Rheumatology International (2018) 38 (Suppl 1):S251–S258
https://doi.org/10.1007/s00296-018-3960-1

Rheumatology
INTERNATIONAL

VALIDATION STUDIES

The Italian version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR)

Alessandro Consolaro[1,2] · Francesca Bovis[1] · Angela Pistorio[3] · Rolando Cimaz[4] · Fabrizio De Benedetti[5] · Angela Miniaci[6] · Fabrizia Corona[7] · Valeria Gerloni[8] · Silvana Martino[9] · Serena Pastore[10] · Patrizia Barone[11] · Sara Pieropan[12] · Elisabetta Cortis[13] · Rosa Anna Podda[14] · Romina Gallizzi[15] · Adele Civino[16] · Francesco La Torre[17] · Donato Rigante[18] · Rita Consolini[19] · Maria Cristina Maggio[20] · Silvia Magni-Manzoni[5] · Francesca Perfetti[5] · Giovanni Filocamo[7] · Claudia Toppino[9] · Francesco Licciardi[9] · Marco Garrone[1] · Silvia Scala[1] · Elisa Patrone[1] · Monica Tonelli[1] · Daniela Tani[1] · Angelo Ravelli[1,2] · Alberto Martini[21] · Nicolino Ruperto[1] · For the Paediatric Rheumatology International Trials Organisation (PRINTO)

Received: 22 December 2017 / Accepted: 11 January 2018

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 Italian 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 1296 JIA patients (7.2% systemic, 59.5% oligoarticular, 21.4% RF negative polyarthritis, 11.9% other categories) and 100 healthy children, were enrolled in 18 centres. The JAMAR components discriminated well healthy subjects from JIA patients except for the Health Related Quality of Life (HRQoL) Psychosocial Health (PsH) subscales. All JAMAR components revealed good psychometric performances.
In conclusion, the Italian 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 Italian 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.

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".

✉ Alessandro Consolaro
alessandroconsolaro@gaslini.org

✉ Nicolino Ruperto
nicolaruperto@gaslini.org

Extended author information available on the last page of the article

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 Italian language.

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 January 2012 to April 2016. 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 3 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 assessable' 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 original Italian JAMAR [1] was only modified in format and in the order of items. Cross-cultural adaptation was not deemed necessary for this version of the questionnaire, since it was routinely administered to JIA patients and to their parents since 2007 at the Italian PRINTO National Coordinating Center in Genoa.

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. The PRINTO National Coordinating Center was asked 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 subscales with the 6 JIA core set 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 Italian parent and patient versions of the JAMAR are available upon request to PRINTO.

Results

Demographic and clinical characteristics of the subjects

A total of 1300 JIA patients and 100 healthy children (total of 1400 subjects), were enrolled at 18 paediatric rheumatology centres. Four patients did not give the consent to use their data.

In the remaining 1296/1300 (99.7%) JIA subjects, the JIA categories were 7.2% with systemic arthritis, 59.5% with oligoarthritis, 21.4% with RF negative polyarthritis, 1.4% with RF positive polyarthritis, 3.8% with psoriatic arthritis, 3.5% with enthesitis related arthritis and 3.2% with undifferentiated arthritis (Table 1).

A total of 1372/1396 (98.3%) subjects had the parent version of the JAMAR completed by a parent (1274 from parents of JIA patients and 98 from parents of healthy children). The JAMAR was completed by 1032/1372 (75.2%) mothers and 340/1372 (24.8%) fathers. The child version of the JAMAR was completed by 876/1396 (62.7%) children age 6.0 or older. Also patients younger than 7 years old, capable to assess their personal condition and able to read and write, were asked to fill in the patient version of the questionnaire.

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. However, there was no significant difference between healthy subjects and their affected peers in psychosocial quality of life items.

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 of findings, unless otherwise specified.

Descriptive statistics (first Likert assumption)

For all JAMAR items, the median number of missing responses were 0.2% (0.1–0.5%).

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, whereas a reduced number of response choices were used for PF items 6 and 15.

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 9% (2–16%) for the PF and 36% (22–59%) for the HRQoL.

