

Outcome Measures in Paediatric Rheumatology

An International Health-Professional Survey and Consensus on a Minimum Core Set

Why?

Many different tools are currently used to measure children's pain, function, fatigue, quality of life, and other important outcomes. This makes it difficult to compare results across clinics and studies.

Who?

Health professionals working with children and adolescents with rheumatic diseases — physiotherapists, nurses, occupational therapists, psychologists, social workers, and others.

Goal

To create an internationally agreed, multidisciplinary **core set of outcome measures** that is practical, widely accepted, and useful in both clinical care and research.

In short, this survey will:

- Identify which tools are already being used,
 - Reach agreement (through surveys and consensus meetings) on the most important and practical ones,
 - Work towards an international minimum core set that improves consistency, quality of care, and comparability of research.
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What is involved?

- The survey takes about **10–12 minutes**. It includes questions on:
 - Your professional background and experience,
 - Outcome measurement domains and tools you currently use,
 - Your priorities for a minimum core set,
 - Feasibility of implementation.
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Confidentiality

All responses are anonymous and analyzed in aggregate. No identifying information will be published.

Your contribution

By sharing your expertise, you will help shape international practice standards and support the development of a core set that reflects real-world, multidisciplinary care

Section A — Consent and Eligibility

This survey is anonymous. Aggregated results will be presented during the PReS 2025 Health Professionals session and may inform a follow-up consensus publication.

I confirm that I am a health professional aged ≥ 18 years and consent to participate in this anonymous survey: *

- ☐ Yes (continue)
- ☐ No (end survey)

Section B — Professional Profile

B1. Primary discipline (select one) *

- ☐ Physiotherapist
- ☐ Nurse
- ☐ Psychologist
- ☐ Physiologist
- ☐ Occupational therapist
- ☐ Dietician
- ☐ Social worker
- ☐ Pharmacist
- ☐ Other (please specify): _____

B2. Which of the following best describes your professional role? *

- ☐ Clinical practice
- ☐ Academic research
- ☐ Both clinical practice & research
- ☐ Other (please specify): _____

B3. Years of experience in paediatric rheumatology *

- ☐ <1 year
- ☐ 1–3 years
- ☐ 4–7 years
- ☐ 8–12 years
- ☐ >12 years

B4. Country / Region *

B5. Primary workplace *

- ☐ Tertiary children's hospital
- ☐ General hospital

- ☐ University clinic
- ☐ Private practice
- ☐ Rehabilitation centre
- ☐ University / university college
- ☐ Research institution
- ☐ Secondary care
- ☐ Other (please specify): _____

B6. Typical patient age range you see (tick all that apply) *

- ☐ 0–5 years
- ☐ 6–12 years
- ☐ 13–18 years
- ☐ >18 years (transition)

B7. Clinical vs research involvement *

- ☐ Exclusively clinical
- ☐ Mostly clinical
- ☐ Balanced
- ☐ Mostly research
- ☐ Exclusively research

Section C — Domains and Measurement Tools

Instructions: For each domain, select the measurement tools you use in clinical care and/or research, and indicate the frequency of use (Always / Often / Sometimes / Rarely / Never). You may select "My profession does not assess this in my place of work" if applicable.

C1. Pain

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Numerical Rating Scale, 0–10 point (NRS-11)						
Visual Analogue Scale (VAS – 10 cm / 100 mm)						
Faces Pain Scale (e.g., Wong–Baker FACES)						
PROMIS – Pain Interference						
Other						

If other, please specify and indicate the frequency of use: _____

C2. Physical Function & Performance

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Childhood Health Assessment Questionnaire (CHAQ) / Modified CHAQ (MD-CHAQ)						
PROMIS – Mobility						
Motor performance tests (small children, e.g. Movement ABC, BOT-2/3 short form or single subcategories such as strength and agility)						
Six-Minute Walk Test (6MWT)						
Timed Up and Go (TUG)						
30-Second Sit-to-Stand Test (30sSTS)						
Observational gait assessment (e.g. clinical scales)						
Instrumented gait / motion analysis (e.g. lab-based, wearable sensors)						
Childhood Myositis Assessment Scale (CMAS)						
Manual Muscle Testing-8 (MMT-8)						
Joint Range of Motion (ROM) Measurement – Goniometry						
Paediatric Gait, Arms, Legs and Spine Screening (PGALS)						
Paediatric Balance Scale (PBS)						
Single-Leg Stance Test						
Curl-Up Test						
Push-Up Test						
Star Excursion Balance Test						
Shuttle Run Test (20-metre multistage fitness test – aerobic capacity)						
Bruce Protocol Treadmill Test (aerobic capacity)						
Watt-max Ergometer Cycle Test (VO ₂ max test, aerobic, indirect)						
Wingate Anaerobic Test (WAnT – anaerobic capacity)						
30-Second Wingate Sprint / Cycle Ergometer Test (anaerobic power)						
Other						

