



VALIDATION STUDIES

## The American English version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR)

Daniel J. Lovell<sup>1</sup> · Hermine I. Brunner<sup>1</sup> · Sarah Ringold<sup>2</sup> · Pamela F. Weiss<sup>3</sup> · Neil Martin<sup>4</sup> · Alessandro Consolaro<sup>5,6</sup> · Francesca Bovis<sup>5</sup> · Nicolino Ruperto<sup>5</sup> · For the Paediatric Rheumatology International Trials Organisation (PRINTO)

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### Abstract

The Juvenile Arthritis Multidimensional Assessment Report (JAMAR) is a new parent/patient-reported outcome measure that enables a thorough assessment of the disease status in children with juvenile idiopathic arthritis (JIA). We report the results of the cross-cultural adaptation and validation of the parent and patient versions of the JAMAR in the American English language. The reading comprehension of the questionnaire was tested in 10 JIA parents and patients. Each participating centre was asked to collect demographic, clinical data and the JAMAR in 100 consecutive JIA patients or all consecutive patients seen in a 6-month period and to administer the JAMAR to 100 healthy children and their parents. The statistical validation phase explored descriptive statistics and the psychometric issues of the JAMAR: the 3 Likert assumptions, floor/ceiling effects, internal consistency, Cronbach's alpha, interscale correlations, test–retest reliability, and construct validity (convergent and discriminant validity). A total of 315 JIA patients (5.1% systemic, 31.1% oligoarticular, 34% RF negative polyarthritis, 29.8% other categories) and 98 healthy children, were enrolled in three centres. The JAMAR components discriminated well healthy subjects from JIA patients. All JAMAR components revealed good psychometric performances. In conclusion, the American English version of the JAMAR is a valid tool for the assessment of children with JIA and is suitable for use both in routine clinical practice and clinical research.

**Keywords** Juvenile idiopathic arthritis · Disease status · Functional ability · Health-related quality of life · JAMAR

### Introduction

The aim of the present study was to cross-culturally adapt and validate the American English parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) [1] in patients with juvenile idiopathic arthritis (JIA). The JAMAR assesses the most

relevant parent/patient-reported outcomes in JIA, including overall well-being, functional status, health-related quality of life (HRQoL), pain, morning stiffness, disease activity/status/course, articular and extra-articular involvement, drug-related side effects/compliance and satisfaction with illness outcome.

This project was part of a larger multinational study conducted by the Paediatric Rheumatology International Trials Organisation (PRINTO) [2] aimed to evaluate the Epidemiology, Outcome and Treatment of Childhood Arthritis (EPOCA) in different geographic areas [3].

We report herein the results of the cross-cultural adaptation and validation of the parent and patient versions of the JAMAR in the American English language.

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The local members of the Paediatric Rheumatology International Trials Organisation (PRINTO) participating in the project are listed in the dedicated tables no. 2 and 3 of "<https://doi.org/10.1007/s00296-018-3944-1> / Cross-cultural adaptation and psychometric evaluation of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in 54 languages across 52 countries: review of the general methodology".

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✉ Daniel J. Lovell  
daniel.lovell@cchmc.org

✉ Nicolino Ruperto  
nicolaruperto@gaslini.org  
<http://www.printo.it>

Extended author information available on the last page of the article

## Materials and methods

The methodology employed has been described in detail in the introductory paper of the supplement [4]. In brief, it was a cross-sectional study of JIA children, classified according to the ILAR criteria [5, 6] and enrolled from March 2012 to December 2013. Children were recruited after Ethics Committee approval and consent from at least one parent.

