



INSTRUCTIONS FOR THE ACTIVLIM QUESTIONNAIRE

The ACTIVLIM questionnaire

The ACTIVLIM questionnaire was developed as a measure of activity limitations in children and adults with **neuromuscular disorders** (Vandervelde et al, Neuromuscul Disord, 2007). Activity limitations are defined as difficulties a patient may have in executing activities of daily living. The questionnaire includes 22 items that are daily activities. Among these 22 items, 4 are specifically designed for child evaluation, 4 for adult evaluation, and the remaining 14 items are common to all patients. ACTIVLIM was built either on the perception of the parents of the affected children or on the perception of the adult patients themselves. This perception concerns the difficulty in performing each activity of the questionnaire. The 22 items of ACTIVLIM defined a valid, reliable and reproducible scale. ACTIVLIM was originally developed using the Rasch measurement model. It allows to convert ordinal scores into linear measures located on a unidimensional scale.

Evaluation

*For a **child** evaluation (between 6 and 15 years-old):*

The **parents** fill in the questionnaire by estimating their child's difficulty or ease in performing each activity.

*For an **adult** evaluation (more than 16 years-old):*

The **patient** fills in himself the questionnaire by estimating their own difficulty or ease in performing each activity.

The activities should be done:

- **Without technical or human help** (even if the patient actually uses help in daily life)
- Irrespective the limb(s) actually used to achieve the activity
- Whatever the strategy used (any compensation is allowed)

Three responses are presented. These assess the perception of the difficulty/ease depending on whether the activity is "impossible", "difficult" or "easy". Activities not attempted in the last 3 months are not scored and entered as missing responses (to tick the question mark).



So, for any activity, the four potential answers are:

- **Impossible:** The patient is unable to perform the activity without using any other help.
- **Difficult:** The patient is able to perform the activity without any help but experiences some difficulty.
- **Easy:** The patient is able to perform the activity without any help and experiences no difficulty.
- **Question mark:** The patient cannot estimate the difficulty of the activity because he has never done the activity.

Watch out!! If the activity was never attempted because it is impossible, then it must be scored “impossible” rather than “question mark”.

Activities order

The activities of the ACTIVLIM questionnaire are presented in a random order to avoid any systematic effect. Ten different random orders of presentation are used. The rater must select the next one of the 10 orders for each new assessment, no matter which patient is tested.

Package content

- 1 instruction sheet.
- Testing forms of ACTIVLIM in 10 random orders (1 sheet for each)

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1	Putting on a T-shirt			
2	Washing one's upper body			
3	Dressing one's lower body			
4	Taking a shower			
5	Sitting on the toilet			
6	Taking a bath			
7	Walking downstairs			
8	Stepping out of a bath tub			
9	Opening a door			
10	Walking outdoors on level ground			
11	Washing one's face			
12	Hanging up a jacket on a hatstand			
13	Wiping one's upper body			
14	Walking upstairs			

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15	Carrying a heavy load	A			
16	Getting into a car	A			
17	Standing for a long time (\pm 10 min)	A			
18	Walking more than 1 kilometre	A			

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19	Closing a door	C			
20	Hopping on one foot	C			
21	Putting on a backpack	C			
22	Running	C			

Order 1

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Stepping out of a bath tub				
2 Hanging up a jacket on a hatstand				
3 Wiping one's upper body				
4 Taking a shower				
5 Putting on a T-shirt				
6 Dressing one's lower body				
7 Sitting on the toilet				
8 Walking upstairs				
9 Walking outdoors on level ground				
10 Washing one's face				
11 Walking downstairs				
12 Taking a bath				
13 Opening a door				
14 Washing one's upper body				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Standing for a long time (\pm 10 min)	A				
16 Walking more than 1 kilometre	A				
17 Getting into a car	A				
18 Carrying a heavy load	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Running	C				
20 Closing a door	C				
21 Putting on a backpack	C				
22 Hopping on one foot	C				

Order 2

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Hanging up a jacket on a hatstand				
2 Opening a door				
3 Wiping one's upper body				
4 Dressing one's lower body				
5 Stepping out of a bath tub				
6 Taking a shower				
7 Washing one's upper body				
8 Walking upstairs				
9 Sitting on the toilet				
10 Taking a bath				
11 Putting on a T-shirt				
12 Washing one's face				
13 Walking outdoors on level ground				
14 Walking downstairs				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Getting into a car	A				
16 Carrying a heavy load	A				
17 Walking more than 1 kilometre	A				
18 Standing for a long time (\pm 10 min)	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Hopping on one foot	C				
20 Closing a door	C				
21 Putting on a backpack	C				
22 Running	C				

Order 3

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Wiping one's upper body				
2 Stepping out of a bath tub				
3 Walking downstairs				
4 Opening a door				
5 Putting on a T-shirt				
6 Sitting on the toilet				
7 Washing one's upper body				
8 Taking a bath				
9 Taking a shower				
10 Dressing one's lower body				
11 Walking upstairs				
12 Walking outdoors on level ground				
13 Washing one's face				
14 Hanging up a jacket on a hatstand				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Carrying a heavy load	A				
16 Getting into a car	A				
17 Walking more than 1 kilometre	A				
18 Standing for a long time (\pm 10 min)	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Running	C				
20 Closing a door	C				
21 Putting on a backpack	C				
22 Hopping on one foot	C				

