**Supplementary materials**

**Supplement A**

**Table: Targets of interventions provided in rehabilitations centers for each disease stage (light and dark grey blocks are the interventions in each phase)**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Most used interventions/interventions aimed at** | **EA** | **LA** | **ENA** | **LNA** |
| Walking/loss of ambulation |  |  |  |  |
| Transfers, advising, and monitoring physical functioning |  |  |  |  |
| Prevention of contractures |  |  |  |  |
| Sports/training |  |  |  |  |
| Help and advice with medical supplies (wheelchair, orthosis, house adjustment, etc.) |  |  |  |  |
| School or work advice, contact with school |  |  |  |  |
| Psychosocial and social-emotional care and advice |  |  |  |  |
| Advising and monitoring by dietician |  |  |  |  |
| Prevention advice by speech-language therapist |  |  |  |  |
| Advice and monitoring by speech-language therapist |  |  |  |  |
| Arm/hand function |  |  |  |  |
| Screening pulmonary function, information about ventilation |  |  |  |  |

**Abbreviations: EA = early ambulatory, LA = late ambulatory, ENA = early non-ambulatory, LNA = late non-ambulatory**

**Supplement B**

**Questionnaire about DMD care for rehabilitation professionals**

**Part 1: Organization of care**

1. Do you treat patients with DMD at your center?
   * Yes
   * No (end of questionnaire)
2. How many patients with DMD are treated at your center?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Which specialists or disciplines are involved for care for patients with DMD in your center? You can fill in multiple answers.

□ Rehabilitation physician

□ Physiotherapist

□ Occupational therapist

□ Speech and language therapist

□ Social worker

□ Psychologist

□ Remedial educationalist

□ Other, namely: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

□ Other, namely: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

□ Other, namely: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. What type of treatment do patients with DMD receive in your center? You can fill in multiple answers and there is room to elaborate.
2. □ Continuous care, go to question 6

□ Intermittent care, go to question 7

□ Single consultations, go to question 8

□ Other, go to question 9

1. You filled in ‘continuous care’. Which disciplines are part of this continuous care for patients with DMD  
   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. You filled in ‘intermittent care’. Please describe the reason why care is intermittent in your center?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. You filled in ‘single consultations’. What is the reason you provide single consultations?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. You filled in ‘other’. Please describe how care for patients with DMD is organized in your center.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. What are the most used interventions per disease stage?
   * Early ambulant phase  
     \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * Late ambulant phase  
     \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * Early non-ambulant phase  
     \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
   * Late non-ambulant phase  
     \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. How satisfied are you with the care you provide for patients with DMD in your center?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Very satisfied | Satisfied | Neutral | Unsatisfied | Very unsatisfied |
|  |  |  |  |  |

1. Which parts of care provided in your center are you satisfied with?  
   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Which parts of care provided in your center are you unsatisfied with?   
   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Are there aspects of DMD care that you would like to provide that cannot be realized?

□ Yes

□ No, go to question 17

1. Which care would you want to provide that cannot be realized?  
   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. What is the reason it cannot be realized?   
   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Do you experience bottlenecks or difficulties in providing care for patients with DMD in you center?

□ Yes

□ No, go to part 2 of the questionnaire

1. What bottlenecks or difficulties do you experience in providing care for patients with DMD in your center?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Part 2: The DMD guideline**

In 2010 the first version of the international DMD guidelines appeared. (referentie: Deel 1: Bushby K, et al. The Diagnosis and Management of Duchenne Muscular Dystrophy, part 1: diagnosis, and pharmacological and psychosocial management, Lancet Neurology 2010, 9(1) 77-93 en Deel 2: Bushby K, et al. The Diagnosis and Management of Duchenne Muscular Dystrophy, part 2: implementation of multidisciplinary care, Lancet Neurology 2010, 9(2) 177-189).

You can find the parts of the guideline related to rehabilitation in the attachments.

1. Are you familiar with the DMD guideline?

□ Yes

□ No

1. Please fill in whether you agree with the following statements about the guideline

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly agree | Agree | Neither agree, nor disagree | Disagree | Strongly disagree |
| The guideline is evidence-based |  |  |  |  |  |
| The guideline is useful in daily clinical work and improves the quality of treatment |  |  |  |  |  |
| The guideline is convenient and the information is easy to find |  |  |  |  |  |
| The guideline offers sufficient information regarding overall care for DMD |  |  |  |  |  |
| The guideline offers sufficient information regarding rehabilitation care for DMD |  |  |  |  |  |
| The guideline is completely implemented in our center |  |  |  |  |  |
| All practitioners are familiar with the guideline |  |  |  |  |  |
| The guideline is hard to implement in daily practice due to lack of medical resources |  |  |  |  |  |
| The guideline is hard to implement in daily practice due to too much strain on or a lack of resources of patients |  |  |  |  |  |
| There is no time to search for information |  |  |  |  |  |
| The guideline is not accessible |  |  |  |  |  |
| The guideline is too complicated and it is difficult to find the information |  |  |  |  |  |
| The guideline reduces doctors’ autonomy (a ‘cookbook’) |  |  |  |  |  |
| The guideline limits treatment options |  |  |  |  |  |
| The guideline limits flexibility and individual approach |  |  |  |  |  |
| There is no need for the guideline as treatment routines exist |  |  |  |  |  |
| Patients do not want doctors to conform to treatment guidelines |  |  |  |  |  |

1. Please tell us, in your own words, your opinion about the guideline.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. If you do not find the guideline sufficiently informative, in which areas would you like more information?  
   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Part 3: The ideal situation**

1. In your opinion, what is the ideal way to organize care for patients with DMD in the Netherlands?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Please indicate to what extent the following items/activities would help to comply to the guideline

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Strongly agree | Agree | Neither agree, nor disagree | Disagree | Strongly disagree |
| Special training courses |  |  |  |  |  |
| Available consultation to answer questions about the guideline |  |  |  |  |  |
| Information through professional societies |  |  |  |  |  |
| Published materials |  |  |  |  |  |

1. What is your profession?  
   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
2. What is your gender?

□ Male  
□ Female

1. What is your age?

\_\_\_\_\_\_ years

1. How many years experience do you have treating patients with DMD?

\_\_\_\_\_\_ years

**Thank you for your help!**