



Universiteit  
Leiden

The Netherlands

**Paediatric health related quality of life : a European perspective : instrument development, validation, and use in clinical practice**

Baars, R.M.

**Citation**

Baars, R. M. (2006, March 30). *Paediatric health related quality of life : a European perspective : instrument development, validation, and use in clinical practice*. Retrieved from <https://hdl.handle.net/1887/18420>

Version: Corrected Publisher's Version

License: [Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden](#)

Downloaded from: <https://hdl.handle.net/1887/18420>

**Note:** To cite this publication please use the final published version (if applicable).

## Appendix

Appendix

## **Appendix**

The DISABKIDS chronic generic module

The DISABKIDS asthma specific module

Contact information

## Chronic generic module

Questionnaire for children and adolescents

Hi,

We would like to ask you some questions about how you have been feeling during the past four weeks. These questions ask about some problems that children like you might have.

We would like you to answer all the questions below.

Please

think back over the past four weeks when answering the questions and choose the answer that fits you best and tick the appropriate box.

If you play with your friends 'very often' you would tick the box as shown in this example:

For example: __	never	seldom	quite often	very often	always
Do you play with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

There are no right or wrong answers. It's what you think that matters.

Appendix

INDEPENDENCE		Please think back over the last 4 weeks...				
		never	seldom	quite often	very often	always
1.	Are you confident about your future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Do you enjoy your life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Are you able to do everything you want to do even though you have a condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Do you feel like everyone else even though you have a condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Are you free to lead the life you want even though you have a condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Are you able to do things without your parents?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PHYSICAL		Please think back over the last 4 weeks...				
		never	seldom	quite often	very often	always
7.	Are you able to run and move as you like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Do you feel tired because of your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Is your life ruled by your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Does it bother you that you have to explain to others what you can and can't do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Is it difficult to sleep because of your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Does your condition bother you when you play?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

EMOTION		Please think back over the last 4 weeks...				
		never	seldom	quite often	very often	always
13.	Does your condition make you feel bad about yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	Are you unhappy because of your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Do you worry about your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Does your condition make you angry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Do you have fears about the future because of your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Does your condition get you down?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Does it bother you that your life has to be planned?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SOCIAL EXCLUSION		Please think back over the last 4 weeks...				
		never	seldom	quite often	very often	always
20.	Do you feel lonely because of your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	Do your teachers behave differently towards you than towards others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	Do you have problems concentrating at school because of your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23.	Do you feel that others have something against you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24.	Do you think that others stare at you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25.	Do you feel different from other children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SOCIAL INCLUSION		Please think back over the last 4 weeks...				
		never	seldom	quite often	very often	always
26.	Do other kids understand your condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27.	Do you go out with your friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28.	Are you able to play or do things with other children/adolescents (e.g. sports)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29.	Do you think that you can do most things as well as other children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30.	Do your friends enjoy being with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31.	Do you find it easy to talk about your condition to other people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MEDICAL TREATMENT		Think about the past four weeks ....				
		never	seldom	quite often	very often	always
<p>Do you take any medication or do you get treatment? (e.g. pufs or sprays )</p> <p><input type="checkbox"/> yes, then please fill in the following questions</p> <p><input type="checkbox"/> no, you may go to the next page</p>						
32.	Does having to get help with medication from others bother you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33.	Is it annoying for you to have to remember your medication?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34.	Are you worried about your medication?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35.	Does taking medication bother you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36.	Do you hate taking your medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37.	Does taking medication disrupt everyday life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Asthma specific module

Now we would like to know some things about your asthma.

