

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

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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 <u>answer all the questions below</u>.

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?				Ø	

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

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

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?	٦				
8.	Do you feel tired because of your condition?	٦	٦		D	
9.	Is your life ruled by your condition?	٦	٦		D	٦
10.	Does it bother you that you have to explain to others what you can and can't do?	٦	٦		D	٦
11.	Is it difficult to sleep because of your condi- tion?		ū			
12.	Does your condition bother you when you play?					

EMOTION Please think back over the last 4 weeks					4 weeks	
		never	seldom	quite often	very often	always
13.	Does your condition make you feel bad about yourself?					ū
14.	Are you unhappy because of your condition?					
15.	Do you worry about your condition?					ū
16.	Does your condition make you angry?					ū
17.	Do you have fears about the future because of your condition?		٦			
18.	Does your condition get you down?		٦			
19.	Does it bother you that your life has to be planned?					

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?				ū	
21.	Do your teachers behave differently towards you than towards others?			ū		
22.	Do you have problems concentrating at school because of your condition?			ū	ū	
23.	Do you feel that others have something against you?					
24.	Do you think that others stare at you?				ū	
25.	Do you feel different from other children?					

SOCIAL INCLUSION Please think back over the last 4 weeks						
		never	seldom	quite often	very often	always
26.	Do other kids understand your condition?					ū
27.	Do you go out with your friends?	ū	٦		D	D
28.	Are you able to play or do things with other children/adolescents (e.g. sports)?		D			
29.	Do you think that you can do most things as well as other children?	ū				
30.	Do your friends enjoy being with you?					
31.	Do you find it easy to talk about your condi- tion to other people?					

#### MEDICAL TREATMENT

Do you take any medication or do you get treatment? (e.g. pufs or sprays )

 $\Box$  yes, then please fill in the following questions

□ no, you may go to the next page

Think about the past four weeks ....

	Think about the past four weeks					
		never	seldom	quite often	very often	always
32.	Does having to get help with medication from others bother you?	٦				
33.	Is it annoying for you to have to remember your medication?					
34.	Are you worried about your medication?					
35.	Does taking medication bother you?					٦
36.	Do you hate taking your medicine?					
37.	Does taking medication disrupt everyday life?					

## Asthma specific module

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

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

WOR	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?					
8.	Do you worry that others do not know what to do if you have an attack?					
9.	Do you feel scared that you might have dif- ficulty breathing?					
10.	Are you scared that you might have to go to the emergency ward?					
11.	Are you scared at night because of your asthma?					

### **Contact information**

<u>www.disabkids.de</u>

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