### The JAMAR

The JAMAR [1] includes the following 15 sections:

1. Assessment of physical function (PF) using 15-items in which the ability of the child to perform each task is scored as follows: 0 = without difficulty, 1 = with some difficulty, 2 = with much difficulty, 3 = unable to do and not applicable if it was not possible to answer the question or the patient was unable to perform the task due to their young age or to reasons other than JIA. The total PF score ranges from 0 to 45 and has three components: PF-lower limbs (PF-LL); PF-hand and wrist (PF-HW) and PF-upper segment (PF-US) each scoring from 0 to 15 [7]. Higher scores indicating higher degree of disability [8–10];
2. rating of the intensity of the patient's pain on a 21-numbered circle Visual Analogue Scale (VAS) [11];
3. assessment of the presence of joint pain or swelling (present/absent for each joint);
4. assessment of morning stiffness (present/absent);
5. assessment of extra-articular symptoms (fever and rash) (present/absent);
6. rating of the level of disease activity on a 21-circle VAS;
7. rating of disease status at the time of the visit (categorical scale);
8. rating of disease course from previous visit (categorical scale);
9. checklist of the medications the patient is taking (list of choices);
10. checklist of side effects of medications;
11. report of difficulties with medication administration (list of items);
12. report of school/university/work problems caused by the disease (list of items);
13. assessment of HRQoL, through the Physical Health (PhH), and Psychosocial Health (PsH) subscales (5 items each) and a total score. The four-point Likert response, referring to the prior month, are 'never' (score = 0), 'sometimes' (score = 1), 'most of the time' (score = 2) and 'all the time' (score = 3). A 'not assess-

able' column was included in the parent version of the questionnaire to designate questions that cannot be answered because of developmental immaturity. The total HRQoL score ranges from 0 to 30, with higher scores indicating worse HRQoL. A separate score for PhH and PsH (range 0–15) can be calculated [12–14];

14. rating of the patient's overall well-being on a 21-numbered circle VAS;
15. a question about satisfaction with the outcome of the illness (yes/no) [15].

The JAMAR is available in three versions, one for parent proxy-report (child's age 2–18), one for child self-report, with the suggested age range of 7–18 years, and one for adults.

### Cross-cultural adaptation and validation

The process of cross-cultural adaptation was conducted according to international guidelines with 2–3 forward and backward translations. In those countries for which the translation of JAMAR had been already cross-cultural adapted in a similar language (i.e. Spanish in South American countries), only the probe technique was performed. For the American English version of JAMAR, cross-cultural adaptation of the British English version was performed. Reading comprehension and understanding of the translated questionnaires were tested in a probe sample of 10 JIA parents and 10 patients.

Each participating centre was asked to collect demographic, clinical data and the JAMAR in 100 consecutive JIA patients or all consecutive patients seen in a 6-month period and to administer the JAMAR to 100 healthy children and their parents.

The statistical validation phase explored the descriptive statistics and the psychometric issues [16]. In particular, we evaluated the following validity components: the first Likert assumption [mean and standard deviation (SD) equivalence]; the second Likert assumption or equal items-scale correlations (Pearson  $r$ : all items within a scale should contribute equally to the total score); third Likert assumption (item internal consistency or linearity for which each item of a scale should be linearly related to the total score that is 90% of the items should have Pearson  $r \geq 0.4$ ); floor/ceiling effects (frequency of items at lower and higher extremes of the scales, respectively); internal consistency, measured by the Cronbach's alpha, interscale correlation (the correlation between two scales should be lower than their reliability coefficients, as measured by Cronbach's alpha); test-retest reliability or intra-class correlation coefficient (reproducibility of the JAMAR repeated after 1 or 2 weeks); and construct validity in its two components: the convergent or external validity which

examines the correlation of the JAMAR sub-scales with the 6 JIA core set of variables, with the addition of the parent assessment of disease activity and pain by the Spearman's correlation coefficients ( $r$ ) [17] and the discriminant validity, which assesses whether the JAMAR discriminates between the different JIA categories and healthy children [18].

Quantitative data were reported as medians with 1st and 3rd quartiles and categorical data as absolute frequencies and percentages.

The complete American English parent and patient versions of the JAMAR are available upon request to PRINTO.

