# Cross-cultural adaptation and psychometric evaluation of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ) in 32 countries. Review of the general methodology

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**ABSTRACT**

*The aim of this project was to cross-culturally adapt and validate the American English version of the Childhood Health Assessment Questionnaire (CHAQ) and of the Child Health Questionnaire (CHQ) in the 32 different member countries of the Paediatric Rheumatology International Trials Organisation (PRINTO). This effort forms part of an international study supported by the European Union to evaluate the health-related quality of life in children with juvenile idiopathic arthritis (JIA) as compared to their healthy peers.*

*A total of 6,644 subjects were enrolled from 32 countries: Argentina, Austria, Belgium, Brazil, Bulgaria, Chile, Croatia, the Czech Republic, Denmark, Finland, France, Georgia, Germany, Greece, Hungary, Israel, Italy, Korea, Latvia, Mexico, the Netherlands, Norway, Poland, Portugal, Russia, Slovakia, Spain, Sweden, Switzerland, Turkey, the United Kingdom, and Yugoslavia. A total of 3,235 patients had JIA (20% systemic onset, 33% polyarticular onset, 17% extended oligoarticular subtype, and 30% persistent oligoarticular subtype) while 3,409 were healthy children.*

*This introductory paper describes the methodology used by all the participants. The results and the translated version of both the CHAQ and the CHQ for each country are fully reported in the following papers.*

*The results of the present study show that cross-cultural adaptation is a valid process to obtain reliable instruments for the different socio-economic and socio-demographic conditions of the countries participating in the project.*

## Introduction

In the last decade the concept of health-related quality of life has become increasingly important and many authors have developed instruments to measure it both quantitatively and qualitatively. These instruments are now used for the evaluation of new therapies and to measure the influence that a certain disease has on the everyday activities of a patient. In recent years there has been increasing interest in the assessment of the quality of life in rheumatic diseases in both adults and children. Indeed, while in the past the assessment of patients with rheumatic diseases traditionally focused on the measurement of disease activity, more emphasis is now being placed on incorporating estimates of physical, social, and mental functioning into health assessments. In a combined meeting held in 1997, the World Health Organisation (WHO) and the International League Against Rheumatism (ILAR) (1) reached a consensus on the following definitions:

*Quality of life:* the perception of individuals of their own position in life in the context of the culture and value systems of the countries in which they live and in relation to their goals, expectations, standard and concerns.

*Health-related quality of life:* the physical, emotional, and social aspects of quality of life influenced by an individual's disease and/or its treatment.

*Disability:* the limitation in an individual's ability to act in a usual,customary, and personally desired way caused by one or more health conditions affecting physical or mental functioning.

To assess the quality of life several instruments have been developed, initially in adults and then in corresponding versions for children. The instruments used for children can usually be divided into two types.

"Generic" instruments, which measure quality of life independently of the disease of the patient, can be used across diseases, allowing the direct comparison of different conditions. The best example is the Child Health Questionnaire (CHQ) (2), which is designed to capture the physical and psychosocial well-being of children at least 5 years of age.

"Disease specific" instruments are those measures developed for a particular condition; they have a greater applicability in clinical trials because of their higher sensitivity to detect important clinical changes. The following are examples of disease specific questionnaires:the Childhood Arthritis Impact Measurement Scales (CHAIMS) (3), which measure physical disability and pain; the Juvenile Arthritis Functional Assessment Report (JAFAR) (4), which measures the ability of a child older than 7 years of age to perform certain physical tasks; the Childhood Health Assessment Questionnaire (CHAQ) (5), which measures disability and discomfort; the Juvenile Arthritis

Self-report Index (JASI) (6), which is primarily designed to help in decisions regarding rehabilitation; the Juvenile Arthritis Quality of Life Questionnaire (JAQQ) (7), which measures physical and psychosocial function by incorporating patient specific data; and the Childhood Arthritis Health Profile (CAHP) which represents an adaptation of the generic CHQ for use in JIA (see above) (8).

These childhood questionnaires are usually completed by the parent(s) or by the children if more than 12 years of age.

The term "juvenile idiopathic arthritis of childhood" (JIA) refers to a group of chronic diseases that can lead to functional, physical, and psychosocial disabilities ranging from minor to severe in extent (9, 10). Few chronic diseases may challenge the child and his family as much as severe JIA, a disease that, by its very nature, has a major impact on the everyday quality of life. The child has to face problems related to joint stiffness, pain, limitation of motion, alterations of his/her body image secondary to joint deformities, and growth problems that can lead to the impossibility of performing everyday activities in the same way as his peers. Moreover, these problems may heavily interfere with the development of independence and self esteem,especially in adolescence.