If other, please specify and indicate the frequency of use: _____

C3. Disease Activity / Clinical Indices

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Juvenile Arthritis Disease Activity Score (JADAS) / Clinical JADAS (cJADAS)						
Physician Global Assessment (NRS)						
Parent/Patient Global Assessment (NRS)						
Active Joint Count						
Enthesitis Count						
Morning Stiffness Duration						
Other						

If other, please specify and indicate the frequency of use: _____

C4. Health-Related Quality of Life & Participation

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Paediatric Quality of Life Inventory (PedsQL) – Generic or Rheumatology Module						
KINDL Questionnaire						
PROMIS – Peer Relationships / Physical Function / Fatigue						
School Attendance / Participation Record						
Children's Assessment of Participation and Enjoyment (CAPE) / Preferences for Activities of Children (PAC)						
Other						

If other, please specify and indicate the frequency of use: _____

C5. Mental Health & Psychosocial

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Revised Child Anxiety and Depression Scale (RCADS)						
Strengths and Difficulties Questionnaire (SDQ)						
Patient Health Questionnaire – 4 items (PHQ-4) / Generalized Anxiety Disorder – 7 items (GAD-7)						

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
Pain Catastrophizing Scale – Child or Parent Version (PCS-C / PCS-P)						
Pain Coping Questionnaire (PCQ)						
Survey of Pain Attitudes, Children (SOPA-C)						
PROMIS – Sleep Disturbance						
Other						

If other, please specify and indicate the frequency of use: _____

C6. Fatigue & Sleep

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
PROMIS – Fatigue						
Paediatric Functional Assessment of Chronic Illness Therapy – Fatigue (PedsFACIT-F)						
PedsQL Fatigue Scale						
Numeric Rating Scale for Fatigue						
Sleep Duration / Quality Logs or Wearable Device Data						
Pittsburgh Sleep Quality Index (PSQI)						
Other						

If other, please specify and indicate the frequency of use: _____

C7. Adherence, Treatment Burden & Experience

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Medication Adherence (self-report, medication logs, or pharmacy refill data)						
Injection or Procedure-Related Pain/Anxiety Scales						
Adverse Effects Checklist						
Patient/Parent Reported Experience Measures (PREMs)						
Other						

If other, please specify and indicate the frequency of use: _____

C8. Physical Activity

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Accelerometer or Pedometer Data						
Wearable Device-Based Activity Tracking (smart watch, band, etc.)						
Self-Reported Physical Activity Logs						
Physical Activity Questionnaire for Children (PAQ-C) / Adolescents (PAQ-A)						
Other						

If other, please specify and indicate the frequency of use: _____

C9. Hand Function

Tool	Always	Often	Sometimes	Rarely	Never	Not assessed*
My profession does not assess this domain						
Jebsen–Taylor Hand Function Test (JTHFT)						
Nine-Hole Peg Test (NHPT)						
Hand Grip Dynamometry						
Pinch Grip Dynamometry						
Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH) / QuickDASH						
Other						

If other, please specify and indicate the frequency of use: _____

Section D — Prioritisation

Top 5 Outcome Measures Overall

*Please indicate your priorities for outcome measures to be included in an international minimum core set. Please indicate for **each of the tools you listed in Section C** whether it is Must-have or Optional.”*

*Please **only** mark the tools that you use or are familiar with in your professional field.*

Must-have: Essential and should be used routinely in all relevant cases.

Optional: Useful in some contexts but not mandatory.

Not relevant: My profession does not assess this in my place of work

Unfamiliar: I am not familiar with this scale; this is the first time I have encountered it

D1. Please indicate for each of the tools whether it is Must-have or Optional.

