

The paediatric rheumatic diseases are rare conditions associated with important sequelae on the quality of life. Research aimed at studying new therapeutic approaches is difficult because of organisational, methodological (i.e., the lack of established measures for outcome evaluation), ethical, regulatory, and financial problems.

To confront these problems, in May 1996 an international research network called the Paediatric Rheumatology International Trials Organisation (PRINTO) was founded with the goals of promoting, facilitating and conducting high quality research in the field of the paediatric rheumatic diseases.

PRINTO is composed of four main vertical structures: the Advisory Council (to act as the steering committee), the international co-ordinating centre (located in Pavia, Italy for the coordination of international efforts), one national coordinator for each country (to coordinate the work among the individual paediatric rheumatology centres in that country, and for all issues connected with the translation of documents), and more than 100 centres (hospitals and/or universities) distributed in 37 countries around the world for data collection.

Thanks to a grant from the European Union (contract BMH4 983531 CA) and one from the IRCCS Policlinico S. Matteo, Pavia, Italy, PRINTO has been able to create this extensive network and to conduct large scale studies on the paediatric rheumatic diseases.

This supplement represents one of the main fruits of this effort; its intent is to make available to the paediatric rheumatology community, and to the paediatric research community in particular, standardised tools to evaluate the health-related quality of life and the disability status of children, both for current clinical practice and for research in the field.

The PRINTO researchers have selected the parent-administered version of the Childhood Health Assessment Questionnaire (CHAQ) as the principal disease-specific instrument to be used for studies involving patients with Juvenile Idiopathic Arthritis (JIA), and the parent-administered version of the generic Child Health Questionnaire (CHQ) to be used for JIA and other paediatric rheumatic diseases. It should be noted that the CHQ offers a very useful tool for the paediatric research community in general since it is a generic instrument applicable to different diseases, and not merely rheumatic conditions.

The aim of this project was therefore to cross-culturally adapt and to evaluate the psychometric properties of the American English versions of the CHAQ and CHQ after translating them into the native languages of the 32 member countries of PRINTO. This project was undertaken by PRINTO as a service to the paediatric rheumatology community and to general paediatricians to facilitate international collaborative studies on quality of life assessments by making available two validated and widely accepted instruments translated in many languages.

The supplement begins with an introductory review article summarising the overall methodology used and the sample collected. It is followed by one article for each of the 32

countries participating in the project. Each paper presents the results of the cross-cultural adaptation and psychometric evaluation of the CHAQ and of the CHQ in that particular country, plus 3 tables which compare the demographic, disability, physical and psychological data for JIA children versus their healthy peers. At the end of each paper the text of the translated questionnaires is reproduced (with permission from the original developers of the CHAQ and CHQ and for illustration purposes only).

Clearly this project could not have been realised without the invaluable help of the PRINTO national coordinators who coordinated the work of the PRINTO paediatric rheumatology centres in their country for the data collection, and that of the families of the JIA patients and the healthy controls which made it possible for us to study 6,644 children.

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