perform swallowing surveillance, deciding texture of food so to avoid aspiration. Identification and assessment of feeding difficulties are essential for optimal care of patients with a muscular dystrophy. Speech therapy intervention should focus on compensatory communication strategies, as necessary.

This quality measure has the potential with appropriate referral to for these types of therapy to improve quality of life and may length of life in people who have a muscular dystrophy.


Level of Measurement

- Individual practitioner

Care setting

- Inpatient Consultations
- Outpatient visits
- Nursing Homes
- Home Services
- Rehabilitation Services

**Technical Specifications: Administrative/Claims Data (Under Development)**

Administrative claims data collection requires users to identify the eligible population (denominator) and numerator using codes recorded on claims or billing forms (electronic or paper). Users report a rate based on all patients in a given practice for whom data are available and who meet the eligible population/denominator criteria.

The specifications listed below are those needed for performance calculation.

<table>
<thead>
<tr>
<th>Denominator</th>
<th>ICD-9 and ICD-10 Diagnosis Codes:</th>
</tr>
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<tbody>
<tr>
<td>(Eligible Population)</td>
<td>ICD-9 Code</td>
</tr>
<tr>
<td>359 Muscular dystrophies and other myopathies</td>
<td></td>
</tr>
<tr>
<td>359.0 Congenital hereditary muscular dystrophy</td>
<td>G71.2 Congenital myopathies</td>
</tr>
<tr>
<td>359.1 Hereditary progressive muscular dystrophy</td>
<td>G71.0 Muscular dystrophy</td>
</tr>
<tr>
<td>359.2 Myotonic disorders</td>
<td></td>
</tr>
<tr>
<td>359.21 Myotonic muscular dystrophy</td>
<td>G71.11 Myotonic muscular dystrophy</td>
</tr>
<tr>
<td>359.22 Myotonia congenital</td>
<td>G71.12 Myotonia congenital</td>
</tr>
<tr>
<td>359.23 Myotonic chondrodystrophy</td>
<td>G71.13 Myotonic chondrodystrophy</td>
</tr>
<tr>
<td>359.8 Other myopathies</td>
<td></td>
</tr>
<tr>
<td>359.89 Other myopathies</td>
<td>G72.89 Other specified myopathies</td>
</tr>
<tr>
<td>359.9 Myopathy, unspecified</td>
<td>G72.9 Myopathy, unspecified</td>
</tr>
</tbody>
</table>

AND

CPT E/M Service Code:
99221, 99222, 99223 (Initial hospital care)
99231, 99232, 99233 (Subsequent hospital care)
99201, 99202, 99203, 99204, 99205 (Office or other outpatient visit-New Patient);
99211, 99212, 99213, 99214, 99215 (Office or other outpatient visit-Established Patient);
99241, 99242, 99243, 99244, 99245 (Office or Other Outpatient Consultation-New or Established Patient);
99304, 99305, 99306 (Initial Nursing Facility Care);
99307, 99308, 99309, 99310 (Subsequent Nursing Facility Care);
99319 (Other Nursing Facility Services);
99324, 99325, 99326, 99327, 99328 (Domiciliary, Rest Home, or Custodial Care Services-New Patient);
99334, 99335, 99336, 99337 (Domiciliary, Rest Home, or Custodial Care Services-Established Patient);
99339, 99340 (Domiciliary, Rest Home, or Home Care Plan Oversight Services);
99341, 99342, 99343, 99344, 99345 (Home Services-New Patient);
99347, 99348, 99349, 99350 (Home Services-Established Patient).
97001, 97002, 97003, 97004 (PT/OT evaluation)