## Results

### Cross-cultural adaptation

The American English JAMAR was fully cross-culturally adapted from the British English version with no forward and backward translation.

All 123 lines of the parent version of the JAMAR were understood by at least 80% of the 10 parents tested (median = 100%; range 90–100%). All the 120 lines of the patient version of the JAMAR were understood by at least 80% of the children (median = 100%; range 90–100%). Both versions of the JAMAR were unmodified after the probe technique.

### Demographic and clinical characteristics of the subjects

A total of 315 JIA patients and 98 healthy children (total of 413 subjects), were enrolled at three paediatric rheumatology centres.

In the 315 JIA subjects, the JIA categories were 5.1% with systemic arthritis, 31.1% with oligoarthritis, 34% with RF negative polyarthritis, 5.1% with RF positive polyarthritis, 8.9% with psoriatic arthritis, 10.8% with enthesitis related arthritis and 5.1% with undifferentiated arthritis (Table 1).

A total of 369/413 (89.3%) subjects had the parent version of the JAMAR completed by a parent (277 from parents of JIA patients and 92 from parents of healthy children). The JAMAR was completed by 307/369 (83.2%) mothers and 62/369 (16.8%) fathers. The child version of the JAMAR was completed by 240/413 (58.1%) children age 7.2 or older.

### Discriminant validity

The JAMAR results are presented in Table 1, including the scores [median (1st–3rd quartile)] obtained for the PF, the PhH, the PsH subscales and total score of the HRQoL scales. The JAMAR components discriminated well between healthy subjects and JIA patients.

In summary, the JAMAR revealed that JIA patients had a greater level of disability and pain, as well as a lower HRQoL than their healthy peers.

### Psychometric issues

The main psychometric properties of both parent and child versions of the JAMAR are reported in Table 2. The following “Results” section refers mainly to the parent's version findings, unless otherwise specified.

### Descriptive statistics (first Likert assumption)

For all JAMAR items, the median number of missing responses were 0.0% (0.0–0.4%).

The response pattern for both PF and HRQoL was positively skewed toward normal functional ability and normal HRQoL. All response choices were used for the different HRQoL items except for item 8, whereas a reduced number of response choices were used for PF items 11 and 12.

The mean and SD of the items within a scale were roughly equivalent for the PF and for the HRQoL items, except for HRQoL item 5 (data not shown). The median number of items marked as not applicable was 1% (0.0–5.0%) for the PF and 1.5% (0.0–8.0%) for the HRQoL.

### Floor and ceiling effect

The median floor effect was 85.9% (74.7–94.6%) for the PF items, 68.8% (31.8–88.4%) for the HRQoL PhH items, and 67.1% (64.3–83.8%) for the HRQoL PsH items. The median ceiling effect was 0.4% (0.0–1.4%) for the PF items, 2.2% (0.4–7.9%) for the HRQoL PhH items, and 1.1% (0.0–1.1%) for the HRQoL PsH items. The median floor effect was 33.9% for the pain VAS, 35.7% for the disease activity VAS and 41.9% for the well-being VAS. The median ceiling effect was 0.0% for the pain VAS, 4.0% for the disease activity VAS and 0.7% for the well-being VAS.

