

In this section we are interested in learning how your disease affects your ability to function in daily life. In the following questions, please check the response which best describes your usual activities (averaged over an entire day) over the past week.

	Without any difficulty	With some difficulty	With much difficulty	Unable to do
1. Dressing and grooming				
Are you able to:				
• Dress, including tying shoelaces and doing buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Shampoo your hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Remove socks?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Cut fingernails?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Arising				
Are you able to:				
• Stand up from a low chair or floor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Get in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Eating				
Are you able to:				
• Cut your own meat?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Lift up a cup or glass to mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Open a new cereal box?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Walking				
Are you able to:				
• Walk outdoors on flat ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Climb up five steps?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Hygiene				
Are you able to:				
• Wash and dry your entire body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Take a tub bath (get in and out of tub)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Get on and off the toilet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Brush teeth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Comb/brush hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Reach				
Are you able to:				
• Reach and get down a heavy object such as a large game or books from just above your head?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Bend down to pick up clothing or a piece of paper from the floor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Pull on a sweater over your head?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Turn neck to look back over shoulder?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Grip				
Are you able to:				
• Write with pen or pencil?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Open car doors?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Open jars which have been previously opened?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Turn faucets on and off?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Push open a door when you have to turn a door knob?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Activities				
Are you able to:				
• Run errands and shop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Get in and out of a car or school bus?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Ride a bike?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Do household chores (e.g. wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Run and play?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check any aids or devices that you usually use for any of the above activities:

I do not need any aids or devices

I usually use the following aids or devices:

1. Dressing and grooming:	<input type="checkbox"/> Devices used for dressing (button hook, zipper pull, long-handled shoe horn, etc.)
2. Arising:	<input type="checkbox"/> Special or built up chair
3. Eating:	<input type="checkbox"/> Devices used for eating
4. Walking:	<input type="checkbox"/> Cane <input type="checkbox"/> Walker <input type="checkbox"/> Crutches <input type="checkbox"/> Wheelchair
5. Hygiene:	<input type="checkbox"/> Raised toilet seat <input type="checkbox"/> Bathtub seat <input type="checkbox"/> Bathtub bar
6. Reach:	<input type="checkbox"/> Long-handled appliances for reach
7. Grip:	<input type="checkbox"/> Long-handled appliances in bathroom <input type="checkbox"/> Built up pencil or special utensils <input type="checkbox"/> Jar openers (for jars previously opened)
8. Other:	<input type="checkbox"/> Specify: _____

Please check any categories for which you usually need help from another person because of your disease:

I do not need any help

I usually need help for:

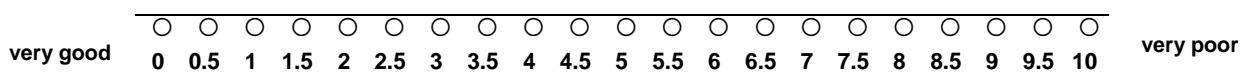
<input type="checkbox"/> Dressing	<input type="checkbox"/> Arising	<input type="checkbox"/> Eating and drinking	<input type="checkbox"/> Hygiene	<input type="checkbox"/> Gripping
<input type="checkbox"/> Walking	<input type="checkbox"/> Reach	<input type="checkbox"/> Errands and chores		

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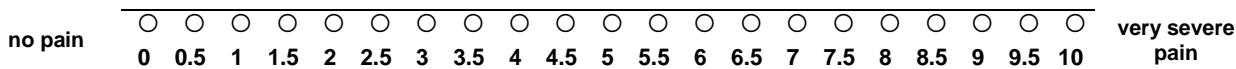
The following asks about your current health status.

Please answer the questions by marking the appropriate circle (○). The scales range from „0“ to „10“ with „0“ representing the best, „10“ the worst. Example: If you have not been limited in your daily routines, please mark the circle (0), if you have been extremely limited, mark the circle (10), otherwise mark a circle between. Please choose only one circle.

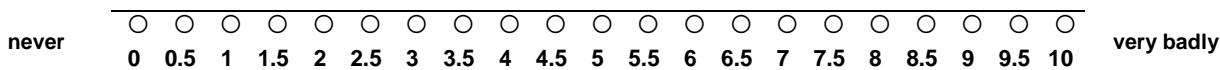
How would you describe your general health at this time?