Performing controlled trials in JIA has always been a difficult task for two main reasons: the relative rarity of the diseases, and the lack of reliable and internationally recognised outcome measures. To overcome these difficulties, in May 1996 in Pavia, Italy an international research network - the Paediatric Rheumatology International Trials Organisation (PRINTO) - was founded with the goal of facilitating and coordinating international controlled clinical trials and outcome studies in children with paediatric rheumatic diseases. Originally comprised of 14 countries, PRINTO now includes 37 member countries.

In 1997 PRINTO, in collaboration with its North American counterpart, the Paediatric Rheumatology Collaborative Study Group (PRCSG), defined a core set of outcome measures and a definition of improvement in JIA for use in clinical trials (11). The core set includes a tool for the assessment of functional ability but does not indicate the specific instrument to be used. Although not included in this core set of measures, there is little doubt that health-related quality of life assessments will be incorporated in future clinical trials and investigations studying the long-term outcome in paediatric rheumatic diseases.

Since all of the instruments cited above were originally developed in American English and were designed for use in the North American population, there was an important need for the countries belonging to PRINTO and the paediatric rheumatology community in general to: (1) choose an appropriate tool and (2) to adapt it cross-culturally to the characteristics of each country in order to facilitate international collaborative studies. The PRINTO researchers selected the parent-administered version of the CHAQ as the principal disease-specific instrument to be used for JIA. The CHAQ was selected because it is already being widely used in the paediatric rheumatology research field, and it is particularly simple to administer and score. The parent-administered version of the CHQ (version CHQ-PF50) was selected as well, because it is a generic instrument that can be used for other paediatric rheumatic diseases such as juvenile dermatomyositis, juvenile systemic lupus erythematosus, linear scleroderma, and systemic sclerosis.

The aim of this project was therefore to cross-culturally adapt the American English version of the CHAQ and the CHQ in the 32 different countries that took part in this effort and to psychometrically evaluate the translated versions. This project formed a part of a larger international survey conducted by PRINTO and supported by the European Union (contract BMH4 983531 CA) (12-14), whose scope is to evaluate the health-related quality of life in children with JIA as compared to their healthy peers.

## Patients and questionnaires

*Patients*

Children were recruited into this prospective study performed by the members of PRINTO from 1998 to 2000. A total of 6,644 subjects were enrolled from 32 countries (Table I):Argentina, Austria, Belgium, Brazil, Bulgaria, Chile, Croatia, the Czech Republic, Denmark, Finland, France, Georgia, Germany, Greece, Hungary, Israel, Italy, Korea, Latvia, Mexico, the Netherlands, Norway, Poland, Portugal, Russia, Slovakia, Spain, Sweden, Switzerland, Turkey, the United Kingdom and Yugoslavia. A total of 3,235 patients had JIA (20% systemic onset, 33% polyarticular onset, 17% extended oligoarticular subtype, and 30% persistent oligoarticular subtype) while 3,409 were healthy children.

The protocol was approved by the ethics committees of the participating institutions and consent was obtained from each child's parents. Standard forms for data collection were designed using consensus methodologies at the PRINTO international co-ordinating centre in Pavia, Italy.

Children with JIA classified as systemic onset,polyarticular onset, extended oligoarticular or persistent oligoarticular subtype according to the Durban classification (15) were included in the study; all the other subtypes of JIA (psoriatic arthritis, enthesitis related arthritis, other form of arthritis that do not fit into any subtype) were excluded from the current project. All patients underwent clinical, rheumatologic, and laboratory assessments to evaluate the current status of the 6 variables included in the core set of outcome measures for JIA which are (11, 16): (i) the physician's evaluation of current disease activity on a 10 cm visual analogue scale (VAS); (ii) the parental assessment of overall well-being on a 10 cm VAS; (iii) a functional assessment tool (exact instrument not specified in the original core set); (iv) the number of joints with active arthritis; (v) the number of joints with limited range of motion; and (vi) the erythrocyte sedimentation rate (Westergren method).

Healthy controls were recruited from local schools (children 6 to 18 years of age) and among the healthy brother(s) and sister(s) of the JIA children attending the clinics. A child was defined as healthy after examination by a physician and/or based on the parent's declaration.

*The questionnaires*

Both the CHAQ and CHQ were completed by the parent(s), the legal representative(s) of each child or by other adult(s).

