About You

1. **Please select your age** (*drop down menu of ages 20-90)*

* 20-30 years
* 31-40 years
* 41-50 years
* 51-70 years
* 71-80
* 81-90

1. **How do you identify:**

* Male
* Female
* Other *Please State*:\_\_\_\_\_\_\_\_\_\_\_\_

1. **What is your healthcare discipline (check all that apply)?**

* Dietitian
  + - Exercise Counselor
    - Life Skills Coach
    - Nurse
* Nurse Practitioner
* Registered Nurse
* Registered Practical Nurse
  + - Occupational Therapist
    - Physician
* Family Doctor
* General Pediatrician
* Endocrinologist
* Neurologist
* Respirologist
* Surgeon
* Other
  + - Physiotherapist
    - Respiratory Therapist
    - Psychologist
    - Pulmonary Function Lab Technologist
    - Social Worker
    - Therapeutic Recreation Staff
    - Other (please specify: \_\_\_\_\_\_\_)

1. **How many year(s) have you worked as ahealthcare professional(not including training)?**

* 0-5 years
* 6-10 years
* 11-15 years
* 16-20 years
* 20+ years

1. **How many year(s) of experience do you have *working with children/youth with Duchenne muscular dystrophy* in your professional career?**

* 0-5 years
* 6-10 years
* 11-15 years
* 16-20 years
* 20+ years

1. **Have you had *training* surrounding the topic of *weight management* as a part of your professional career?**

* Yes (Please specify the length and type of training you had:\_\_\_\_\_\_\_\_\_)
* No
* This is not in my scope of practice

About Your Clinic

1. **Please indicate the province/ territory in which you work:**

* Alberta
* British Columbia
* Manitoba
* New Brunswick
* Newfoundland and Labrador
* Northwest Territories
* Nova Scotia
* Nunavut
* Ontario
* Prince Edward Island
* Quebec
* Saskatchewan
* Yukon

1. **Please indicate the city in which your clinic is located:**

**(Note: data for this question is used for tracking only and will not be reported)**

1. **In what type of city/community do you practice?**

* Major urban (population over 100,000)
* Small urban (population between 3,000- 99,999)
* Rural (population less than 3,000)

1. **Which of the following best describes your clinic (check all that apply)?**

* Duchenne muscular dystrophy clinic only
* Duchenne muscular dystrophy clinic and neuromuscular clinic
* Child development clinic
* Neuromuscular clinic only
* General respiratory medicine clinic
* Respiratory Clinic for children with Chronic Respiratory Failure and Children at Risk of Chronic Respiratory Failure
* Other (please specify\_\_\_\_\_\_)

1. **Which type of healthcare professionals work in your clinic (check all that apply)?**

* Clinic Coordinator
* Dietitian
  + - Exercise Counselor
    - Life Skills Coach
    - Nurse
* Nurse Practitioner
* Registered Nurse
* Registered Practical Nurse
  + - Occupational Therapist
    - Physician
* Family Doctor
* General Pediatrician
* Endocrinologist
* Neurologist
* Respirologist
* Surgeon
* Other
  + - Physiotherapist
    - Respiratory Therapist
    - Psychologist
    - Pulmonary Function Lab Technologist
    - Social Worker
    - Therapeutic Recreation Staff
    - Other (please specify: \_\_\_\_\_\_\_)

1. **Approximately how many children with Duchenne muscular dystrophy does your clinic serve annually?**

* 0-10
* 11-25
* 26-50
* 51-100
* >100

1. **How many children do YOU see in the course of a typical clinic day in which you see Duchenne muscular dystrophy patients?**

1. **How often does your clinic take place when YOU see clients with Duchenne muscular dystrophy?**

* Daily
* 2-4 days/week
* Weekly
* Bi-Weekly
* Monthly
* Bi-Monthly
* Other (please specify \_\_\_\_\_\_\_)

About Assessment

1. **Is HEIGHT routinely measured in your clinic?**

* Yes
* **How often?**
* Every visit
* Most visits
* Some visits
* Rarely
* No
* Unsure

1. **HOW is HEIGHT or proxy measured in your clinic? (Check all that apply)**

* Arm-board
* Arm-span
* Standing
* Supine
* Segmental (e.g., foot to knee, hip to knee)
* Ulnar length
* Other (please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_)
* Unsure