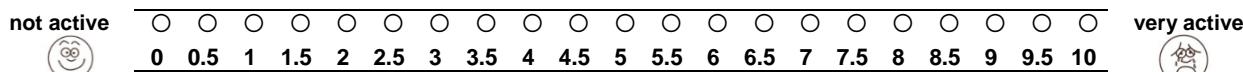
During the past 7 days, how much pain have you had because of your disease? I have had



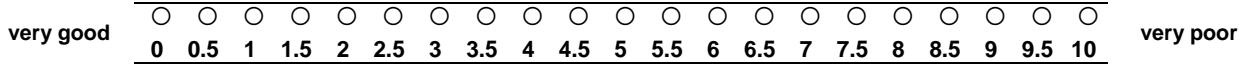
Have you suffered from unusual exhaustion and fatigue during the past 7 days?



How active is your rheumatic disease at the moment?



How do you cope with your rheumatic disease at this time

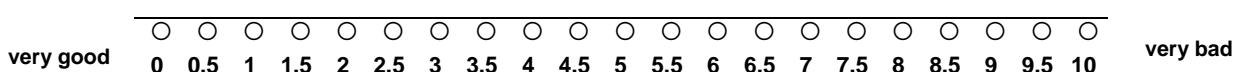


The following questions are related to your physical activities.

On how many days during a normal week are you physically active for at least 60 minutes?

on 7 days on 6 days on 5 days
 on 4 days on 3 days on 2 days
 on one day none

Overall, how would you rate your sleep over the last 2 weeks?



How many hours per day ...	The total number of hours must add up to 24 hours	
	weekdays	weekend
... do you sleep? (e. g. night sleep and afternoon nap together)	_____ hours	_____ hours
... do you spend sitting and lying down? (e. g. in school, reading, watching TV, mobile phone, in a car)	+ _____ hours	+ _____ hours
... do you engage in light physical activity*? (e. g. going from one place to another, leisurely cycling, light playing)	+ _____ hours	+ _____ hours
... do you engage in moderate to strenuous activity **? (e. g. sports, running, playing ball games, fast cycling on a bike or physical labor)	+ _____ hours	+ _____ hours
Please note: * <i>Light physical activity</i> means that you are moving but not breaking a sweat. ** <i>Moderate to strenuous activity</i> means that you become noticeably out of breath or sweat.	= 24 hours	= 24 hours

The following questions will help us understand the situations in which you mainly sit.

Please think of a typical weekday (with school or work) in the last week. If you do several things at once (e.g., using your cell phone while watching TV), please only indicate the main activity.

How many hours per day ...	per day
... do you use screen devices in your free time? (e.g., TV, streaming, gaming, smartphone/tablet, PC)	_____ hour(s)
... do you spend on school or learning activities? (e.g., lessons, reading, writing, homework, studying, or practicing)	_____ hour(s)
... do you sit during leisure activities where you chat with others or relax? (e.g., meeting friends, listening to music, doing crafts, playing board games)	_____ hour(s)
... do you spend driving/traveling? (e.g., car, bus, train, scooter, e-bike, e-scooter)	_____ hour(s)

How often do you sit for more than 60 minutes at a time without getting up?

○ never ○ rarely ○ sometimes ○ often ○ very often

For the next 3 questions, please think about your last appointment at the rheumatology clinic.

How much effort was put into helping you understand, why you are here?	<input type="radio"/>	a lot
none	0 1 2 3 4 5 6 7 8 9	
How much attention was paid to what matters most to you?	<input type="radio"/>	a lot
none	0 1 2 3 4 5 6 7 8 9	
How much consideration was given to what is most important to you when planning the next steps?	<input type="radio"/>	a lot
none	0 1 2 3 4 5 6 7 8 9	

Please also answer the following questions about your satisfaction with the care you received.

Are you sufficiently involved in decisions about your treatment?

yes, almost always mostly sometimes rarely not at all
 not applicable, as no treatment is currently being administered

Many thanks for your help!



Are you 16 years of age or older? Do you have juvenile idiopathic arthritis (JIA)?
 Scan the QR code, transfer your ID number from this questionnaire to the form on the website, and receive an overview of your disease and treatment history to download.

Questionnaire for parents

ID-No.:

Please transfer ID number!

This additional form is for your parents. Please first enter the ID number from the first page in the box at the top right. Then hand the form to your parents or accompanying person.

Year of child's birth child's sex female male other

Todays date **26**

Please start by answering the following questions about your child's medical care.

When did your child's rheumatic complaints begin? month year

When did your child first see a pediatric rheumatologist? day month year

How long did it take from the referral to your child's first appointment with a pediatric and adolescent rheumatologist?

number of days and weeks I don't know

The following three questions concern your assessment of how you were treated. Please think about your last appointment at the rheumatology clinic. Please also answer the following questions about your satisfaction with your child's care.