The CHAQ (5) is the principal rheumatic "disease-specific" instrument to be used for studies involving patients with JIA and other pediatric rheumatic diseases (juvenile dermatomyositis, juvenile systemic lupus erythematosus etc). It measures functional ability in 8 activities of daily living: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities. In the CHAQ, several questions were added to the HAQ so that there is at least 1 question in each functional area that is relevant to children of all ages under 18. Each of the items within a single domain has 4 possible categories of answers: "without any difficulty" (score 0); "with some difficulty" (score 1); "with much difficulty" (score 2); "unable to do"(score 3). The category "not applicable" was added for the items that may not apply due to the age of the child. Parents were instructed to take note only of impairment due to the disease in the preceding week. The items with the highest score in a domain determine the score for that domain, while the use of any aids or devices or help from another person is assigned a minimum score of 2 for that domain. These 8 domains are then averaged into a summary score called the disability index (DI) which may range from 0 to 3 with higher scores meaning higher disability. The CHAQ also provides an assessment of discomfort using a 10 cm VAS for the evaluation of pain and a 10 cm VAS for the evaluation of overall well-being.

The CHQ (2) is a generic health instrument designed to capture the physical and psy-

chosocial well-being of children 5 years of age and older. Parents are instructed to take into consideration the 4-week period preceding their compilation of the questionnaire. The CHQ measures by means of 50 items (questions), the following health concepts: global health (GGH); physical functioning (PF); role/social, emotional/behavioural limitations (REB); role/social physical limitations (RP); bodily pain discomfort (BP); behaviour (BE); global behaviour (GBE); mental health (MH); self-esteem (SE); general health perception (GH); change in health (CH); emotional impact on the parent (PE); impact on the parent's personal time (PT); limitations in family activities (FA); and family cohesion (FC). The 50 items are re-coded to ensure that all questions are positively scored, so that a higher score indicates better health, and recalibrated to ensure that the responses taken together represent a continuum.

The scores for each health concept are then transformed according to the following formula: actual score (sum of the item responses divided by the number of completed items) minus the lowest possible score divided by the possible score range; the transformed scores are therefore on a scale ranging from 0 to 100, with a higher score indicating better functioning and well-being. The score for each health concept can be evaluated only if half or more of the items within a scale have been answered, or half plus one in the case of scales with an odd number of items.

By means of two subsequent steps 2 final grouping scores are then obtained by the procedures described below, namely the physical summary score (PhS) and the psychosocial summary score (PsS).

As instructed by the developer of the CHQ, only 10 out of 15 possible health concepts are currently used to calculate the PhS and PsS summary scores:PF, RP, BP, GH,REB, PT, PE, SE, MH, BE. The use of the 5 remaining scales (GGH, GBE, CH, FA, FC) in calculating the PhS and PsS summary scores is still being evaluated and tested by the author of the CHQ.

The first step is to calculate the standardised z-score for each of the 10 health concepts using the following formula: the transformed score minus the estimated mean for that health concept in the reference population divided by the estimated standard deviation for the reference population. For the purposes of this project the means and standard deviation estimates were derived from the entire sample (that is all countries were combined and children with JIA and healthy children were also combined). The second step is to compute the aggregate summary scale scores (referred to as PhSRAW and PsSRAW) by multiplying the standardised z-score by its factor score coefficients (obtained by factor analysis; see below) and then summing the product of the ten scales used. Finally, in the third step each aggregate score is transformed to the norm-based PhS and PsS scores that have a mean of 50, and a standard deviation of 10. This is done by multiplying each aggregate summary scale score by 10 and adding the resulting product to 50.

CHQ scores were calculated using the proprietary algorithms and SAS programming code created specifically for the CHQ by its author.

**Outline of the methods**

The PRINTO project was divided into 2 phases (Fig. 1): phase I, the cross-cultural adaptation, which involved the translation procedures and preliminary probe in the target population; and phase II, the validation, which consisted of large scale data collection for psychometric and statistical evaluation.

*Phase I: Cross-cultural adaptation*

The process of cross-cultural adaptation followed the guidelines provided by Guillemin *et al*. (17) and was approved by the original developers of the CHAQ and the CHQ. To facilitate comparisons among the different languages, the 2 questionnaires were divided into 69 lines of translation for the CHAQ and 99 lines of translation for the CHQ (see the American English versions of the CHAQ and the CHQ at the end of this paper).

*Forward translation(s) into each national language*. One to three forward translations were carried out by 1 to 3 independent translators from American English into their native tongue, the language of each participating country. These translators were of different educational levels, background, and sex, were fluent in American English,and were instructed to use wording that could be understood by a 10 to 12-year old child, and at least two of them were unaware of the purpose of the project.