1. **Is WEIGHT routinely measured in your clinic?**

* Yes
* **How often?**
* Every visit
* Most visits
* Some visits
* Rarely
* No
* Unsure

1. **HOW is WEIGHT measured in your clinic? (Check all that apply)**

* Sitting
* Standing
* Supported by a hoist/lift
* Wheel-on scale
* Other (please specify: \_\_\_\_\_\_\_\_\_\_)
* Unsure

1. **Does your clinic conduct any other body composition assessments? (Check all that apply)**

* Bioelectrical impedance
* Calorimetry
* Mid-arm parameters
* Mid-arm circumference
* Other (please specify: \_\_\_\_\_\_\_\_\_\_)
* Skinfold thickness
* Subscapular
* Triceps
* Other (please specify: \_\_\_\_\_\_\_\_\_\_)
* Waist circumference
* Neck circumference
* Other (please specify: \_\_\_\_\_\_\_)
* Unsure

1. **Does your clinic have a standard for the frequency of measuring HEIGHT?**

* Yes (please specify the frequency: \_\_\_\_\_\_\_\_\_)
* No
* Would a clinic standard be helpful?
* Yes (please specify why:\_\_\_\_\_\_\_\_\_\_\_)
* No (please specify why not:\_\_\_\_\_\_\_\_\_\_\_)
* Unsure

1. **Does your clinic have a standard for the frequency of measuring WEIGHT?**

* Yes (please specify the frequency: \_\_\_\_\_\_\_\_\_)
* No
* Would a clinic standard be helpful?
* Yes (please specify why:\_\_\_\_\_\_\_\_\_\_\_)
* No (please specify why not:\_\_\_\_\_\_\_\_\_\_\_)
* Unsure

1. **If height and weight are NOT measured routinely, what do you think are the reasons for this? (Check all that apply)**

* Insufficient time
* Lack of equipment
* Lack of expertise
* Lack of personnel
* Other (please specify: \_\_\_\_\_\_\_)
* Unsure

1. **Who is primarily responsible for MEASURING and RECORDING height and weight for ambulatory children in your clinic?**

* Clinic Coordinator
* Dietitian
  + - Exercise Counselor
    - Life Skills Coach
    - Nurse
* Nurse Practitioner
* Registered Nurse
* Registered Practical Nurse
  + - Occupational Therapist
    - Physician
* Family Doctor
* General Pediatrician
* Endocrinologist
* Neurologist
* Respirologist
* Surgeon
* Other
  + - Physiotherapist
    - Respiratory Therapist
    - Psychologist
    - Pulmonary Function Lab Technologist
    - Social Worker
    - Therapeutic Recreation Staff
    - Other (please specify: \_\_\_\_\_\_\_)
    - Unsure

1. **Who is primarily responsible for MEASURING and RECORDING height and weight for non-ambulatory children in your clinic?**

* Clinic Coordinator
* Dietitian
  + - Exercise Counselor
    - Life Skills Coach
    - Nurse
* Nurse Practitioner
* Registered Nurse
* Registered Practical Nurse
  + - Occupational Therapist
    - Physician
* Family Doctor
* General Pediatrician
* Endocrinologist
* Neurologist
* Respirologist
* Surgeon
* Other
  + - Physiotherapist
    - Respiratory Therapist
    - Psychologist
    - Pulmonary Function Lab Technologist
    - Social Worker
    - Therapeutic Recreation Staff
    - Other (please specify: \_\_\_\_\_\_\_)
    - Unsure

1. **Do you use a specific method to classify overweight or obesity? (Check all that apply)**

* Centre for Disease Control & Prevention (CDC) Growth Chart (2000)
* World Health Organization (WHO) Growth Chart (2006)
* Other (please specify: \_\_\_\_\_\_\_)
* What z-score do you use to identify malnutrition?