How much help did you receive to understand the reason for your child being here?

none at all 0 1 2 3 4 5 6 7 8 9 a lot

How much attention was paid to what matters most to you?

none at all 0 1 2 3 4 5 6 7 8 9 a lot

How much consideration was given to what is most important to you when planning the next steps?

none at all 0 1 2 3 4 5 6 7 8 9 a lot

Were you sufficiently involved in decisions about your child's treatment?

yes, (almost) always often sometimes rarely not at all
 not applicable, no treatment was carried out

How satisfied are you with your child's drug therapy?

not satisfied partially satisfied satisfied very satisfied extremely satisfied
 not applicable, my child does/did not receive any drug therapy

Were you informed about your child's rheumatic disease and therapy as part of your child's care or were you told where to find further information?

yes, sufficiently yes, but not sufficiently no

Information concerning your child's illness and its diagnosis.

Were you satisfied with...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
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...the information about different treatment options?

... with the information given about your child's illness?

... with the time it took to diagnose the illness?

The way your child was treated by the specialist. Please keep in mind your last visit at the clinic/outpatient practice

Were you satisfied with ...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
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... with the efforts made to make your child feel comfortable?

... with the doctor's attention to your child?

Satisfaction with the specialist. Please keep in mind your last visit at the clinic/outpatient practice.

Were you satisfied with ...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
... with the doctors' ability to explain things clearly?	<input type="radio"/>				
... with the time the doctors had for you and your child?	<input type="radio"/>				

Overall satisfaction with your child's health care. Please think about the last 12 months.

Were you satisfied with ...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
... the health care of your child in general?	<input type="radio"/>				

Finally, we have a few more questions about your child and your family.

Have you had to take time off work in the last 6 months because of your child's rheumatic disease?

Own information

- not applicable, not employed
- no
- yes, in fact: days

Information for another person with custody rights

- not applicable, not employed
- no
- yes, in fact: |__|__ days

Are there other children living in your household? Please fill in the number of children and their age.

no yes, namely _____ children aged _____ year

With whom does the child live in a household?

mother father stepmother/-father grandparents
 siblings other persons child does not live within its family

Finally, for reasons of comparability, we ask you to answer some questions taken from the Robert Koch Institute's KiGGS study on the health of children and adolescents in Germany. By father and mother, we mean the persons who live in a household with the child. The term mother or father also refers to those persons who take the place of the natural parents, e.g., the father's partner, stepfather, or others.

What is your highest general school-leaving qualification?

	mother	father
not yet graduated (still a student)	<input type="radio"/>	<input type="radio"/>
graduation after a maximum of 7 years of school attendance	<input type="radio"/>	<input type="radio"/>
lower secondary school education	<input type="radio"/>	<input type="radio"/>
middle secondary school education	<input type="radio"/>	<input type="radio"/>
higher education entrance qualification	<input type="radio"/>	<input type="radio"/>
other school-leaving qualification	<input type="radio"/>	<input type="radio"/>

The following questions are about your professional training and your professional position.

Highest professional qualification

Occupational status (If you are no longer in employment, please state your last occupation).

			State your last occupation:			
	mother	father			mother	father
still in vocational training	<input type="radio"/>	<input type="radio"/>	employee		<input type="radio"/>	<input type="radio"/>
no vocational qualification	<input type="radio"/>	<input type="radio"/>	worker		<input type="radio"/>	<input type="radio"/>
apprenticeship (vocational-operational training)	<input type="radio"/>	<input type="radio"/>	civil servant		<input type="radio"/>	<input type="radio"/>
technical college (vocational-educational training)	<input type="radio"/>	<input type="radio"/>	self-employed (with employees)		<input type="radio"/>	<input type="radio"/>
professional school (master craftsman school, technician school, vocational or technical academy)	<input type="radio"/>	<input type="radio"/>	self-employed (without employees)		<input type="radio"/>	<input type="radio"/>
			assisting family member		<input type="radio"/>	<input type="radio"/>
polytechnic college	<input type="radio"/>	<input type="radio"/>	apprentice		<input type="radio"/>	<input type="radio"/>
university	<input type="radio"/>	<input type="radio"/>	never been gainfully employed		<input type="radio"/>	<input type="radio"/>
other professional qualification	<input type="radio"/>	<input type="radio"/>	other		<input type="radio"/>	<input type="radio"/>

Thank you very much for your participation!