*First unified forward translation*. A meeting was then convened among the 3 forward translators, and 1 or 2 other persons not involved in the translation procedures. The goal of this meeting was to reach a consensus (that is, to reconcile differences in the forward translations) among the members of the group to obtain a first unified version of the 3 forward translations.

*Backward translation(s) into American English.* The first unified version of the questionnaires was then back-translated by 1 to 3 independent translators with American English as their first language, and who were fluent into the idioms and colloquial forms of the forward language. These 3

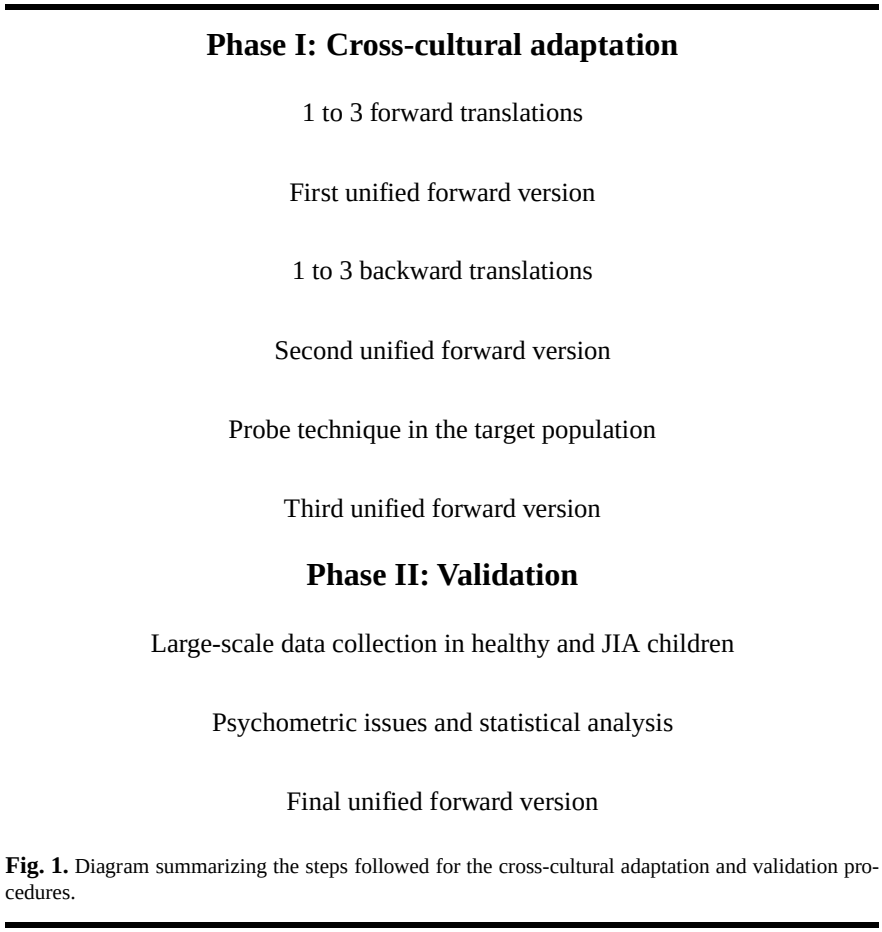


**Fig. 1.** Diagram summarizing the steps followed for the cross-cultural adaptation and validation procedures.

translators were different persons from the forward translators. Back-translation is retained to improve the quality of the final version of a questionnaire, by amplifying any misunderstandings in the forward translations (18). The back-translators had not seen the original American English text of the questionnaires, were unaware of the purpose of the project, and were of different educational levels, background, and sex.

*Review of backward translations*. The 1 to 3 backward translations were then reviewed by one of the authors of this paper (LGW) for the CHAQ, and by the original developer of the CHQ (JML) to check their correspondence with the original American English version of the respective instruments. The aim of this phase was to make sure that the introductory material, instructions for the questionnaires, and all the items were still relevant based upon the final version, that the translation was fully comprehensible, and finally to verify the cross-cultural equivalence of the source and final versions by comparing their semantic, idiomatic, experiential and conceptual equivalencies. Where 3 backward translations were available, a concordance in at least 2 out of 3 backward translations with the original American English version was required in order to accept as final a given line of the translated version.

*Second unified forward version*. A second meeting was then convened among all of the forward and backward translators in order to discuss the comments received from the reviewers of the backward translations. The purpose of this meeting was to reach a consensus among the translators for a second unified version of the questionnaires in each national language.

