National paediatric rheumatology database 2026

Hier bitte „Einrichtungsetikett“ aufkleben!

ID-No.: |_|_|_|_|_|_|_|_|
Bitte ID-Nummer eintragen unter welcher Pat. geführt wird!

Hier bitte Etikett für neue / erstmalig dok. Patient:innen aufkleben!

Questionnaire for adolescents and young adults with rheumatic diseases (for patients ≥ 12 years)

Dear patient, please complete this questionnaire very carefully.
Please try to answer every question.

In which year were you born? |__|__|__|__| **Name your gender** ❍ female ❍ male ❍ other, namely: _____

Today's date: |_|_|.|_|_|.|2|6|

Where do you live? Please enter your postcode _____

Which school do you attend?
❍ lower secondary school/”Hauptschule” ❍ secondary school/”Realschule”
❍ comprehensive school/”Gesamtschule“ ❍ grammar school/“Gymnasium“ ❍ vocational secondary school
❍ other school _____
❍ I don't go to school anymore

In case of going to school, have you participated in school sports in the last 4 weeks?
❍ almost always ❍ sometimes not ❍ often not
❍ I am partly exempt from school sports ❍ I am fully exempt from school sports

Have you already graduated, which school leaving qualification did you obtain?
❍ I'm still going to school ❍ secondary school (10 yrs.)/”MSA” ❍ matriculation standard (12-13 yrs.)/”Abitur”
❍ (qualified) lower secondary school leaving certificate/”(qualifizierter) Hauptschulabschluss”
❍ professional school (12 yrs) ❍ not applicable

Have you got a disabled person's pass?
❍ no ❍ yes ⇨ **degree of disability** |__|__|__| **code** |___|

Have you ever been absent from school/work in the last 12 months due to your rheumatic disease?
❍ no ❍ yes, namely: |__|__|__| days

Have you been hospitalized due to your rheumatic disease in the past 12 months?
❍ no ❍ yes, namely: |__|__| weeks and |__| days

Which of the following treatments have you received in the past 12 months?
Please indicate only those treatments that have been prescribed by a doctor and that you received on an outpatient basis, i.e. not during a hospital stay or a rehabilitation or cure measure
❍ physiotherapy (individually or in a group) ❍ aquatic training (individually or in a group)
❍ occupational therapy (e.g. joint protection consultation, aids) ❍ I have **not** received such kind of treatment

Have you or your parents participated in an education program to manage your rheumatic disease in the last 12 months? Examples: Training weekend of the Rheuma-Liga, Rheumacamp
❍ no ❍ yes

Have you taken part in a rehabilitation or medical cure measure due to your rheumatic disease in the past 12 months?
❍ no ❍ yes

Do you use orthopedic aids?
❍ no ❍ yes, namely:
❍ splints and bandages (e.g. for knee, wrist)
❍ orthopedic shoes
❍ cervical cuff
❍ insoles/shoe lifts

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?	☐	☐	☐	☐
• Shampoo your hair?	☐	☐	☐	☐
• Remove socks?	☐	☐	☐	☐
• Cut fingernails?	☐	☐	☐	☐
2. Arising				
Are you able to:				
• Stand up from a low chair or floor?	☐	☐	☐	☐
• Get in and out of bed?	☐	☐	☐	☐
3. Eating				
Are you able to:				
• Cut your own meat?	☐	☐	☐	☐
• Lift up a cup or glass to mouth?	☐	☐	☐	☐
• Open a new cereal box?	☐	☐	☐	☐
4. Walking				
Are you able to:				
• Walk outdoors on flat ground?	☐	☐	☐	☐
• Climb up five steps?	☐	☐	☐	☐
5. Hygiene				
Are you able to:				
• Wash and dry your entire body?	☐	☐	☐	☐
• Take a tub bath (get in and out of tub)?	☐	☐	☐	☐
• Get on and off the toilet?	☐	☐	☐	☐
• Brush teeth?	☐	☐	☐	☐
• Comb/brush hair?	☐	☐	☐	☐
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?	☐	☐	☐	☐
• Bend down to pick up clothing or a piece of paper from the floor?	☐	☐	☐	☐
• Pull on a sweater over your head?	☐	☐	☐	☐
• Turn neck to look back over shoulder?	☐	☐	☐	☐
7. Grip				
Are you able to:				
• Write with pen or pencil?	☐	☐	☐	☐
• Open car doors?	☐	☐	☐	☐
• Open jars which have been previously opened?	☐	☐	☐	☐
• Turn faucets on and off?	☐	☐	☐	☐
• Push open a door when you have to turn a door knob?	☐	☐	☐	☐
8. Activities				
Are you able to:				
• Run errands and shop?	☐	☐	☐	☐
• Get in and out of a car or school bus?	☐	☐	☐	☐
• Ride a bike?	☐	☐	☐	☐
• Do household chores (e.g. wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?	☐	☐	☐	☐
• Run and play?	☐	☐	☐	☐

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

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:

☐ Dressing ☐ Arising ☐ Eating and drinking ☐ Hygiene ☐ Gripping

☐ Walking ☐ Reach ☐ Errands and chores

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 <u>at this time?</u>

very good ○ **very poor**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

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

no pain ○ **very severe pain**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

Have you suffered from unusual exhaustion and fatigue during the <u>past 7 days?</u>

never ○ **very badly**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

How active is your rheumatic disease <u>at the moment</u>?

not active ○ **very active**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

How do you cope with your rheumatic disease <u>at this time</u>

very good ○ **very poor**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

The following questions are related to your physical activities.

On how many <u>days during a normal week</u> 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 <u>last 2 weeks</u>?

very good ○ **very bad**

0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

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: * ***Light physical activity*** *means that you are moving but not breaking a sweat.* ** ***Moderate to strenuous activity*** *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?

none ○ **0** ○ **1** ○ **2** ○ **3** ○ **4** ○ **5** ○ **6** ○ **7** ○ **8** ○ **9** **a lot**

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

none ○ **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 ○ **0** ○ **1** ○ **2** ○ **3** ○ **4** ○ **5** ○ **6** ○ **7** ○ **8** ○ **9** **a lot**

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 |_|_|.|_|_|.|2|6|

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										a lot
❍	❍	❍	❍	❍	❍	❍	❍	❍	❍	
0	1	2	3	4	5	6	7	8	9	

How much attention was paid to what matters most <u>to you</u>?

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

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

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

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
...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 <u>your last</u> 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?	❍	❍	❍	❍	❍
... 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?	❍	❍	❍	❍	❍
... with the time the doctors had for you and your child?	❍	❍	❍	❍	❍

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?	❍	❍	❍	❍	❍

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)	❍	❍
graduation after a maximum of 7 years of school attendance	❍	❍
lower secondary school education	❍	❍
middle secondary school education	❍	❍
higher education entrance qualification	❍	❍
other school-leaving qualification	❍	❍

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

Highest professional qualification

	mother	father
still in vocational training	❍	❍
no vocational qualification	❍	❍
apprenticeship (vocational-operational training)	❍	❍
technical college (vocational-educational training)	❍	❍
professional school (master craftsman school, technician school, vocational or technical academy)	❍	❍
polytechnic college	❍	❍
university	❍	❍
other professional qualification	❍	❍

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

	mother	father
employee	❍	❍
worker	❍	❍
civil servant	❍	❍
self-employed (with employees)	❍	❍
self-employed (without employees)	❍	❍
assisting family member	❍	❍
apprentice	❍	❍
never been gainfully employed	❍	❍
other	❍	❍

Thank you very much for your participation!