Floor and ceiling effect

The median floor effect was 90.9% (85.3–94.3%) for the PF items, 69.7% (63.3–73.5%) for the HRQoL PhH items, and 66.6% (65.5–70.0%) for the HRQoL PsH items. The median ceiling effect was 0.2% (0.1–0.4%) for the PF items, 1.7% (0.8–2.3%) for the HRQoL PhH items, and 0.7% (0.7–0.7%) for the HRQoL PsH items. The median floor effect was 50.8% for the pain VAS, 46.9% for the disease activity VAS and 45.7% for the well-being VAS. The median ceiling effect was 0.4% for the pain VAS, 0.7% for the disease activity VAS and 0.4% for the well-being VAS.

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 90% of the HRQoL items, with the exception of HRQoL item 1.

Table 1 Descriptive statistics (medians, 1st 3rd quartiles or absolute frequencies and %) for the 1296 JIA patients

	Systemic $N=93$	Oligoarthritis $N=772$	RF − poly-arthritis $N=277$	RF+ poly-arthritis $N=18$	Psoriatic arthritis $N=49$	Enthesitis related arthritis $N=45$	Undifferentiated arthritis $N=42$	All JIA patients $N=1296$	Healthy $N=100$
Female	46 (49.5%)	601 (77.8%)	222 (80.1%)	16 (88.9%)	33 (67.3%)	14 (31.1%)	30 (71.4%)	962 (74.2%)#	55 (55%)#
Age at visit	12.2 (8.2–16)	9.1 (5.5–13)	9.3 (5.5–13.6)	14.7 (12.8–17.5)	12.5 (8.4–15.5)	13.7 (12.1–16.4)	7.4 (5.1–13)	9.8 (6–13.8)#	11 (8.9–13)*
Age at onset	6.8 (2.2–10.9)	2.9 (1.8–5.7)	3.5 (1.7–7.1)	9.2 (5.9–11.1)	4.9 (2–10)	9.8 (8.5–12.4)	3.6 (2.3–5.4)	3.4 (1.8–7.4)#	
Disease duration	3.7 (1.6–7.5)	4.2 (1.8–7.8)	3.8 (1.9–6.8)	6.3 (3-8.6)	5.4 (2.7–7.6)	3.4 (1.5–4.9)	3.6 (1.6–7.3)	4.1 (1.8–7.4)	
ESR	10 (5–21)	10 (6–20)	11 (6–24)	13 (12–15)	11 (7–18)	9 (4–12)	12 (5.5–26.5)	10 (6–20)	
MD VAS (0–10 cm)	0.5 (0–3)	0 (0–2.5)	0.5 (0–3)	1 (0–3)	0 (0–2.5)	0 (0–2)	0.8 (0–3)	0 (0–2.5)	
No. of swollen joints	0 (0–1)	0 (0–1)	0 (0–2)	0 (0–1)	0 (0–1)	0 (0–0)	0 (0–1)	0 (0–1)*	
No. of joints with pain	0 (0–2)	0 (0–1)	0 (0–0)	0 (0–1)	0 (0–0)	0 (0–1)	0 (0–1)	0 (0–1)	
No. of joints with LOM	0 (0–2)	0 (0–1)	0 (0–2)	1 (0–2)	0 (0–2)	0 (0–1)	0.5 (0–2)	0 (0–1)**	
No. of active joints	0 (0–2)	0 (0–1)	0 (0–2)	0 (0–2)	0 (0–1)	0 (0–1)	0 (0–1)	0 (0–1)	
Active systemic features	9 (9.7%)	1/771 (0.1%)	1 (0.4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	11/1295 (0.8%)**	