*Pre-testing in a target population using the probe technique.* Prior to using the translated CHAQ and CHQ on a large scale, the second unified version was administered to 20 parents of patients with JIA, of different educational levels and background, using a probe technique (19) to ensure parent comprehension in the target population. The probe method works as follows: a health professional who was aware of the purpose of each question administered the questionnaires to the parents,asking them to consider each question and elucidate their understanding of each item in an open-ended manner. The health professional judged whether the question was perfectly understood by each parent. Each of the 69 lines of the translated CHAQ and the 99 lines of the translated CHQ had to be understood by at least 80% of the parents tested; items that were misunderstood by 20% or more of the parents were reviewed and revised appropriately.

*Third unified forward version*. A third meeting was convened among all of the forward and backward translators to review the results of this pre-testing of the questionnaires. The goal of this meeting was to reach a consensus on a final unified version of the questionnaires in each language considered.

*Phase II: Validation*

Following the process of cross-cultural adaptation, a large scale data collection phase was set up using the third unified forward version of the questionnaires.

*Data collection.* A minimum sample of at least 60 parents of children with JIA and at least 60 parents of healthy children per country were administered the adapted CHAQ and CHQ (Table I).

*Psychometric issues.* To evaluate the underlying framework and psychometric properties of the questionnaires, PRINTO used an item scaling multi-trait/multi-item analysis program (MAP-R revised version 1.0) created by Ware and colleagues (20), from a method originally proposed and developed by Campbell *et al.* (21) and then simplified for general use by others (22). Multi-trait analysis was one of the hallmark methods used by Dr. Landgraf in evaluating the scaling properties of the CHQ (23) and was also used for the analysis of CHAQ. Since the main validation analysis was conducted at the time when the original American English versions of the CHAQ and the CHQ were developed in the USA, the current revalidation of the questionnaires was set up as a "confirmatory" step, meaning that the PRINTO results were considered as "successful" if they were equal to or superior to the results published for the original American English versions of the 2 questionnaires. In particular, MAP-R evaluates the Likert scaling assumptions (see below) (24).

*Clinical discriminant validity*. This reflects the ability of the instruments to discriminate healthy children from patients with the different subtypes of JIA considered in this project: systemic onset, polyarticular onset, extended oligoarticular subtype and persistent oligoarticular subtype. The data were generally skewed for the CHAQ toward normal functional ability, and for the CHQ toward normal physical and psychological well being. Even if the values were skewed, for the scope of this project it was felt necessary to present means and standard deviations instead of medians to facilitate comprehension by the average reader. Analysis of variance was then applied to determine whether there was a difference among the 5 groups of children (4 JIA subtypes plus healthy controls). *Post hoc* comparison of the means according to Scheffé or a similar method, in order to find out where the differences among the 5 groups of children lay, was not performed.

*Descriptive statistics*. The extent of missing and out-of-range values (that is, possible responses to a given question) were calculated to see if all the response choices were used; 10% was the cut-off point for missing values for each item. The pattern of responses was also evaluated to determine whether the data were normally distributed or skewed in distribution (i.e., did parents report at either extreme of the response continuum). The means and standard deviations of the items within a scale should be roughly equivalent (first Likert assumption); if this assumption is met, then it is possible to avoid a weighting of the items.

*Equal items-scale correlation*. These should be roughly equivalent for items within a scale when corrected for overlap. This analysis was carried out using the Pearson correlation coefficients to test the second Likert assumption (equal item scale correlations); that is, each item should contribute a roughly equal proportion of information to the total score with regard to the construct being measured. If the items have roughly equal variances,they do not need to be standardised.

*Item internal consistency (linearity).* This tests the third Likert assumption that items should be substantially linearly related to the total score computed from the items in that scale. It requires a Pearson item correlation of at least 0.4 (or at the very minimum 0.3) after correction for item scale overlap. Items not meeting this criteria might have to be revised. The internal consistency is considered satisfactory if 90% or more of the items meet this criteria.

*Item discriminant validity*. This requires that the correlation of an item with its scale is significantly higher (by at least 1, and preferably 2 standard errors) than the correlation of that item with all of the other scales. The discriminant validity is considered satisfactory if 90% or more of the items meet this criteria.

*Floor and ceiling effects*. The floor effect refers to the frequency of the lowest possible responses within an item, while the ceiling effect refers to the frequency of the highest possible responses within an item. This was performed to check whether scale scores had substantial variability in the population of interest.

*Internal consistency (Cronbach's alpha)*. This refers to the extent to which the measured variance in a score reflects the true score rather than random error; that is, the extent to which measures give consistent or accurate results. Reliability was measured by Cronbach's alpha coefficients of at least 0.7 (minimum 0.5) (25).

