



## Questionnaire Thalassaemia major or Beta Thalassaemia

August 9, 2023

### Why this form

Rare Care World's website brings together information about rare conditions such as Beta Thalassaemia to provide people with a rare condition worldwide, their families and others the same information. For this purpose, the ICF coding established by the WHO (World Health Organisation) is used.

We intend to ensure that people with a rare condition in the Netherlands, and in principle in any country developing a personal health record, can fill out a form within their own PGO (personal health environment) about a number of activities with which they have problems in accordance with the ICF coding. The form you are reading now is an example, in this case for people with Beta Thalassaemia.

### Explanation of the questions

The form is built the same way as using the ICF as is done through the website of the WHO, but is rewritten for someone with Thalassaemia in the Netherlands, who can fill out a form him/herself, with or without help from others. Moreover there is extra explanation at each activity.

The different activities have been numbered as used in the ICF. The ICF d describes activities and participation. Activities refer to what someone can or cannot do. Participation refers to the extent to which a person can participate in society.

Activities and participation are divided into areas of life. Areas of life are important areas in which life takes place. Think of leisure, school, work, household, finances. The degree of the limitation or difficulty with participation can give you a score per area of life: 0 = no effort, neutral 1 = light effort, 2 = moderate effort, 3 = severe effort, 4 = not possible.

Do you have questions about the form? Please contact Liesbeth Siderius via [e.siderius@kpnplanet.nl](mailto:e.siderius@kpnplanet.nl)

### More about the ICF::

- More information about the International Classification of Functioning, Disability and Health can be found at
  - <https://www.rarecare.world>
  - <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>
- The Dutch summary can be found at <https://www.rivm.nl/media/WHO-FIC/ICFwebuitgave.pdf>

ACTIVITIES AND PARTICIPATION		Thal						
<p>The purpose of this questionnaire is to get a clearer picture of the problems you experience in carrying out activities. You are asked to give yourself a rating for each component.</p> <p>. At the first question it says 'with help' or 'with tool'. Please fill in if you can do this in daily life with help or tool.</p> <p>. At the second questions you are asked if you can do it Without that help or tool</p>								
<b>Severity of the problem</b>		No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
<b>d460</b>	<b>Moving around in different locations</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
	<p>Explanation: Walking and moving around in various places and situations, such as walking between rooms in a house, within a building, or down the street of a town.</p> <p><i>Think of:</i>  <i>Moving around in rooms at home or a building different than home, or outside. Walking in schoolbuildings with a (heavy) bag, height of chairs.</i></p>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							
<b>d4750</b>	<b>Driving human-powered transportation</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
	<p>Explanation: Driving human-powered transportation such as a bicycle, tricycle, or rowboat.</p> <p><i>Think of:</i>  <i>Fatigueness, for instance from cycling.</i></p>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							

<b>d570</b>	<b>Looking after one's health</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
<p>Explanation: Ensuring physical comfort, health and physical and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations.</p> <p><i>Think of:</i>  <i>Taking good care of yourself (medicine use, mental and physical health), making independent decisions, being dependent on others, cold, infections, fatigueness, endurance, etc.</i></p>								
<b>Tell us about the difficulties you have faced and what has been of help:</b>								
<b>d 610</b>	<b>Acquiring a place to live</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
<p>Explanation: Buying, renting, furnishing and arranging a room, house, apartment or other dwelling. Inclusions: buying or renting a place to live and furnishing a place to live.</p> <p><i>Think of:</i>  <i>Living independently, assisted living, accessibility, affordable, help in furnishing your home, help in administration and finances, etc. In case of bying: mortgage, insurance, etc.</i></p>								
<b>Tell us about the difficulties you have faced and what has been of help:</b>								
<b>d640</b>	<b>Doing housework</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
<p>Explanation: Managing a household by cleaning the house, washing clothes, using household appliances, storing food and disposing of garbage, such as by sweeping, mopping, washing counters, walls and other surfaces; collecting and disposing of household garbage; tidying rooms, closets and drawers; collecting, washing, drying, folding and ironing clothes; cleaning footwear; using brooms, brushes and vacuum cleaners; using washing machines, dryers and irons</p> <p><i>Think of:</i>  <i>Provide food and drinks, washing and ironing, changing bedding, cleaning toilet and bathroom, window cleaning, vacuum cleaning, storing shoppings, removing garbage, fatigueness, etc.</i></p>								
<b>Tell us about the difficulties you have faced and what has been of help:</b>								