ANA status	3 (3.2%)	317 (41.1%)	91 (32.9%)	6 (33.3%)	15 (30.6%)	3 (6.7%)	16 (38.1%)	451 (34.8%)#	
Uveitis	0 (0%)	203/767 (26.5%)	41/272 (15.1%)	1 (5.6%)	11/48 (22.9%)	5 (11.1%)	3 (7.1%)	264/1284 (20.6%)#	
PF total score	0 (0–3)	0 (0–2)	0 (0–3)	0 (0–3)	1 (0–3)	0 (0–1)	0 (0–2)	0 (0–2)	0 (0–0)#
Pain VAS	0 (0–2)	0 (0–2.5)	0.5 (0–3)	0.5 (0–3.5)	0.5 (0–4)	0.5 (0–3)	0.3 (0–1.8)	0 (0–2.5)	0 (0–0)#
Disease activity VAS	0 (0–3)	0.5 (0–3)	0.5 (0–3)	1 (0–3)	0.5 (0–3.3)	0.3 (0–3.5)	0.5 (0–2)	0.5 (0–3)	
Well-being VAS	0.5 (0–3.5)	0.5 (0–2.5)	0.5 (0–3)	1 (0–2)	0.5 (0–2)	1 (0–3)	1.3 (0–2.8)	0.5 (0–3)	
HRQoL PhH	1 (0–3)	1 (0–3)	1 (0–3)	2 (0–3)	1 (0–4)	1 (0–3)	1 (0–3)	1 (0–3)	0 (0–1)#
HRQoL PsH	2 (0–4)	1 (0–3)	1 (0–3)	1 (0–4)	1 (0–4)	2 (0–3)	0 (0–3)	1 (0–3)	0 (0–3)
HRQoL total score	2 (0–8)	2 (0–6)	3 (0–6)	3 (1–8)	2 (0–8.5)	3 (0–8)	2 (0–8)	2 (0–6)	0 (0–3)#
Pain/swell. in > 1 joint	33/91 (36.3%)	354/760 (46.6%)	128/272 (47.1%)	7 (38.9%)	27/48 (56.3%)	16 (35.6%)	16/40 (40%)	581/1274 (45.6%)	5/98 (5.1%)#
Morning stiffness > 15 min	15/90 (16.7%)	85/755 (11.3%)	41/268 (15.3%)	1 (5.6%)	6/48(12.5%)	8 (17.8%)	7/40 (17.5%)	163/1264 (12.9%)	0 (0%)**
Subjective remission	34/91 (37.4%)	300/753 (39.8%)	95/268 (35.4%)	7 (38.9%)	18/48 (37.5%)	14 (31.1%)	19/40 (47.5%)	487/1263 (38.6%)	
In treatment	68/91 (74.7%)	514/759 (67.7%)	230/272 (84.6%)	17 (94.4%)	32/48 (66.7%)	37 (82.2%)	27/40 (67.5%)	925/1273 (72.7%)#	
Reporting side effects	19/68 (27.9%)	157/510 (30.8%)	68/229 (29.7%)	4/17 (23.5%)	10/32 (31.3%)	9/37 (24.3%)	8/27 (29.6%)	275/920 (29.9%)	
Taking medication regularly	63/67 (94%)	489/510 (95.9%)	221/229 (96.5%)	17/17 (100%)	32/32 (100%)	36/37 (97.3%)	26/27 (96.3%)	884/919 (96.2%)	
With problems attending school	8/55 (14.5%)	29/553 (5.2%)	21/202 (10.4%)	1/15 (6.7%)	2/32 (6.3%)	2/35 (5.7%)	1/29 (3.4%)	64/921 (6.9%)	1/86 (1.2%)*
Satisfied with disease outcome	74/90 (82.2%)	578/755 (76.6%)	210/270 (77.8%)	15/17 (88.2%)	39/48 (81.3%)	36 (80%)	28/40 (70%)	980/1265 (77.5%)	

Data related to the JAMAR refers to the 1274 JIA patients and to the 98 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 refers to the comparison of the different JIA categories or to JIA versus healthy. *$p<0.05$ **$p<0.001$ #$p<0.0001$