*Interscale correlation.* This was tested using the means of the Pearson correlation coefficients. It requires that the correlation between 2 scales is less than their reliability

coefficients as measured by Cronbach's alpha. It can be viewed as a correlation between a scale and itself, and is used to evaluate how each scale is distinct from other scales.

*Test-retest reliability (intra-class correla - tion coefficient).* This is a test of stability and represents the reproducibility within the same individual 1 to 2 weeks after the first administration of the questionnaire. An intra-class correlation coefficient < 0.4 indicates poor reproducibility, ≥ 0.4 < 0.75 indicates fair to good reproducibility, while ≥ 0.75 indicates excellent reproducibility (26, 27).

*External validity (convergent or construct validity).* This is the correlation of the summary scores with external criterion variables not used to score the scales. This was done using the Spearman rank order correlation coefficients of the DI summary scores of the CHAQ, and the PhS and PsS of the CHQ with the other variables included in the core set of outcome measures for JIA, i.e. the physician's evaluation of current disease activity on a 10 cm VAS, the parental assessment of overall well-being on a 10 cm VAS, the number of joints with active arthritis, the number of joints with limited range of motion, and the ESR (see *Patients* section for more details) (11). Convergent validity was tested only for the subgroup of patients with JIA.

*Parents-children agreement.* The parents-children a greement was evaluated only for the CHAQ in a subgroup of French children with JIA and in their respective parents, who were asked to complete the questionnaire separately on the same day. Agreement for the ordinal variables of the 8 CHAQ domains was evaluated according to the kappa coefficient (28); according to Landis and Kock (29) agreement is classified as very low if the kappa coefficient is less than 0.01, low if between 0.01 - 0.20, sufficient if between 0.21-0.40, moderate if between 0.41 - 0.60, substantial if between 0.61 - 0.80, and almost perfect if between 0.81 - 1. The parents-children agreement for continuous variables (VAS for pain assessment and VAS for overall well being assessment) was evaluated according to Bland and Altman (30). These authors combine a graphic method (x-axis paired data mean versus y-axis paired data difference) of data depiction with a p value coming from a t-test for paired samples; if the p value is not significant then there is good agreement between the parents and children.

*Factor analysis (only for CHQ).* Factor analytic studies were conducted to evaluate the construct validity of the CHQ in relation to the 10 health concepts (PF, RP, BP, GH, REB, PT, PE, SE, MH, BE) that were included in the analysis performed by Landgraf *et al.* (2). Factorial analysis was performed, as detailed in the CHQ manual, according to the following specifications:a) prior communality estimates according to the squared multiple correlation method (that is, for each health concept the square of the multiple linear correlation coefficient between that health concept and all the others); b) the factorised matrix represented the correlation matrix (that is, the original health concepts were standardised by taking the means and standard deviations of children with the 4 JIA subtypes considered, combined with the values for the healthy children, and all countries, grouped into a single data set); c) the factors were extracted according to the principal factors method; d) the number of factors was identified by choosing that number which expressed 100% of the common variance explained by the factor model [this was also supported by an analysis of the eigenvalues graph (scree plot)]; d) the factors were rotated by the varimax method.

*Software*. All of the data were entered into a database (Microsoft Access) for the scoring calculation and were analysed using the Statistica (1999 edition by StatSoft, Inc) or SAS Windows (version 6.12, release 1989-1996, Institute Inc., Cary, NC, USA) software programs.

*Final forward version.* In some cases a final modification of the items contained in the final forward version was made based on the results from the psychometric evaluations.

**Table I.** Number of patients with JIA (frequency in parenthesis) and number of healthy children who participated in the study.

