

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

	without any difficulty	with some difficulty	with much difficulty	unable to do	not applicable
1. Dressing and Grooming					
Is your child able to:					
• Dress, including tying shoelaces and doing buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Shampoo his/her hair?	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
• Cut fingernails?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Arising					
Is your child able to:					
• Stand up from a low chair or the floor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Get in and out of bed or stand in crib?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Eating					
Is your child able to:					
• Cut his/her own meat?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Lift a cup or a glass to mouth?	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
4. Walking					
Is your child able to:					
• Walk outdoors on a flat ground?	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
5. Hygiene					
Is your child able to:					
• Wash and dry entire body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Take a tub bath (get in and out of the tub)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Get on and off the toilet or the potty chair?	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
• Comb/Brush hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Reach					
Is your child able to:					
• Reach and get down a heavy object such as a large game or books from just above his/her head?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Bend down to pick up a piece of clothing or a piece of paper from the floor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Pull on a sweater over his/her head?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Turn neck to look over shoulder?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Grip					
Is your child able to:					
• Write or scribble with a pen or pencil?	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
• Open jars which have been previously opened?	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
• Push open a door when he/she has to turn knob?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Errands, chores and play					
Is your child able to:					
• Run errands and shop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Get in and out of car or toy car or school bus?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Ride bike or tricycle?	<input type="checkbox"/>	<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"/>	<input type="checkbox"/>
• Run and play?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check any aids or devices that your child usually uses for the mentioned activities:

☐ My child does not need any aids or devices

My child usually uses 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 your child usually needs help from another person because of his/her disease:

☐ My child does not need any help

My child usually needs help for:

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

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The following questions are about your child's physical activities and sleeping patterns.

15. On how many days during a normal week is your child physically active for at least 60 minutes?

- | | | | |
|---------------------------------|---------------------------------|----------------------------------|---------------------------------|
| <input type="radio"/> on 7 days | <input type="radio"/> on 6 days | <input type="radio"/> on 5 days | <input type="radio"/> on 4 days |
| <input type="radio"/> on 3 days | <input type="radio"/> on 2 days | <input type="radio"/> on one day | <input type="radio"/> none |

16. How would you rate your child's sleep for the past 2 weeks overall?

- | | | | | | | | | | | | | | | | | | | | | | | |
|-----------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|--------------------------|-----------|
| very good | <input type="radio"/> 0 | <input type="radio"/> 0.5 | <input type="radio"/> 1 | <input type="radio"/> 1.5 | <input type="radio"/> 2 | <input type="radio"/> 2.5 | <input type="radio"/> 3 | <input type="radio"/> 3.5 | <input type="radio"/> 4 | <input type="radio"/> 4.5 | <input type="radio"/> 5 | <input type="radio"/> 5.5 | <input type="radio"/> 6 | <input type="radio"/> 6.5 | <input type="radio"/> 7 | <input type="radio"/> 7.5 | <input type="radio"/> 8 | <input type="radio"/> 8.5 | <input type="radio"/> 9 | <input type="radio"/> 9.5 | <input type="radio"/> 10 | very poor |
|-----------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|--------------------------|-----------|

17. How is your child coping with his or her rheumatic disease at the moment?

- | | | | | | | | | | | | | | | | | | | | | | | |
|-----------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|--------------------------|-------------|
| very well | <input type="radio"/> 0 | <input type="radio"/> 0.5 | <input type="radio"/> 1 | <input type="radio"/> 1.5 | <input type="radio"/> 2 | <input type="radio"/> 2.5 | <input type="radio"/> 3 | <input type="radio"/> 3.5 | <input type="radio"/> 4 | <input type="radio"/> 4.5 | <input type="radio"/> 5 | <input type="radio"/> 5.5 | <input type="radio"/> 6 | <input type="radio"/> 6.5 | <input type="radio"/> 7 | <input type="radio"/> 7.5 | <input type="radio"/> 8 | <input type="radio"/> 8.5 | <input type="radio"/> 9 | <input type="radio"/> 9.5 | <input type="radio"/> 10 | very poorly |
|-----------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|-------------------------|---------------------------|--------------------------|-------------|

In the following three questions we ask for your evaluation of the way you were treated. Please keep in mind the last appointment at the rheumatology outpatient clinic.

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

- | | | | | | | | | | | | |
|-------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------|
| none at all | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 | <input type="radio"/> 7 | <input type="radio"/> 8 | <input type="radio"/> 9 | a lot |
|-------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------|

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

- | | | | | | | | | | | | |
|-------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------|
| none at all | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 | <input type="radio"/> 7 | <input type="radio"/> 8 | <input type="radio"/> 9 | a lot |
|-------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------|

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

- | | | | | | | | | | | | |
|-------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------|
| none at all | <input type="radio"/> 0 | <input type="radio"/> 1 | <input type="radio"/> 2 | <input type="radio"/> 3 | <input type="radio"/> 4 | <input type="radio"/> 5 | <input type="radio"/> 6 | <input type="radio"/> 7 | <input type="radio"/> 8 | <input type="radio"/> 9 | a lot |
|-------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------------------------|-------|

Please also answer the following questions about your satisfaction with your child's care.

21. 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

22. 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

23. 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

24. Information concerning your child's illness and its diagnosis.

Were you satisfied with...	not satisfied	partially satisfied	satisfied	very satisfied	extremely satisfied
...the information about different treatment options?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with the information given about your child's illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with the time it took to diagnose the illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. 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
... with the efforts made to make your child feel comfortable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with the doctor's attention to your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. 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"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... with the time the doctors had for you and your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. 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"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

28. Which school does your child attend?

- ☐ no school ☐ elementary school ☐ lower secondary school (Hauptschule) ☐ secondary school (Realschule)
☐ comprehensive school (Gesamtschule) ☐ grammar school (Gymnasium) ☐ other school: _____

29. In case of going to school, did your child participate in PE (physical education) in the last 4 weeks?

- ☐ almost always ☐ sometimes not ☐ often not
☐ my child is partly exempt from school sports ☐ my child is fully exempt from school sports

☐ at home ☐ daycare mother ☐ Kindergarten
☐ day nursery ☐ after-school care / all-day school ☐ other care
☐ my child does not need any care after school

Information for another person with custody rights

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

☐ no ☐ yes, namely children aged years
Please fill in the number of children and their age!

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

☐ no ☐ yes ⇒ **degree of disability** |__|__|__| **code** |__|

35. 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"/> |

Highest professional qualification

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

- | | mother | father | employment, please state your last occupation | 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 <u>with</u> employees | <input type="radio"/> | <input type="radio"/> |
| professional school(e.g. master school,
technical school vocational academy) | <input type="radio"/> | <input type="radio"/> | self-employed <u>without</u> 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"/> |

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Today's date:

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Many thanks for your help!