Tool	Not relevant	Unfamiliar	Must-have	Optional
Numerical Rating Scale, 0–10 point (NRS-11)				
Visual Analogue Scale (VAS – 10 cm / 100 mm)				
Faces Pain Scale (e.g., Wong–Baker FACES)				
PROMIS – Pain Interference				
Childhood Health Assessment Questionnaire (CHAQ) / Modified CHAQ (MD-CHAQ)				
PROMIS – Mobility				
Childhood Myositis Assessment Scale (CMAS)				
Six-Minute Walk Test (6MWT)				
Observational gait assessment (e.g. clinical scales)				
Instrumented gait / motion analysis (e.g. lab-based, wearable sensors)				
Timed Up and Go (TUG)				
30-Second Sit-to-Stand Test (30sSTS)				
Joint Range of Motion (ROM) Measurement – Goniometry				
Paediatric Gait, Arms, Legs and Spine Screening (PGALS)				
Paediatric Balance Scale (PBS)				
Single-Leg Stance Test				
Curl-Up Test				
Push-Up Test				
Star Excursion Balance Test				
Shuttle Run Test (20-metre multistage fitness test – aerobic capacity)				
Bruce Protocol Treadmill Test (aerobic capacity)				
Wingate Anaerobic Test (WAnT – anaerobic capacity)				
30-Second Wingate Sprint / Cycle Ergometer Test (anaerobic power)				
Juvenile Arthritis Disease Activity Score (JADAS) / Clinical JADAS (cJADAS)				
Physician Global Assessment (NRS)				
Parent/Patient Global Assessment (NRS)				
Active Joint Count				
Enthesitis Count				
Morning Stiffness Duration				

Tool	Not relevant	Unfamiliar	Must-have	Optional
Paediatric Quality of Life Inventory (PedsQL) – Generic or Rheumatology Module				
KINDL Questionnaire				
PROMIS – Peer Relationships / Physical Function / Fatigue				
School Attendance / Participation Record				
Children’s Assessment of Participation and Enjoyment (CAPE) / Preferences for Activities of Children (PAC)				
Revised Child Anxiety and Depression Scale (RCADS)				
Strengths and Difficulties Questionnaire (SDQ)				
Patient Health Questionnaire – 4 items (PHQ-4) / Generalized Anxiety Disorder – 7 items (GAD-7)				
Pain Catastrophizing Scale – Child or Parent Version (PCS-C / PCS-P)				
Pain Coping Questionnaire (PCQ)				
PROMIS – Sleep Disturbance				
PROMIS – Fatigue				
Paediatric Functional Assessment of Chronic Illness Therapy – Fatigue (PedsFACIT-F)				
PedsQL Fatigue Scale				
Numeric Rating Scale for Fatigue				
Sleep Duration / Quality Logs or Wearable Device Data				
Medication Adherence (self-report, medication logs, or pharmacy refill data)				
Injection or Procedure-Related Pain/Anxiety Scales				
Adverse Effects Checklist				
Patient/Parent Reported Experience Measures (PREMs)				
Accelerometer or Pedometer Data				
Wearable Device-Based Activity Tracking (smart watch, band, etc.)				
Self-Reported Physical Activity Logs				
Physical Activity Questionnaire for Children (PAQ-C) / Adolescents (PAQ-A)				
Jebsen–Taylor Hand Function Test (JTHFT)				
Hand Grip Dynamometry				
Pinch Grip Dynamometry				
Nine-Hole Peg Test (NHPT)				
Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH) / QuickDASH				

Tool	Not relevant	Unfamiliar	Must-have	Optional
Other				

If other, please specify and indicate the frequency of use: _____

Section E — Barriers and Facilitators

In this section, we aim to understand the factors that may hinder or support the use of outcome measures in your clinical and/or research practice. Please indicate which barriers you have experienced and which facilitators you believe could help in increasing the use of outcome measures. You may select more than one option where applicable.