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

	Parent $N = 1274/1372$	Child $N = 805/876$
Missing values (1st–3rd quartiles)	0.2 (0.1–0.5)	0.3 (0.1–0.6)
Response pattern	PF and HRQoL positively skewed	PF and HRQoL positively skewed
Floor effect, median		
PF	90.9%	92.2%
HRQoL PhH	69.7%	73.2%
HRQoL PsH	66.6%	70.4%
Pain VAS	50.8%	51.3%
Disease activity VAS	46.9%	50.2%
Well-being VAS	45.7%	49.1%
Ceiling effect, median		
PF	0.2%	0.1%
HRQoL PhH	1.7%	1.1%
HRQoL PsH	0.7%	0.9%
Pain VAS	0.4%	0.5%
Disease activity VAS	0.7%	0.6%
Well-being VAS	0.4%	0.6%
Items with equivalent item-scale correlation	87% for PF, 90% for HRQoL	87% for PF, 90% for HRQoL
Items with items–scale correlation ≥ 0.4	87% for PF, 100% for HRQoL	100% for PF, 100% for HRQoL
Cronbach's alpha		
PF-LL	0.90	0.88
PF-HW	0.89	0.84
PF-US	0.76	0.72
HRQoL-PhH	0.87	0.86
HRQoL-PsH	0.85	0.83
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	0.94	0.90
HRQoL-PhH	0.18	0.70
HRQoL-PsH	1.0	0.92
Spearman correlation with JIA core-set variables, median		
PF	0.5	0.5
HRQoL PhH	0.5	0.5
HRQoL PsH	0.2	0.2
Pain VAS	0.5	0.4
Disease activity VAS	0.4	0.4
Well-being VAS	0.5	0.4

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

Items internal consistency (third Likert assumption)

Pearson items–scale correlations were ≥ 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 0.90 for PF-LL, 0.89 for PF-HW, 0.76 for PF-US. Cronbach's alpha was 0.87 for HRQoL-PhH and 0.85 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 86 JIA patients, by re-administering both versions (parent and child) of the JAMAR after a median of 2 days (0–5 days). The intraclass correlation coefficients (ICC) for the PF total score showed an almost perfect reproducibility (ICC = 0.94). The ICC for the HRQoL PhH score showed a poor reproducibility (ICC = 0.18) while for the HRQoL PsH score showed an almost perfect reproducibility (ICC = 1.0).

Convergent validity

The Spearman correlation of the PF total score with the JIA core set of outcome variables ranged from 0.4 to 0.6 (median = 0.5). The PF total score best correlation was observed with the parent assessment of pain ($r = 0.6$, $p < 0.001$). For the HRQoL, the median correlation of the PhH with the JIA core set of outcome variables ranged from 0.4 to 0.7 (median = 0.5), whereas for the PsH ranged from 0.2 to 0.4 (median = 0.2). The PhH showed the best correlation with the parent's assessment of pain ($r = 0.8$, $p < 0.001$) and the PsH with the parent global assessment of well-being ($r = 0.5$, $p < 0.001$). The median correlations between the pain VAS, the well-being VAS, and the disease activity VAS and the physician-centered and laboratory measures were 0.5 (0.4–0.5), 0.4 (0.3–0.5), 0.5 (0.4–0.6), respectively.

Discussion

In this study, the Italian version of the JAMAR was cross-culturally adapted from the original standard English version with 3 forward and 2 backward translations. According to the results of the validation analysis, the Italian 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. Notably, there was no significant difference between the healthy subjects and their affected peers in the psychosocial quality of life variable. This finding indicates that children with JIA adapt well to the consequences of JIA.

Psychometric performances were good for all domains of the JAMAR with few exceptions: PF items 11 and 15 ("stretch out arms" and "bite a sandwich or an apple") showed a lower items internal consistency. However, the overall internal consistency was good for all the domains. Notably the ICC for the HRQoL PhH score showed a poor reproducibility. 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 Italian 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.

Acknowledgements We thank all families who participated in the project, the team that prepared and reviewed the forward and backward translations, and all members of PRINTO in Italy. In particular we thank Dr. Chiara Sandrin, University of Trieste, Dr. Andrea Taddio, University of Trieste, Institute for Maternal and Child Health–IRCCS "Burlo Garofolo" Trieste, Italy, Dr. Elena Tronconi, Sant'Orsola-Malpighi Hospital. We thank the staff of the PRINTO International Coordinating Centre in Genoa (Italy) and in particular Luca Villa, Giuseppe Silvestri and Mariangela Rinaldi for the database development and management and the remaining PRINTO team for data entry.