**Table 1** Descriptive statistics (medians, 1st 3rd quartiles or absolute frequencies and %) for the 315 JIA patients

	Systemic <i>N</i> =16	Oligoarthritis <i>N</i> =98	RF– poly- arthritis <i>N</i> =107	RF+ poly- arthritis <i>N</i> =16	Psoriatic arthritis <i>N</i> =28	Enthesitis related arthritis <i>N</i> =34	Undifferenti- ated arthritis <i>N</i> =16	All JIA patients <i>N</i> =315	Healthy <i>N</i> =98
Female	7 (43.8%)	79 (80.6%)	94 (87.9%)	14 (87.5%)	18 (64.3%)	15 (44.1%)	10 (62.5%)	237 (75.2%)**	49 (50%) <sup>#</sup>
Age at visit	10.8 (7.9–12.4)	11.7 (8–15.6)	13.5 (10.9– 16.8)	15.6 (13.3– 16.8)	14.2 (11–16.5)	14.5 (10.4– 15.9)	15.1 (13.7– 16.8)	13.5 (10.1– 16.1)*	12 (8.1– 15.4)*
Age at onset	5.5 (2.7–10.7)	4 (2.4–8.7)	7.4 (3.3–11)	11.5 (9–13.2)	9.2 (6–12.3)	10.4 (6.8–12.5)	9.5 (8.3–12.9)	7.8 (3.3–11.1)*	
Disease duration	3.4 (1.6–6.1)	4.9 (1.6–7.9)	4.2 (2–9.3)	2.4 (1.7–6.5)	3.9 (2.2–6.2)	3 (1.7–6)	4.3 (1.2–6)	4.1 (1.8–7.9)	
ESR	11 (5–18)	6 (4–12)	7 (5–13)	7 (6–20)	6.5 (3–10.5)	6.5 (2–14)	9.5 (6–11)	7 (4–13)	
MD VAS	0 (0–0)	0 (0–1)	0 (0–2)	1 (0–2)	0 (0–2)	1 (0–3)	0.5 (0–3)	0 (0–2)*	
No. swollen joints	0 (0–0)	0 (0–0)	0 (0–1)	0 (0–2)	0 (0–0)	0 (0–0)	0 (0–1)	0 (0–0)*	
No. joints with pain	0 (0–0)	0 (0–0)	0 (0–1)	0 (0–0)	0 (0–0)	0 (0–0)	0 (0–1)	0 (0–0)	
No. joints with LOM	0 (0–0)	0 (0–0)	0 (0–2)	0 (0–2)	0 (0–2)	0 (0–3)	1 (0–1.5)	0 (0–1)**	
No. active joints	0 (0–0)	0 (0–0)	0 (0–1)	0 (0–2)	0 (0–0)	0 (0–0)	0 (0–1.5)	0 (0–1)*	
Active systemic features	2 (12.5%)	2 (2%)	1 (0.9%)	0 (0%)	1 (3.6%)	0 (0%)	0 (0%)	6 (1.9%)	
ANA status	0 (0%)	2 (2%)	3 (2.8%)	0 (0%)	2 (7.1%)	0 (0%)	1 (6.3%)	8 (2.5%)	
Uveitis	1 (6.3%)	21/97 (21.6%)	9/105 (8.6%)	0 (0%)	3 (10.7%)	1/33 (3%)	1 (6.3%)	36/311 (11.6%)*	