| Countries | Systemic onset No. (%JIA) | Poliarticular onset No. (%JIA) | Extended oligoart. No. (%JIA) | Persistent oligoart. No. (%JIA) | Total JIA | Healthy subjects | TOTAL JIA and Healthy |
|---|---|---|---|---|---|---|---|
| Argentina | 18 (29%) | 23 (38%) | 4 (7%) | 16 (26%) | 61 | 63 | 124 |
| Austria | 7 (9.5%) | 31 (42%) | 7 (9.5%) | 29 (39%) | 74 | 60 | 134 |
| Belgium | 6 (11%) | 21 (40%) | 7 (13%) | 19 (36%) | 53 | 146 | 199 |
| Brasil | 42 (27%) | 60 (38%) | 14 (9%) | 41 (26%) | 157 | 314 | 471 |
| Bulgaria | 28 (36%) | 23 (30%) | 3 44%) | 23 (30%) | 77 | 60 | 137 |
| Chile | 21 (29%) | 28 (39%) | 3 (4%) | 20 (28%) | 72 | 54 | 126 |
| Croatia | 14 (19%) | 15 (20%) | 13 (17%) | 33 (44%) | 75 | 64 | 139 |
| Czech Rupublic | 11 (14%) | 36 (44%) | 8 (10%) | 26 (32%) | 81 | 69 | 150 |
| Denmark | 19 (25%) | 23 (30%) | 14 (19%) | 20 (26%) | 76 | 63 | 139 |
| Finland | 8 (9%) | 39 (44%) | 23 (26%) | 19 421%) | 89 | 72 | 161 |
| France | 70 (23%) | 66 (22%) | 77 (25%) | 93 (30%) | 306 | 194 | 500 |
| Georgia | 24 (44%) | 15 (28%) | 4 (7.5%) | 11 (20.5%) | 54 | 61 | 115 |
| Germany | 7 (5%) | 19 (13%) | 11 (8%) | 105 (74%) | 142 | 55 | 197 |
| Greece | 23 (28%) | 20 (24 %) | 8 (10%) | 31 (38%) | 82 | 61 | 143 |
| Hungary | 9 (13.5%) | 28 (42%) | 9 (13.5%) | 21 (31%) | 67 | 60 | 127 |
| Israel | 10 (12%) | 27 (34%) | 18 (23%) | 25 (31%) | 80 | 64 | 144 |
| Italy | 63 (16%) | 126 (31%) | 86 (21%) | 129 (32%) | 404 | 788 | 1192 |
| Korea | 16 (18%) | 32 (37%) | 10 (12%) | 29 (33%) | 87 | 134 | 221 |
| Latvia | 13 (16%) | 26 (32.5%) | 15 (19%) | 26 (32.5%) | 80 | 61 | 141 |
| Mexico | 23 (26%) | 42 (47%) | 12 (13.5%) | 12 (13.5%) | 89 | 93 | 182 |
| Netherlands | 17 (17%) | 31 (31%) | 18 (18%) | 34 (34%) | 100 | 80 | 180 |
| Norway | 5 (6%) | 40 (45%) | 9 (10%) | 34 (39%) | 88 | 60 | 148 |
| Poland | 6 (35%) | 3 (18%) | 5 (29%) | 3 (18%) | 17 | 13 | 30 |
| Portugal | 22 (32%) | 13 (19%) | 18 (26%) | 16 (23%) | 69 | 61 | 130 |
| Russia | 20 (23%) | 33 (39%) | 13 (15%) | 20 (23%) | 86 | 60 | 146 |
| Slovakia | 8 (15%) | 19 (37%) | 5 (10%) | 20 (38%) | 52 | 67 | 119 |
| Spain | 22 (28%) | 27 (34%) | 14 (17%) | 17 (21%) | 80 | 69 | 149 |
| Sweden | 9 (13%) | 27 (39%) | 17 (25%) | 16 (23%) | 69 | 60 | 129 |
| Switzerland | 19 (22%) | 26 (31%) | 27 (32%) | 13 (15%) | 85 | 62 | 147 |
| Turkey | 30 (35%) | 35 (41%) | | 20 (24%) | 85 | 60 | 145 |
| United Kingdom | 38 (17%) | 89 (41%) | 73 (33%) | 19 (9%) | 219 | 221 | 440 |
| Yugoslavia | 24 (30%) | 22 (28%) | 5 (6%) | 28 (36%) | 79 | 60 | 139 |
| Total 32 countries | 652 (20%) | 1,064 (33%) | 551 (17%) | 968 (30%) | 3,235 | 3,409 | 6,644 |

## Outcome of the project

*CHAQ cross-cultural adaptation*

Translated versions of the CHAQ have already been published in the following 7 countries: Argentina (31), Brazil (Portuguese) (32),Spain (Castillian Spanish) (33), Italy (34), Mexico (Spanish) (35), Norway (36), and Sweden (37). The CHAQ is also available in the medical literature (not as a part of this project) in Arabic (38) and Costa Rican Spanish (39).

For some countries with similar languages there was only an adaptation of the already translated version, involving the changing

of specific words whose usage is different in the two respective countries. This was done for 3 countries: Austria from the German version, Chile from the European Spanish version, and the French and German Swiss versions from the original French and German versions.

Only one forward and one backward translation were carried out for 3 countries: Bulgaria, Latvia, and Poland. For Finland and Yugoslavia 3 forward translations and 1 backward translation were made. For France 2 forward and 1 backward translations were carried out.