The Principal Investigator of the study was Prof. Angelo Ravelli, MD. The scientific coordinator and study methodologist was Nicolino Ruperto, MD, MPH. The project coordinators were Alessandro Consolaro, MD, PhD, Francesca Bovis, BsA.

Funding was provided by the Istituto G. Gaslini, Genoa (Italy).

Permission for use of JAMAR and its translations must be obtained in writing from PRINTO, Genoa, Italy. All JAMAR-related inquiries should be directed to at printo@gaslini.org. Permission for use of CHAQ and CHQ derived-material is granted through the scientific cooperation of the copyright holder ICORE of Woodside CA and HealthActCHQ Inc. of Boston, Massachusetts USA. All CHQ-related inquiries should be directed to licensing@healthactchq.com. All CHAQ-related inquiries should be directed to gsingh@stanford.edu.

Funding This study was funded and coordinated by Istituto Giannina Gaslini, Genoa, Italy.

Compliance with ethical standards

Conflict of interest Prof. De Benedetti, Prof. Cimaz, Dr. Magni-Manzoni, Dr. Pastore, Dr. Corona, Dr. Filocamo and Dr. Gerloni report funding support from Istituto Giannina Gaslini, Genoa, Italy, for the data collection and translation performed at their sites within the EPOCA project. 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, Am-

gen, AstraZeneca, Baxalta Biosimilars, Biogen Idec, Boehringer, Bristol Myers Squibb, Celgene, Eli-Lilly, EMD Serono, Gilead Sciences, Janssen, Medimmune, Novartis, Pfizer, Rpharm, Roche, Sanofi, Servier and Takeda. Prof. Ravelli has received speaker's bureaus and consulting fees from AbbVie, BMS, Pfizer, Hoffman LaRoche, Novartis, Centocor. Dr. Consolaro, Dr. Bovis, Dr. Galizzi, Dr. La Torre, Dr. Licciardi, Dr. Maggio, Dr. Martino, Dr. Miniaci, Dr. Perfetti, Dr. Pieropan, Dr. Pistorio, Dr. Podda, Dr. Rigante, Dr. Scala, Dr. Garrone, Dr. Patrone, Dr. Tani, Dr. Toppino, Dr. Barone, Dr. Civino, Dr. Consolini, Prof. Martini, Dr. Tonelli and Dr. Cortis 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

Alessandro Consolaro[1,2] · Francesca Bovis[1] · Angela Pistorio[3] · Rolando Cimaz[4] · Fabrizio De Benedetti[5] · Angela Miniaci[6] · Fabrizia Corona[7] · Valeria Gerloni[8] · Silvana Martino[9] · Serena Pastore[10] · Patrizia Barone[11] · Sara Pieropan[12] · Elisabetta Cortis[13] · Rosa Anna Podda[14] · Romina Gallizzi[15] · Adele Civino[16] · Francesco La Torre[17] · Donato Rigante[18] · Rita Consolini[19] · Maria Cristina Maggio[20] · Silvia Magni-Manzoni[5] · Francesca Perfetti[5] · Giovanni Filocamo[7] · Claudia Toppino[9] · Francesco Licciardi[9] · Marco Garrone[1] · Silvia Scala[1] · Elisa Patrone[1] · Monica Tonelli[1] · Daniela Tani[1] · Angelo Ravelli[1,2] · Alberto Martini[21] · Nicolino Ruperto[1] · For the Paediatric Rheumatology International Trials Organisation (PRINTO)