PF Total Score	1 (0–4)	0 (0–2)	1 (0–4)	0 (0–3)	1 (0–4)	2 (0–7)	0 (0–4)	1 (0–4)	0 (0–0) <sup>#</sup>
Pain VAS	0.5 (0–2)	1 (0–3.5)	1 (0–2.5)	0.3 (0–1.5)	1 (0–3)	3 (1–5)	0 (0–3.5)	1 (0–3)*	0 (0–0) <sup>#</sup>
Disease Activity VAS	0.5 (0–2.5)	0.5 (0–4)	1 (0–3)	0.8 (0–5)	1 (0–5.5)	3 (1–7)	1 (0–3)	1 (0–4)	
Well-being VAS	0 (0–2)	0.5 (0–2.5)	0.5 (0–2)	0 (0–3)	1 (0–2.5)	2 (1–3.5)	1 (0–3.5)	0.5 (0–3)*	
HRQoL PhH	0 (0–5)	1 (0–4)	1 (0–4)	1 (0–1)	2 (1–4)	3 (2–5)	0 (0–2)	1 (0–4)*	0 (0–0) <sup>#</sup>
HRQoL PsH	0 (0–2)	0 (0–3)	1 (0–3)	0.5 (0–2)	2 (0–3)	2 (1–4)	1 (0–3)	1 (0–3)	0 (0–0) <sup>#</sup>
HRQoL Total Score	0 (0–6)	2 (0–6)	3 (1–7)	2 (0–5)	3 (2–7)	6 (3–9)	2 (0–5)	3 (1–7)*	0 (0–1) <sup>#</sup>
Pain/swell. in > 1 joint	4 (26.7%)	44 (50.6%)	50 (55.6%)	5 (35.7%)	13 (56.5%)	27 (81.8%)	7 (46.7%)	150 (54.2%)*	2 (2.2%) <sup>#</sup>
Morning stiff- ness > 15 min	3 (20%)	20 (23%)	21 (23.3%)	3 (21.4%)	4 (17.4%)	22 (66.7%)	1 (6.7%)	74 (26.7%)*	0 (0%) <sup>#</sup>
Subjective remis- sion	4 (26.7%)	50 (57.5%)	49 (54.4%)	6 (42.9%)	12 (52.2%)	26 (78.8%)	9 (60%)	156 (56.3%)*	
In treatment	13 (86.7%)	59 (67.8%)	80 (88.9%)	13 (92.9%)	20 (87%)	27 (81.8%)	10 (66.7%)	222 (80.1%)	
Reporting side effects	2/13 (15.4%)	19/97 (32.2%)	24/80 (30%)	3/13 (23.1%)	9/20 (45%)	8/27 (29.6%)	1/10 (10%)	66/222 (29.7%)	
Taking medication regularly	12/13 (92.3%)	57/97 (96.6%)	67/80 (83.8%)	12/13 (92.3%)	18/20 (90%)	26/27 (96.3%)	7/9 (77.8%)	199/221 (90%)	
With problems attending school	1/8 (12.5%)	7/97 (11.9%)	10/63 (15.9%)	1/13 (7.7%)	3/17 (17.6%)	6/20 (30%)	1/14 (7.1%)	29/194 (14.9%)	0 (0%)**
Satisfied with dis- ease outcome	13 (86.7%)	70 (80.5%)	71 (78.9%)	11 (78.6%)	18 (78.3%)	21 (63.6%)	11 (73.3%)	215 (77.6%)	