Three backward and three forward translations were obtained for the other 16 countries:Belgium,Croatia,the Czech Republic, Denmark, Georgia, Germany, Greece, Hungary, Israel, South Korea, the Netherlands, Portugal, Russia, Slovakia, Turkey and the United Kingdom.

*CHQ cross-cultural adaptation*

Psychometric work on several CHQ translations has been previously published, specifically the French-Canadian, German, and United Kingdom English versions in one study (23), and the Swedish (40), Norwegian (41), Dutch (42), French (43), Australian (44), and Yugoslavian (45) versions in separate studies. Translations of the CHQ into other languages are also pending.

As with the CHAQ, for countries with similar languages the already translated version of the CHQ was simply adapted by changing those words whose usage is different in the two respective countries. This was done for 6 countries: Austria from the German version, Belgium from the Dutch version, Brazil from the Portuguese version, Chile from the Spanish Castillian version,Mexico from the Spanish Castillian version, and French and German Swiss versions from the original French and German versions.

One forward and one backward translation were carried out for 3 countries: Bulgaria, Latvia, and Poland. For Finland and Yugoslavia, 3 forward translations and 1 backward translation were done.

Three backward and three forward translations were obtained for the other 15 countries: Argentina, Croatia, the Czech Republic, Denmark, Georgia, Greece, Hungary, Israel, Italy, South Korea, Portugal, Russia, Slovakia, Spain, and Turkey.

**Final remarks**

The results of the present study show that cross-cultural adaptation is a valid process through which reliable instruments may be obtained for use in different countries despite differing socio-economic conditions.

The process of cross-cultural adaptation refers to the measurement of the same phenomenon in different cultures using the same instruments and should be distinguished from the concept of cross-cultural comparison that refers to comparative studies of a phenomenon across cultures aimed at identifying differences attributable to cultures. It was decided to follow the guidelines proposed by Guillemin *et al*. (17) for the cross-cultural adaptation procedures in order to have a standardised approach that could be easily applied to all the countries which are members of PRINTO. The cross-cultural adaptation procedures were not applied in the countries for which translations of the CHAQ (31-37) and CHQ were already available (2, 23, 40-43).

For the countries which share similar languages, the questionnaires were adapted from the translations prepared in the original mother tongue country (i.e., the versions for Argentina, Mexico and Chile were derived from the European Spanish version, while the British English version was derived from the American English version). The process for these countries required merely a change in certain words whose use is different in the different countries. For all the other countries, the translation guidelines (17) proved both easy to apply and reliable. The back translations showed that the concepts most difficult to render in the target language were the questionnaire instructions and the categories of answers to the item questions. For all the other concepts there was an excellent concordance between the back translations and the original American English version, indicating the reliability of the method.

All of the translations presented in this supplement were evaluated using traditional multi-trait item scaling analysis (20, 23), irrespective of whether they had already been published or not. The probe technique confirmed that the categories of answers were the most difficult concepts for parents to understand in the cases of both the CHAQ and the CHQ. For the CHAQ, other concepts difficult to understand were the part of the questionnaire that uses a different format to elicit responses (use of aids and devices, or the categories for which help is needed, and the 2 VAS for pain assessment and global evaluation), and those items that are related to everyday life in North America such as "the cereal box' (line 18) and "the door knob' (line 51), items that are not commonly found in other countries. The CHQ was in general more difficult to understand, especially with regard to certain concepts such as behaviour, self esteem, and global health.

Given the large number of countries participating and the complexity of the project,the PRINTO researchers decided to include only the parent-administered versions of the two questionnaires. Another limit to this analysis was its cross-sectional nature, but the PRINTO participants will continue to follow the patients recruited for this study over time, and see how the questionnaires perform in an on-going clinical trial in children with JIA treated with higher doses of methotrexate (12, 13).

In conclusion,PRINTO has cross-culturally adapted and evaluated the original American English versions of the CHAQ and the CHQ for use in 32 different countries. The translated versions proved to be reliable and valid tools for the functional, physical and psychosocial assessment of children with JIA and can be easily applied in routine clinical practice and in clinical trials. The use of carefully validated translations will allow the standardised evaluation of the health-related quality of life in children with JIA and other paediatric rheumatic diseases.

The papers in this supplement present the preliminary psychometric findings for the cross-cultural adaptation and psychometric evaluation of the CHAQ and the CHQ by the 32 countries that took part in this effort. Permission to reproduce the texts of the translations for the purposes of illustrating the findings in this project were obtained from the original developers of the CHAQ and the CHQ.

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