Francesca Bovis
francescabovis@gaslini.org

Angela Pistorio
angelapistorio@gaslini.org

Rolando Cimaz
r.cimaz@meyer.it

Fabrizio De Benedetti
fabrizio.debenedetti@opbg.net

Angela Miniaci
angela.miniaci@aosp.bo.it

Fabrizia Corona
fcorona@policlinico.mi.it

Valeria Gerloni
valeria_gerloni@yahoo.it

Silvana Martino
silvana.martino@unito.it

Serena Pastore
serena.pastore@burlo.trieste.it

Patrizia Barone
barone@policlinico.unict.it

Sara Pieropan
sara.pieropan@aovr.veneto.it

Elisabetta Cortis
elisabetta.cortis@uslumbria2.it

Rosa Anna Podda
rpodda@unica.it

Romina Gallizzi
rgallizzi@unime.it

Adele Civino
adelecivino@gmail.com

Francesco La Torre
latorre_francesco@virgilio.it

Donato Rigante
drigante@gmail.com

Rita Consolini
rita.consolini@med.unipi.it

Maria Cristina Maggio
sbenfratello@libero.it

Silvia Magni-Manzoni
silvia.magnimanzoni@opbg.net

Francesca Perfetti
francesca.perfetti81@gmail.com

Giovanni Filocamo
giovanni.filocamo@gmail.com

Claudia Toppino
claudia.toppino@gmail.com

Francesco Licciardi
francesco.licciardi@gmail.com

Marco Garrone
marcogarrone@gaslini.org

Silvia Scala
silviascala@gaslini.org

Elisa Patrone
elisapatrone@gaslini.org

Monica Tonelli
tonelli_m@libero.it

Daniela Tani
danielatani@gaslini.org

Angelo Ravelli
angeloravelli@gaslini.org

Alberto Martini
albertomartini@gaslini.org

[1] Clinica Pediatrica e Reumatologia, Paediatric Rheumatology International Trials Organisation (PRINTO), Istituto Giannina Gaslini, Via Gaslini 5, 16147 Genoa, Italy

[2] Dipartimento di Pediatria, Università di Genova, Genoa, Italy

[3] Servizio di Epidemiologia e Biostatistica, Istituto Giannina Gaslini, Genoa, Italy

[4] Dipartimento di Pediatria, Azienda Ospedaliero-Universitaria Meyer, Florence, Italy

[5] Division of Rheumatology, IRCCS Ospedale Pediatrico Bambino Gesù, Rome, Italy

[6] Salute della Donna, del Bambino e dell'Adolescente-Padiglione 16 Ambulatorio di reumatologia, Azienda Ospedaliero-Universitaria S.Orsola-Malpighi, Bologna, Italy

[7] Clinica Pediatrica II De Marchi, Fondazione IRCCS Ca' Granda-Ospedale Maggiore Policlinico, Milan, Italy

[8] Divisione di Reumatologia, Istituto Gaetano Pini, Milan, Italy

[9] Clinica Pediatrica, Paediatrics Departments, Università di Torino, Turin, Italy

[10] Scienze della Riproduzione e dello Sviluppo, IRCCS Burlo Garofolo, Trieste, Italy

[11] Clinica Pediatrica, Azienda Policlinico Università di Catania, Catania, Italy

[12] Reumatologia, Policlinico G.B.Rossi, Verona, Italy

[13] Struttura Complessa Pediatria, Ospedale Santa Maria Della Stella, Località Ciconia-Orvieto, Terni, Italy

[14] Clinica e Biologia dell'età evolutiva, Ospedale Regionale Microcitemia-II Clinica Pediatrica, Cagliari, Italy

[15] Department of Human Pathology in Adulthood and Childhood, University of Messina, Messina, Italy

[16] Pediatria, Azienda Ospedaliera Cardinale G. Panico, Tricase, LE, Italy

[17] Centro Regionale-HUB-di Reumatologia Pediatrica, Ospedale Antonio Perrino, Brindisi, Italy

[18] Pediatria, Università Cattolica Sacro Cuore, Roma, Italy

[19] Pediatria, Ospedale Santa Chiara, Università di Pisa, Pisa, Italy

[20] University Department Pro.Sa.M.I. "G. D'Alessandro", University of Palermo, Palermo, Italy

[21] Direzione Scientifica, Istituto Giannina Gaslini, Via Gaslini 5, 16147 Genoa, Italy