Data related to the JAMAR refers to the 277 JIA patients and to the 92 healthy subjects for whom the questionnaire has been completed by the parents

JAMAR Juvenile Arthritis Multidimensional Assessment Report, ESR erythrocyte sedimentation rate, MD Medical Doctor, VAS visual analogue scale (score 0–10; 0=no activity, 10=maximum activity), LOM limitation of motion, ANA anti-nuclear antibodies, PF physical function (total score ranges from 0 to 45), HRQoL health-related quality of life (total score ranges from 0 to 30), PhH physical health (total score ranges from 0 to 15), PsH psychosocial health (total score ranges from 0 to 15)

*p* values refer to the comparison of the different JIA categories or to JIA versus healthy. \**p*<0.05, \*\**p*<0.001, <sup>#</sup>*p*<0.0001

**Table 2** Main psychometric characteristics between the parent and child version of the JAMAR

	Parent <i>N</i> =277/369	Child <i>N</i> =233/240
Missing values (1st–3rd quartiles)	0.0 (0.0–0.4)	0.0 (0.0–0.4)
Response pattern	PF and HRQoL positively skewed	PF and HRQoL positively skewed
Floor effect, median		
PF	85.9%	88.0%
HRQoL PhH	68.8%	71.2%
HRQoL PsH	67.1%	69.5%
Pain VAS	33.9%	33.1%
Disease activity VAS	35.7%	40.3%
Well-being VAS	41.9%	48.9%
Ceiling effect, median		
PF	0.4%	0.0%
HRQoL PhH	2.2%	3.0%
HRQoL PsH	1.1%	0.4%
Pain VAS	0.0%	0.0%
Disease activity VAS	4.0%	0.0%
Well-being VAS	0.7%	0.4%
Items with equivalent item-scale correlation	87% for PF, 80% for HRQoL	80% for PF, 87% for HRQoL
Items with item-scale correlation $\geq 0.4$	87% for PF, 100% for HRQoL	80% for PF, 90% for HRQoL
Cronbach's alpha		
PF-LL	0.88	0.81
PF-HW	0.87	0.81
PF-US	0.72	0.71
HRQoL-PhH	0.86	0.87
HRQoL-PsH	0.77	0.73
Items with item-scale correlation lower than the Cronbach alpha	100% for PF, 100% for HRQoL	100% for PF, 100% for HRQoL
Test–retest intraclass correlation		
PF total score	0.92	0.47
HRQoL-PhH	0.92	0.71
HRQoL-PsH	0.83	0.11
Spearman's correlation with JIA core-set variables, median		
PF	0.4	0.3
HRQoL PhH	0.3	0.3
HRQoL PsH	0.2	0.1
Pain VAS	0.2	0.3
Disease activity VAS	0.2	0.2
Well-being VAS	0.3	0.3

JAMAR Juvenile Arthritis Multidimensional Assessment Report, JIA juvenile idiopathic arthritis, VAS visual analogue scale, PF physical function, HRQoL health-related quality of life, PhH physical health, PsH psychosocial health, PF-LL PF-lower limbs, PF-HW PF-hand and wrist, PF-US PF-upper segment

### Equal items-scale correlations (second Likert assumption)

Pearson items-scale correlations corrected for overlap were roughly equivalent for items within a scale for 87% of the PF items, with the exception of PF items 11 and 15, and for 80% of the HRQoL items, with the exception of items 1 and 8.

### Items internal consistency (third Likert assumption)

Pearson items-scale correlations were  $\geq 0.4$  for 87% of items of the PF (except for PF items 11 and 15) and 100% of items of the HRQoL.

## Cronbach's alpha internal consistency

Cronbach's alpha was 0.88 for PF-LL, 0.87 for PF-HW, 0.72 for PF-US. Cronbach's alpha was 0.86 for HRQoL-PhH and 0.77 for HRQoL-PsH.

## Interscale correlation

The Pearson correlation of each item of the PF and the HRQoL with all items included in the remaining scales of the questionnaires was lower than the Cronbach's alpha.

## Test–retest reliability

Reliability was assessed in 7 JIA patients, by re-administering both versions (parent and child) of the JAMAR after a median of 3 days (1–4 days). The intraclass correlation coefficients (ICC) for the PF total score showed an almost perfect reproducibility (ICC = 0.92). The ICC for the HRQoL PhH and for the HRQoL PsH showed an almost perfect reproducibility (ICC = 0.92 and ICC = 0.83, respectively).

## Convergent validity

The Spearman's correlation of the PF total score with the JIA core set of outcome variables ranged from  $-0.01$  to  $0.6$  (median =  $0.4$ ). The PF total score best correlation was observed with the parent assessment of pain ( $r = 0.6$ ,  $p < 0.001$ ). The correlation of the PF total score with the ESR was not significant ( $p = 0.87$ ). For the HRQoL, the median correlation of the PhH with the JIA core set of outcome variables ranged from  $0.1$  to  $0.7$  (median =  $0.3$ ), whereas for the PsH ranged from  $0.1$  to  $0.6$  (median =  $0.2$ ). The PhH showed the best correlation with the parent's assessment of pain ( $r = 0.7$ ,  $p < 0.001$ ) and the PsH with the parent global assessment of well-being ( $r = 0.6$ ,  $p < 0.001$ ). The median correlations between the pain VAS, the well-being VAS, and the disease activity VAS and the physician-centred and laboratory measures were  $0.2$  ( $-0.01$  to  $0.4$ ),  $0.2$  ( $0.01$ – $0.4$ ),  $0.3$  ( $-0.02$  to  $0.4$ ), respectively.