****

* What are your cut offs?
* -2
* -1
* This is not in my scope of practice

1. **Do you think any of the above listed methods of weight classification are appropriate for the Duchenne muscular dystrophy population?**

* Yes
* Click all methods that ARE appropriate
* Centre for Disease Control & Prevention (CDC) Growth Chart (2000)
* **Why do you think this is appropriate for the Duchenne muscular dystrophy population?**
* World Health Organization (WHO) Growth Chart (2006)
* **Why do you think this is appropriate for the Duchenne muscular dystrophy population?**
* Other (please specify: \_\_\_\_\_\_\_)
* **Why do you think this is appropriate for the Duchenne muscular dystrophy population?**
* No
* Click all methods that are NOT appropriate
* Centre for Disease Control & Prevention (CDC) Growth Chart (2000)
* **Why do you think this is NOT appropriate for the Duchenne muscular dystrophy population?**
* World Health Organization (WHO) Growth Chart (2006)
* **Why do you think this is NOT appropriate for the Duchenne muscular dystrophy population?**
* Other (please specify: \_\_\_\_\_\_\_)
* **Why do you think this is NOT appropriate for the Duchenne muscular dystrophy population?**
* Unsure
* This is not in my scope of practice

1. **Do you find that having clients’ height and weight information is helpful in providing care (aside from informing pulmonary function tests) for the Duchenne muscular dystrophy population?**

* Yes
* **Why do you think this information helpful?**
* No
* **Why do you think this information is NOT helpful?**
* Unsure
* This is not in my scope practice

About Consultations

1. **Do ever you discuss a child’s weight in a consultation?**

* Yes
* No this is not in my scope of practice

*<<If the participant replies “No” to this question, they will skip the rest of the questions within this section, and will be directed to the “About Responsibility and Referral” section>>*

**28a. How often do you discuss a child's weight with the child and/or the family?**

* Every visit
* Most visits
* Some visits
* Rarely

28B. What are the specific triggers that prompt a discussion about weight with children and families?(check all that apply)

* Body Mass Index
* Change in corticosteroid usage/dosage
* Client or family bring up the topic
* Family history
* Identified by parent and/or child
* Increased weight velocity on growth chart
* Pain on transfers
* Drop in FVC% predicted
* Diagnosis of Obstructive Sleep Apnoea
* Diagnosis of Hypoventilation
* Recent pulmonary exacerbation requiring admission to hospital;
* Decline in ejection fraction
* Upcoming surgery
* Other (please specify: \_\_\_\_\_\_\_)

**28c. What topics do you focus on in this discussion? In order of importance, please RANK your responses from 1 (most important) to 8 (least important). (Each topic should have unique numbers)**

|  |  |
| --- | --- |
| TOPIC | RANKING (1-8) |
| Activity/exercise |  |
| Diet |  |
| Healthy food choices |  |
| Dietitian Referral |  |
| Limiting sedentary activities |  |
| Participating in the community |  |
| Referral to a formal weight loss program |  |
| Other |  |

* Other (Please specify this discussion topic):

**28d. Do you use any resources as part of your discussion about weight with the child and/or family?**

* Yes
* **How often?**
* Every visit
* Most visits
* Some visits
* Rarely
* No *<<Skip to “Outcomes” question>>*
* Unsure

**28d (i). Which of the following resources do you use in these discussions? (Check all that apply)**

* Canada Food Guide
* Canadian Society for Exercise Physiology (CSEP) Exercise Guidelines
* Canadian Physical Activity Guidelines
* Clinic generated material
* International Duchenne muscular dystrophy material
* Other nutrition documents (e.g., handout on fibre)
* Other (please specify: \_\_\_\_\_\_\_)
* None (please specify: \_\_\_\_\_\_\_)
* Unsure

**28e. Rate the appropriateness of the resources for individuals with Duchenne muscular dystrophy from 1 (very appropriate) to 5 (not appropriate at all).**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **1**  **(Very appropriate)** | **2** | **3**  **(Neutral)** | **4** | **5**  **(Not appropriate at all)** | **Unsure** |
| Canada Food Guide |  |  |  |  |  |  |
| Canadian Society for Exercise Physiology (CSEP) Exercise Guidelines |  |  |  |  |  |  |
| Canadian Physical Activity Guidelines |  |  |  |  |  |  |
| Clinic generated material |  |  |  |  |  |  |
| Local Duchenne muscular dystrophy material |  |  |  |  |  |  |
| Other nutrition documents |  |  |  |  |  |  |

**28e (i). What outcomes do you often focus on with children and their parents when discussing the impact of weight management on different aspects of their lives? Please RANK your responses from 1 (most often) to 10 (least often). (Each topic should have unique numbers)**

|  |  |
| --- | --- |
| OUTCOMES | RANKING (1-10) |
| Physical Movement |  |
| Independence |  |
| Pain management |  |
| Participation in the community |  |
| Physical health |  |
| Reduction in the severity of obstructive sleep apnoea |  |
| Anaesthetic risk when undergoing surgical interventions |  |
| Cardiopulmonary function |  |
| Self-image/esteem |  |
| Other |  |