<b>d730</b>	<b>Relating with strangers</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
	Explanation: Engaging in temporary contacts and links with strangers for specific purposes, when asking for directions or other information, or making a purchase.  <i>Think of: Uncertainty because of being short statured.</i>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							
<b>d770</b>	<b>Intimate relationships</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
	Explanation: Engaging in temporary contacts and links with strangers for specific purposes, when asking for directions or other information, or making a purchase.  <i>Think of: Fear to be rejected because of a chronic condition.</i>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							
<b>d 820</b>	<b>School education</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
	Explanation: Gaining administration school, education, engaging in all school-related responsibilities and privileges, and learning the course material, subjects and other curriculum requirements in primary and secondary school education, including attending school regularly, working cooperatively with other students, taking directions from teachers, organizing, studying and completing assignments tasks and projects, and advancing the other stages of education.  <i>Think of: School choice, learning problems, concentration problems, fatigueness, being sick more often, needing more support and explanation, performance anxiety, cooperation with others (classmates, teachers), in further education: get stuck between shore and ship, absence for medical reasons, etc.</i>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							

d830	Higher education	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Engaging in the activities of advanced educational programmes in universities, colleges and professional schools and learning all aspects of the curriculum required for degrees, diplomas, certificates and other accreditations, such as completing a university bachelor's or master's course of study, medical school or other professional school.</p> <p><i>Think of:</i>  <i>Fatigueness, reduced concentration, absence for medical reasons during curriculum activities, practicals, tentamination for reaching a grade, diploma certificates or other accreditaion, statisfying the obligation of being present.</i></p>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							
d840	Apprenticeship (work preparation)	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Engaging in programmes related to preparation for employment, such as performing the tasks required of an apprenticeship, internship, articling and in-service training.</p> <p><i>Think of:</i>  <i>Being rejected due to too many limitations.</i></p>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							
d 850	Remunerative employment	0	1	2	3	4	8	9
	With help or tool							
	Without help or tool							
	<p>Explanation: Engaging in all aspects of work, as an occupation, trade, profession or other forms of employment, for payment, as an employee, full or part-time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups.</p> <p><i>Think of:</i>  <i>Being rejected due to limitations. Difficulty finding and keeping suitable work, independently or with the help of an authority (UWV (= Dutch Employee Insurance Agency), municipality, job coach), disability working hours and fatigue (part-time or full-time), fewer possibilities, guidance needed, in case of referral UWV: application for assessment of work capacity, incapacitated for work (Wajong = Young Persons Disability Benefits Act).</i></p>							
	<b>Tell us about the difficulties you have faced and what has been of help:</b>							

<b>d8501</b>	<b>Part-time employment</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
<p>Explanation: Engaging in all aspects of work for payment on a part-time basis, as an employee, such as seeking employment and getting a job, doing the tasks required of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups.</p> <p>Think of: does not deliver financial advantages next to security payment</p>								
<p><b>Tell us about the difficulties you have faced and what has been of help:</b></p>								
<b>d870</b>	<b>Economic self-sufficiency</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
<p>Explanation: Having command over economic resources, from private or public sources, in order to ensure economical security for present and future needs.</p> <p>Think of: Being rejected due to too many limitations.</p>								
<p><b>Tell us about the difficulties you have faced and what has been of help:</b></p>								
<b>d 9201</b>	<b>Sports</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>8</b>	<b>9</b>
	With help or tool							
	Without help or tool							
<p>Explanation: Engaging in competitive and informal or formally organized games or athletic events, performed alone or in a group, such as bowling, gymnastics or soccer.</p> <p>Think of: Fatigueness and other physical limitations and risks.</p>								
<p><b>Tell us about the difficulties you have faced and what has been of help:</b></p>								

GENERAL QUESTIONS / PERSONAL DATA	
These questions are about general data that can affect people's functioning.	
<b>1.</b> <b>What is your age</b>	<input type="radio"/> 15 – 20 <input type="radio"/> 21 – 30 <input type="radio"/> 31 – 40 <input type="radio"/> 41 – 50 <input type="radio"/> 51 – 60 <input type="radio"/> 61 – 70 <input type="radio"/> 71 – 80 <input type="radio"/> 81 or older
<b>2.</b> <b>What is your gender</b>	<input type="radio"/> man <input type="radio"/> woman <input type="radio"/> .....
<b>3.</b> <b>Are there any agencies or people who know so little about your illness or condition that you have to explain your situation over and over again?</b> Think of uwv, government, the doctors, the employer....	
<b>4.</b> <b>Who filled out this form</b>	<input type="radio"/> myself <input type="radio"/> with someone else <input type="radio"/> someone else
<b>5.</b> <b>Are there items that you miss in this questionnaire?</b>	