## Discussion

In this study, the American English version of the JAMAR was cross-culturally adapted from the British English version. According to the results of the validation analysis, the American English parent and patient versions of the JAMAR possess satisfactory psychometric properties. The disease-specific components of the questionnaire discriminated well between patients with JIA and healthy controls. The HRQoL

total score proved to discriminate between the different JIA subtypes with children with enthesitis related arthritis having a lower HRQoL.

Psychometric performances were good for all domains of the JAMAR with few exceptions: 2 PF items (stretch arms and bite a sandwich or an apple) showed a lower items internal consistency. However, the overall internal consistency was excellent for all the domains.

In the external validity evaluation, the Spearman's correlations of the PF and HRQoL scores with JIA core set parameters ranged from weak to moderate.

The results obtained for the parent version of the JAMAR are very similar to those obtained for the child version, which suggests that children are equally reliable proxy reporters of their disease and health status as their parents. The JAMAR is aimed to evaluate the side effects of medications and school attendance, which are other dimensions of daily life that were not previously considered by other HRQoL tools. This may provide useful information for intervention and follow-up in health care.

In conclusion, the American English version of the JAMAR was found to have satisfactory psychometric properties and it is, thus, a reliable and valid tool for the multidimensional assessment of children with JIA.

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## Compliance with ethical standards

**Conflict of interest** Dr. Martin, Dr. Ringold and Dr. Weiss report funding support from Istituto Giannina Gaslini, Genoa, Italy, for the translation and data collection performed at their sites within the EPOCA project. Dr. Ringold has also received a grant from Crescendo Biosciences outside the submitted work. Dr. Ruperto has received grants from BMS, Hoffman-La Roche, Janssen, Novartis, Pfizer, Sobi, during the conduct of the study and personal fees and speaker honorarium from Abbvie, Ablynx, Amgen, AstraZeneca, Baxalta Biosimilars, Biogen Idec, Boehringer, Bristol Myers Squibb, Celgene, Eli-Lilly, EMD Sero, Gilead Sciences, Janssen, Medimmune, Novartis, Pfizer, R-pharm, Roche, Sanofi, Servier and Takeda. Dr. Consolaro, Dr. Bovis, Dr. Brunner and Dr. Lovell have nothing to disclose.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all individual participants included in the study as per the requirement of the local ethical committee.

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## Affiliations

Daniel J. Lovell<sup>1</sup> · Hermine I. Brunner<sup>1</sup> · Sarah Ringold<sup>2</sup> · Pamela F. Weiss<sup>3</sup> · Neil Martin<sup>4</sup> · Alessandro Consolaro<sup>5,6</sup> · Francesca Bovis<sup>5</sup> · Nicolino Ruperto<sup>5</sup> · For the Paediatric Rheumatology International Trials Organisation (PRINTO)

Hermine I. Brunner  
hermine.brunner@cchmc.org

Sarah Ringold  
sarah.ringold@seattlechildrens.org

Pamela F. Weiss  
Weisspa@email.chop.edu

Neil Martin  
Neil.Martin@ggc.scot.nhs.uk

Alessandro Consolaro  
alessandroconsolaro@gaslini.org

Francesca Bovis  
francescabovis@gaslini.org

<sup>1</sup> Division of Rheumatology, Cincinnati Children's Hospital Medical Center, 3333 Burnet Avenue, ML 4010, Cincinnati, OH 45229-3039, USA

<sup>2</sup> Division of Rheumatology, Seattle Children's Hospital, Seattle, WA, USA

<sup>3</sup> Division of Rheumatology, The Children's Hospital of Philadelphia, Philadelphia, PA, USA

<sup>4</sup> Rheumatology Department, Royal Hospital for Children, Glasgow, UK

<sup>5</sup> Clinica Pediatrica e Reumatologia, Paediatric Rheumatology International Trials Organisation (PRINTO), Istituto Giannina Gaslini, Via Gaslini 5, 16147 Genoa, Italy

<sup>6</sup> Dipartimento di Pediatria, Università di Genova, Genoa, Italy