* Other (Please specify this outcome):

**28f. Research has shown that obesity is associated with serious end-organ dysfunction including cardiorespiratory and metabolic sequelae in typically developing children. These negative health outcomes are even more relevant for children with DMD because of the natural history of the disease leading to respiratory and cardiac failure. From a respiratory perspective, children with DMD and obesity are at risk of developing: 1) obstructive sleep apnoea (OSA), episodes of complete or partial upper airway obstruction; 2) hypoventilation, elevated carbon dioxide levels in the blood secondary to ventilatory failure; and 3) recurrent pneumonias because of the underlying neuromuscular weakness. Do you ever discuss the link between weight and respiratory function with the child and/or the family?**

* Yes
* **How often?**
* Every visit
* Most visits
* Some visits
* Rarely
* **How do they respond?**
* No

About Responsibility And Referral

1. **Who do you think is the most appropriate professional to DISCUSS weight related issues in children/ youth with Duchenne muscular dystrophy?**

* Dietitian
  + - Exercise Counselor
    - Life Skills Coach
    - Nurse
* Nurse Practitioner
* Registered Nurse
* Registered Practical Nurse
  + - Occupational Therapist
    - Physician
* Family Doctor
* General Pediatrician
* Endocrinologist
* Neurologist
* Respirologist
* Surgeon
  + - Physiotherapist
    - Respiratory Therapist
    - Psychologist
    - Pulmonary Function Lab Technologist
    - Social Worker
    - Therapeutic Recreation Staff
    - Other (please specify: \_\_\_\_\_\_\_)
* **Why do you think they are the most appropriate?**
* **Does your clinic include this professional resource?**
* Yes
* **In YOUR clinic, does this professional DISCUSS weight related issues with children and youth with Duchenne Muscular Dystrophy?**
* Yes
* No
* Unsure
* No
* Unsure

About Weight Management

1. **Who do you think is the most appropriate professional to COORDINATE weight management/ treatment care?**

* Dietitian
  + - Exercise Counselor
    - Life Skills Coach
    - Nurse
* Nurse Practitioner
* Registered Nurse
* Registered Practical Nurse
  + - Occupational Therapist
    - Physician
* Family Doctor
* General Pediatrician
* Endocrinologist
* Neurologist
* Respirologist
* Surgeon
* Other
  + - Physiotherapist
    - Respiratory Therapist
    - Psychologist
    - Pulmonary Function Lab Technologist
    - Social Worker
    - Therapeutic Recreation Staff
    - Other (please specify: \_\_\_\_\_\_\_)
    - Unsure
* **Why do you think they are the most appropriate?**

1. **Do you ever refer clients to specialized weight management programs?**

* Yes
* **How often?**
* Every visit
* Most visits
* Some visits
* Rarely
* No (why not? \_\_\_\_\_\_\_\_\_\_\_\_)
* This is not in my scope of practice *<<Skip “Referral Criteria” question below>>*

**31a. What is the referral criteria? (Check all that apply)**

* BMI (Please specify cut-off point) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Obesity-related co-morbidity
* Co-existing chronic condition
* Age (Please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Unsure
* Other (please specify or provide details of how criteria can be obtained - e.g. website)

1. **Does overweight or obesity impact your ability to offer a particular intervention/treatment plan for a child/youth with Duchenne muscular dystrophy?**

* Yes
* **How does the excess weight impact your ability to provide care/intervention?**
* No
* This is not in my scope of practice

1. **Rate your level of confidence in addressing the topic of weight management**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **1**  **(Very confident)** | **2** | **3**  **(Neutral)** | **4** | **5**  **(Not at all confident)** |
|  |  |  |  |  |

1. **What would help you to feel more confident to discuss weight related issues? (Check all that apply)**

* Better assessment tools and guidelines
* Better management options
* Family initiates discussion
* Obesity-specific training
* More consultation time
* More patient engagement with topic
* Other (please specify: \_\_\_\_\_\_\_)
* This is not in my scope of practice

End questions

1. **Would you like to be entered into a prize draw for one of two $150 gift card? Please note that your contact information will not be linked to your survey responses.**

⮊ directed to separate page to provide contact details

1. **Would you be interested in participating in an one-time interview about some the topics raised in this survey?**

⮊ directed to separate page to provide contact details