E1. Top Barriers (tick up to 3) *

- ☐ Lack of awareness / knowledge of the existence of outcome measures
- ☐ Lack of training / education on how to use outcome measures
- ☐ Time constraints
- ☐ Staff capacity
- ☐ Training or competency requirements
- ☐ Patient burden
- ☐ Language or translation issues
- ☐ Licensing or cost issues
- ☐ Integration into Electronic Health Record (EHR) systems
- ☐ Device availability
- ☐ Other (please specify): _____

E2. Top Facilitators (tick up to 3) *

- ☐ Short and child-friendly tools
- ☐ Digital data capture systems
- ☐ Automated scoring within Electronic Health Record (EHR) systems
- ☐ Multilingual validated forms
- ☐ Training materials and workshops
- ☐ Dedicated clinic time for assessments
- ☐ Research support staff
- ☐ Funding or subsidies for licensing
- ☐ Access to training / education on how to use outcome measures
- ☐ Clear guidance or standardized protocols
- ☐ Other (please specify): _____

E3. Data Capture Methods Used (tick all that apply)*

This section asks about the methods you currently use to collect outcome measure data in your clinical and/or research practice. Please select all that apply.

- ☐ Paper forms / questionnaires

- ☐ Electronic forms (Excel, Word, PDF, etc.)
- ☐ Electronic medical record (EMR) / hospital system entry
- ☐ Mobile apps / digital tools
- ☐ Web-based survey platforms (e.g. REDCap, Qualtrics, Google Forms)
- ☐ Direct patient interview (face-to-face)
- ☐ Telephone interview
- ☐ Observational assessment (clinician-rated)
- ☐ Wearable devices / sensors
- ☐ Other (please specify): _____

Section F — Most Frequently Used Tools in Your Discipline

F1. Select up to 5 outcome measurement tools you personally use most often in your work *

- ☐ Six-Minute Walk Test (6MWT)
- ☐ Timed Up and Go (TUG)
- ☐ 30-Second Sit-to-Stand Test (30sSTS)
- ☐ Hand Grip Dynamometry
- ☐ Pinch Grip Dynamometry
- ☐ Joint Range of Motion (ROM) Measurement – Goniometry
- ☐ Observational gait assessment (e.g. clinical scales)
- ☐ Instrumented gait/motion analysis (e.g. lab-based, wearable sensors)
- ☐ Paediatric Balance Scale (PBS)
- ☐ Numerical Rating Scale, 0–10 point (NRS-11)
- ☐ Visual Analogue Scale (VAS – 10 cm / 100 mm)
- ☐ Juvenile Arthritis Disease Activity Score (JADAS) / Clinical JADAS (cJADAS)
- ☐ Childhood Health Assessment Questionnaire (CHAQ) / Modified CHAQ (MD-CHAQ)
- ☐ Paediatric Quality of Life Inventory (PedsQL)
- ☐ CMAS
- ☐ MMT-8
- ☐ Revised Child Anxiety and Depression Scale (RCADS)
- ☐ Strengths and Difficulties Questionnaire (SDQ)
- ☐ PROMIS domains
- ☐ Paediatric Functional Assessment of Chronic Illness Therapy – Fatigue (PedsFACIT-F)
- ☐ Pain Catastrophizing Scale – Child or Parent Version (PCS-C / PCS-P)
- ☐ Patient/Parent Reported Experience Measures (PREMs)
- ☐ Shuttle Run Test (20-metre multistage fitness test – aerobic capacity)
- ☐ Bruce Protocol Treadmill Test (aerobic capacity)
- ☐ Wingate Anaerobic Test (WAnT – anaerobic capacity)

- ☐ 30-Second Wingate Sprint / Cycle Ergometer Test (anaerobic power)
- ☐ Physical Activity Questionnaire for Children (PAQ-C) / Adolescents (PAQ-A)
- ☐ Jebsen–Taylor Hand Function Test (JTHFT)
- ☐ Nine-Hole Peg Test (NHPT)
- ☐ Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH) / QuickDASH
- ☐ Other

If other, please specify and indicate the frequency of use: _____

Section G — Additional Comments

Please use the space below to suggest any outcome measurement tool you believe should be included in the minimum core set but was not listed above, or to share any other comments related to outcome measures in paediatric rheumatology

Section H — Collaboration & Contact

H1. Willingness to contribute to the consensus paper *

- ☐ Yes, as an author (active drafting)
- ☐ Yes, to be acknowledged
- ☐ Maybe

If “Yes” — please specify your Name, Email, and Institution. If you prefer your responses to remain anonymous, you can send your details separately to: nilayarman@iuc.edu.tr

Comment Box

If there is anything you would like to add regarding the study design, outcome measures, or any other relevant aspect — or if there is something you think we should be aware of — please write it here.