Order 4

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Sitting on the toilet				
2 Dressing one's lower body				
3 Stepping out of a bath tub				
4 Taking a shower				
5 Walking upstairs				
6 Taking a bath				
7 Hanging up a jacket on a hatstand				
8 Walking outdoors on level ground				
9 Washing one's face				
10 Walking downstairs				
11 Putting on a T-shirt				
12 Opening a door				
13 Washing one's upper body				
14 Wiping one's upper body				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Walking more than 1 kilometre	A				
16 Carrying a heavy load	A				
17 Getting into a car	A				
18 Standing for a long time (\pm 10 min)	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Hopping on one foot	C				
20 Running	C				
21 Putting on a backpack	C				
22 Closing a door	C				

Order 5

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Putting on a T-shirt				
2 Walking downstairs				
3 Taking a shower				
4 Sitting on the toilet				
5 Stepping out of a bath tub				
6 Wiping one's upper body				
7 Washing one's upper body				
8 Washing one's face				
9 Opening a door				
10 Dressing one's lower body				
11 Hanging up a jacket on a hatstand				
12 Walking outdoors on level ground				
13 Taking a bath				
14 Walking upstairs				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Standing for a long time (\pm 10 min)	A				
16 Carrying a heavy load	A				
17 Walking more than 1 kilometre	A				
18 Getting into a car	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Hopping on one foot	C				
20 Putting on a backpack	C				
21 Closing a door	C				
22 Running	C				

Order 6

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Wiping one's upper body				
2 Taking a bath				
3 Washing one's upper body				
4 Washing one's face				
5 Dressing one's lower body				
6 Putting on a T-shirt				
7 Sitting on the toilet				
8 Walking outdoors on level ground				
9 Walking downstairs				
10 Opening a door				
11 Hanging up a jacket on a hatstand				
12 Walking upstairs				
13 Stepping out of a bath tub				
14 Taking a shower				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Getting into a car	A				
16 Walking more than 1 kilometre	A				
17 Carrying a heavy load	A				
18 Standing for a long time (\pm 10 min)	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Hopping on one foot	C				
20 Putting on a backpack	C				
21 Running	C				
22 Closing a door	C				

Order 7

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Wiping one's upper body				
2 Sitting on the toilet				
3 Taking a bath				
4 Taking a shower				
5 Walking downstairs				
6 Walking outdoors on level ground				
7 Walking upstairs				
8 Putting on a T-shirt				
9 Opening a door				
10 Washing one's upper body				
11 Hanging up a jacket on a hatstand				
12 Dressing one's lower body				
13 Washing one's face				
14 Stepping out of a bath tub				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Getting into a car	A				
16 Carrying a heavy load	A				
17 Walking more than 1 kilometre	A				
18 Standing for a long time (\pm 10 min)	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Closing a door	C				
20 Putting on a backpack	C				
21 Hopping on one foot	C				
22 Running	C				

Order 8

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1 Hanging up a jacket on a hatstand				
2 Stepping out of a bath tub				
3 Walking upstairs				
4 Sitting on the toilet				
5 Taking a bath				
6 Walking outdoors on level ground				
7 Taking a shower				
8 Walking downstairs				
9 Wiping one's upper body				
10 Washing one's upper body				
11 Washing one's face				
12 Putting on a T-shirt				
13 Opening a door				
14 Dressing one's lower body				

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15 Getting into a car	A				
16 Carrying a heavy load	A				
17 Walking more than 1 kilometre	A				
18 Standing for a long time (\pm 10 min)	A				

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19 Hopping on one foot	C				
20 Running	C				
21 Closing a door	C				
22 Putting on a backpack	C				

Order 9

ACTIVLIM - Activity Limitations Measure

English version

Name: _____

Date: _____

How difficult are the following activities?	Impossible	Difficult	Easy	?
1	Sitting on the toilet			
2	Taking a bath			
3	Dressing one's lower body			
4	Stepping out of a bath tub			
5	Putting on a T-shirt			
6	Walking downstairs			
7	Walking outdoors on level ground			
8	Taking a shower			
9	Washing one's upper body			
10	Wiping one's upper body			
11	Opening a door			
12	Washing one's face			
13	Walking upstairs			
14	Hanging up a jacket on a hatstand			

To evaluate an **adult** patient (age 16-80), please answer to the following questions.

To evaluate a **child** patient (age 6 -15), please mark the following questions with the "?"

15	Carrying a heavy load	A			
16	Walking more than 1 kilometre	A			
17	Getting into a car	A			
18	Standing for a long time (\pm 10 min)	A			

To evaluate a **child** patient (age 6-15), please answer to the following questions.

To evaluate an **adult** patient (age 16-80), please mark the following questions with the "?"

19	Running	C			
20	Closing a door	C			
21	Hopping on one foot	C			
22	Putting on a backpack	C			

Order 10