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# Questionnaire Qol gNMD in english (patient reported functioning outcome in genetic NMD adults : a new rasch measure)

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**Université de Reims Champagne-Ardenne  
Faculté de Médecine  
EA3797**

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**Main investigator: Pr François Constant BOYER, CHU Reims**



**Quality of Life Measure for people  
with slowly progressive and genetic  
neuromuscular disease.  
QoL-gNMD v1.0**

Date of completion      |\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|

Name of investigator      .....

Investigator's phone contact      |\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|

Place administered      .....

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Assessing your quality of life is important for your doctor to understand your general feelings about your neuromuscular disease and how those feelings evolve. This questionnaire will help your doctor to understand how you are feeling so as to suit the care provided to you needs and design a personalised care plan taking account of your aims and wishes for the future.

## Instructions :

1. Your answers to this questionnaire should reflect your own feelings and not the feelings of anyone else.
2. You should read each question yourself.
3. Someone can write the answers for you, but should not answer for you.
4. Please answer all questions by circling the one number that best describes your situation. A spontaneous answer will give a better indication of how you are feeling. There are no right or wrong answers.
5. If you want to correct an answer, cross it out and circle the one you have finally chosen.
6. Your answers will remain strictly confidential.

## How to calculate scores:

1. There are two ways to calculate this QOL-gNMD measure:
  - a. Calculation of the reasearch score
  - b. Calculation of the clinical score
2. To obtain a guide to the scoring system, file a request to: [fboyer@chu-reims.fr](mailto:fboyer@chu-reims.fr)

Dany A, Rapin A, Lavrard B, Saoût V, Réveillère C, Bassez G, Tiffreau V, Péréon Y, Sacconi S, Eymard B, Dramé M, Jolly D, Novella JL, Hardouin JB, Boyer FC. The quality of life in genetic neuromuscular disease questionnaire: Rasch validation of the French version. Muscle Nerve. 2017 Dec;56(6):1085-1091. doi: 10.1002/mus.25598.

Dany A, Barbe C, Rapin A, Réveillère C, Hardouin JB, Morrone I, Wolak-Thierry A, Dramé M, Calmus A, Sacconi S, Bassez G, Tiffreau V, Richard I, Gallais B, Prigent H, Taiar R, Jolly D, Novella JL, Boyer FC. Construction of a Quality of Life Questionnaire for slowly progressive neuromuscular disease. Qual Life Res. 2015 Nov;24(11):2615-23. doi: 10.1007/s11136-015-1013-8.

Dany A, Rapin A, Réveillère C, Calmus A, Tiffreau V, Morrone I, Novella JL, Jolly D, Boyer FC. Exploring quality of life in people with slowly progressive neuromuscular disease. Disabil Rehabil. 2017 Jun;39(13):1262-1270. doi: 10.1080/09638288.2016.1191552.

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## General questions

- 1) Given your neuromuscular disease, **how has your health been** over the last four weeks ?

Poor	Moderate	Good	Excellent
0	1	2	3

- 2) Given your neuromuscular disease, how would you describe your **quality of life** over the last four weeks ?

Poor	Moderate	Good	Excellent
0	1	2	3

## Part I. The impact of your physical symptoms

Please describe the effect of your neuromuscular disease on your health **over the last four weeks**: for each question, circle the closest answer.

- 3) Have you felt physically **tired on waking** up in the morning because of your neuromuscular disease ?

Every morning	Often	Occasionally	Never
0	1	2	3

- 4) How often have you needed to **rest during the day** because of your neuromuscular disease ?

Several times a day	Once a day	Sometimes, but not every day	Never
0	1	2	3

- 5) Given your neuromuscular disease, **how have you been sleeping** ?

Badly	Moderately well	Well	Very well
0	1	2	3

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- 6) How often have your daily activities been restricted because of **pain** linked to your neuromuscular disease ?

Every day	Sometimes, but not every day	Never
0	1	2

- 7) Have you been troubled by a frequent **need to urinate** because of your neuromuscular disease ?

Yes	No
0	1

- 8) Have you found it **difficult to concentrate on everyday tasks** because of your neuromuscular disease ?

Very often	Often	Occasionally	Never
0	1	2	3

- 9) Have you found it difficult **remembering** things because of your neuromuscular disease ?

Very often	Often	Occasionally	Never
0	1	2	3

## Part II. How you see yourself

Please describe your feelings **today** towards your neuromuscular disease. For each question, circle the closest answer.

- 10) Does your neuromuscular disease **cause you anxiety** ?

Very often	Often	Seldom	Never
0	1	2	3

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11) Does your neuromuscular disease **affect your morale** ?

Very often	Often	Seldom	Never
0	1	2	3

12) Compared to other people, does your neuromuscular disease **make you irritable** ?

Much more than others	Somewhat more than others	Neither more nor less than others	Less than others
0	1	2	3

13) Do you ever think that in the future, because of your neuromuscular disease, you **are likely to rely more heavily on those around you** ?

Very often	Often	Seldom	Never
0	1	2	3

14) Are your **future plans** conditioned by your neuromuscular disease ?

Very often	Often	Occasionally	Never
0	1	2	3

15) Does your neuromuscular disease prevent you from **being in control of your life** ?

Very often	Often	Occasionally	Never
0	1	2	3

16) Do you think that your neuromuscular disease **changes the way people see you** ?

Enormously	A great deal	A little	Not at all
0	1	2	3

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17) Does your neuromuscular disease **affect your love life** ?

Very often	Often	Occasionally	Never
0	1	2	3

### Part III. Getting around and taking part

Please tell us your feelings about how easy it has been to get around **over the last four weeks** ?  
For each question, circle the closest answer.

18) Given your neuromuscular disease, have you felt able to **get about outside your home** on your own over the last four weeks ?

Never	Occasionally	Often	Very often
0	1	2	3

19) Because of your neuromuscular disease, have you had difficulty **getting around in your home (or place of residence)** ?

Very often	Often	Occasionally	Never
0	1	2	3

20) Have you had difficulty **getting around in other people's homes** (friends or family) because of your neuromuscular disease ?

Very often	Often	Occasionally	Never
0	1	2	3

21) Has **anxiety about getting around** on your own stopped you going out because of your neuromuscular disease ?

Very often	Often	Occasionally	Never
0	1	2	3

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22) Have you been avoiding certain places because **of risk of a fall** (whether on foot or in a wheelchair) ?

Very often	Often	Occasionally	Never
0	1	2	3

These questions concern the outside environment (public places, public transport) around where you live and the impact of your neuro-muscular disease on your relations with family and friends **over the last twelve months**. For each question circle the closest answer.

23) Given your neuromuscular disease, does **getting to the toilet** restrict your activities outside your home ?

Very often	Often	Occasionally	Never
0	1	2	3

24) Has your neuromuscular disease **deprived you of certain activities** (hobbies, eating out, theatre, sport, etc...) ?

Very often	Often	Occasionally	Never
0	1	2	3

25) Do you think that **cold weather** has restricted your activities more than it does for other people because of your neuromuscular disease ?

Very often	Often	Occasionally	Never
0	1	2	3

26) Does your neuromuscular disease restrict your **participation in family activities** ?

Very often	Often	Occasionally	Never
0	1	2	3

**Thank you for taking time to complete this questionnaire**