IMPACT		Please think back over the last 4 weeks...				
		never	seldom	quite often	very often	always
1.	Do you feel that you get easily exhausted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Does asthma bother you if you want to go out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Are you unable to take part in certain sports?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Do you feel short of breath when you do sports?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Are you bothered by the amount of time you spend wheezing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Do you feel terrible when you are out of breath?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WORRY		Please think back over the last 4 weeks...				
		never	seldom	quite often	very often	always
7.	Are you worried that you might have an asthma attack?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Do you worry that others do not know what to do if you have an attack?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Do you feel scared that you might have difficulty breathing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Are you scared that you might have to go to the emergency ward?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Are you scared at night because of your asthma?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## Contact information

[www.disabkids.de](http://www.disabkids.de)

### Coordination centre

Monika Bullinger ([bullinger@uke.uni-hamburg.de](mailto:bullinger@uke.uni-hamburg.de))

Silke Schmidt ([sischmid@uke.uni-hamburg.de](mailto:sischmid@uke.uni-hamburg.de))

Corinna Petersen ([copeters@uke.uni-hamburg.de](mailto:copeters@uke.uni-hamburg.de))

Department of Medical Psychology

University Hospital of Hamburg-Eppendorf

Martinistr. 52 Pav. 69, 20246 Hamburg, Germany

Tel: +49-40-42803 6430

### The Netherlands

Hendrik Koopman ([H.M.Koopman@lumc.nl](mailto:H.M.Koopman@lumc.nl))

Rolanda Baars ([R.M.Baars@lumc.nl](mailto:R.M.Baars@lumc.nl))

Department of Paediatrics

Leiden University Medical Center, PO Box 9600

2300 RC Leiden, The Netherlands

Tel: +31-71-526 1666 / 2824

### Germany

Ute Thyen ([thyen@paedia.ukl.mu-luebeck.de](mailto:thyen@paedia.ukl.mu-luebeck.de))

Esther Müller-Godeffroy ([mueller-g@paedia.ukl.mu-luebeck.de](mailto:mueller-g@paedia.ukl.mu-luebeck.de))

Department of Paediatrics

Medical University of Luebeck, Ratzeburger Allee 160

23538 Luebeck, Germany

Tel: +49-451-500 2615

### United Kingdom

Mick Power ([mjpower@staffmail.ed.ac.uk](mailto:mjpower@staffmail.ed.ac.uk))

Peter Hoare ([phoare@staffmail.ed.ac.uk](mailto:phoare@staffmail.ed.ac.uk))

Section of Clinical and Health Psychology

University of Edinburgh, Morningside Park

Edinburgh EH 10 5HF, United Kingdom

Tel: +44-131-537-6578/79

### France

Marie Claude Siméoni ([disabkids.phys-med-rehab@univie.ac.at](mailto:disabkids.phys-med-rehab@univie.ac.at))

Department of Public Health

University Hospital of Marseille, 27 BD. J. Moulin

13885 Marseille cedex 5, France

Tel: +33-49132-4474

**Greece**

John Tsanakas ([tsanakas@spark.net.gr](mailto:tsanakas@spark.net.gr))

Athanasios Vidalis ([vidalis@med.auth.gr](mailto:vidalis@med.auth.gr))

Department of Psychiatry and Department of Paediatrics Respiratory Unit

Hippocratio Hospital, Konstantinoupoleos 49

Thessaloniki T.K. 54642, Greece

Tel: +30-31-838004

**Sweden**

John Eric Chaplin ([john.chaplin@vgregion.se](mailto:john.chaplin@vgregion.se))

The Growth Centre (Växthuset),

Queen Silvia's Children's Hospital

SE-416 85 Gothenburg, Sweden

Tel: +46-31-343 5788

**Austria**

Michael Quittan ([Michael.quittan@akh-wien.ac.at](mailto:Michael.quittan@akh-wien.ac.at))

Othmar Schuhfried ([Othmar.Schuhfried@univie.ac.at](mailto:Othmar.Schuhfried@univie.ac.at))

Department of Physical Medicine and Rehabilitation

University of Vienna, Währinger Gürtel 18-20

1090 Wien, Austria

Tel: +43-1-40400-5277

