Instruments that evaluate health status, functional status, disability and quality of life (QoL) in adults with rheumatoid arthritis (RA) are prominent in recent literature, and their inclusion as outcome measures in clinical trials now is mandated by regulatory agencies, such as the FDA. Such measures also have been developed for the assessment of children with juvenile idiopathic arthritis (JIA). One of these measures has been included in the core set of six outcome measures for clinical trials (as decided by the Pediatric Rheumatology Collaborative Study Group [PRCSG] and the Paediatric Rheumatology International Trials Organization [PRINTO]). The inclusion of a functional measure for children represents an important milestone for rheumatology in Canada.

Functional status, health status and QoL, as referenced in the medical literature, frequently are used interchangeably, and thus may not have distinct meaning.1 “Functional status” is a broad summary phrase used to explain the effect of a disease on one’s ability to carry out usual tasks.

“Health status” refers to an overall point estimate of a person’s well-being in physical, psychological and social terms compared to baseline.

The “QoL” measurement includes both health status and functional status, and should attempt to incorporate some aspect of the patient’s own perception of those particular aspects of life that have been affected significantly and the extent to which these are influenced by the disease.1 In this context, one is attempting to measure health-related quality of life (HRQoL). Indeed, it seems that individuals, including children, are capable of distinguishing between health status, QoL and HRQoL,2 although this has been questioned.3

HRQoL may be generic or disease-specific, with the latter having greater applicability for clinical trials because of its greater sensitivity in the detection of important clinical change (responsiveness). Various groups have attempted to develop the definitive measure for application in children with JIA.

The ideal instrument should be practical and easy to use, should be capable of completion by the parents and/or child within a short time, and should measure physical function. The ideal instrument also should measure psychological function and social function, including school, family and behaviour issues, and should include a measurement of pain. It also should be reliable, valid and responsive. Such an instrument also should be appropriate for use in different countries, and hence different cultures, and thus must undergo translation as well as other important changes to ensure adaptability to the particular setting in which it ultimately will be used. Thus, international use of these measures presents an important challenge.4,5

None of the measures to be discussed in this article fulfills all of the above criteria. Nonetheless, important strides have been made. The following instruments are reviewed in detail elsewhere,5,6 below, they will be discussed in brief.
DISEASE-SPECIFIC INSTRUMENTS—
MEASURES OF PHYSICAL FUNCTION

The Childhood Arthritis Impact Measurement Scales (CHAIMS). The CHAIMS was the first disease-specific measure developed for JIA. This instrument was a modification of the AIMS. The measurement properties of this instrument are not particularly good, however (except for the pain dimension, which showed good reliability and convergent validity). This was due mainly to the fact that most items do not apply to children under six years of age. Also, the face validity, content validity and responsiveness of CHAIMS have not been demonstrated, so this instrument is not in current use.

The Childhood Health Assessment Questionnaire (CHAQ). The CHAQ—which was derived from the adult HAQ—comprises two indices: Disability and Discomfort. The Disability Index assesses function in eight areas (dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities), distributed among a total of 30 items. In each functional area, there is at least one question that is relevant to children of all ages.

Each question is rated on a four-point scale of difficulty in performance, scored from 0-3. The question with the highest score determines the score for that functional area. If aids or devices are used, or assistance is required, the minimum score for that functional area is 2. The Disability Index is calculated as the mean of the eight functional areas. Discomfort is determined by the presence of pain, measured by a 100-mm visual analogue scale (VAS), extrapolated to a score of 0-3. In addition, a 100-mm VAS measures patient/parent global assessment of arthritis.

The CHAQ has excellent reliability and validity, and good discriminative properties; it has good predictive qualities and is of value for longitudinal studies, and has been used extensively for this purpose. Preliminary data suggest that the CHAQ is responsive, although this needs to be clearly established in a controlled trial before concluding that it is the definitive instrument for efficacy trials. The CHAQ, however, can be administered to children of all ages, in several languages, and is of great potential use in the clinical setting for the long-term follow up of children with JIA (and probably other rheumatic childhood diseases).

The Juvenile Arthritis Functional Assessment Report (JAFAR). The JAFAR was derived from the AIMS, the HAQ and the McMaster Health Index Questionnaire. JAFAR comprises one dimension and contains 23 items that assess ability to perform physical tasks in children older than seven years of age on a three-point scale scored from 0-2. The overall score range is 0-46, with lower scores indicating better function. Two separate versions are available, one for the child (JAFAR-C) and one for the parents (JAFAR-P).

The JAFAR has excellent reliability and validity. While data from a small controlled trial suggest that the JAFAR is responsive, further work is needed in larger trials to clearly establish its responsiveness, and to determine its true value for use in efficacy trials.

The greatest drawback of the JAFAR is the fact that it cannot be administered to children under seven years of age, and this prohibits its use in children with early onset of JIA.

The JAFAR is, nonetheless, a practical instrument of great use in the clinical setting and in the

Functional status, health status and QoL, as referenced in the medical literature, frequently are used interchangeably, and thus may not have distinct meaning.
The longitudinal follow up of a majority of children with chronic arthritis, although it offers little beyond the CHAQ.

**The Juvenile Arthritis Self-Report Index (JASI).**
The JASI was developed with a specific focus on physical activity in children over eight years of age with JIA. The emphasis of JASI is on responsiveness, and it is aimed primarily at rehabilitation interventions. The JASI contains 100 items, distributed among five categories of physical function (self-care, domestic, mobility, school, and extracurricular). Scores range from 0 to 100, with higher scores indicating better function. A seven-point Likert scale of difficulty in performing tasks is included. As a secondary component (JASI Part II), patients identify up to five tasks that are most problematic, and these tasks are evaluated on sequential follow up. This maneuver makes this component of the JASI potentially more responsive and patient-specific.

The JASI has been developed in a meticulous fashion, resulting in excellent reliability and validity. Its greatest drawback is the fact that it cannot be administered to children under eight years of age, and this prohibits its use in children with early-onset JIA. Also, because it is comprehensive, the JASI takes a long time to complete (45 minutes), which may make it less attractive for clinical use.

The JASI is, nonetheless, a comprehensive instrument with excellent measurement properties, whose greatest value probably is as a research tool for longitudinal studies.

**These six instruments differ significantly from one another, and have been developed with different objectives in mind, giving each its own unique qualities.**

**DISEASE-SPECIFIC INSTRUMENTS—QUALITY OF LIFE MEASURES**

**The Juvenile Arthritis Quality of Life Questionnaire (JAQQ).** The JAQQ measures physical and psychosocial function; it incorporates patient-specific data and is focused on the disease (and, thus, on measures of HRQoL). The JAQQ is applicable to all age groups and chronic-arthritis subtypes, and can be self-administered within a brief period of time.

The JAQQ comprises 74 items distributed among four dimensions: gross motor function (17 items), fine motor function (16 items), psychosocial function (22 items) and general symptoms (19 items). Each item is scored from 1 to 7 (“none of the time” to “all of the time,” based on how often the particular item is a problem for the child), with 7 indicating worst function. While respondents score all items on each occasion, the patient’s score is computed as the mean of the five highest scoring items in each dimension. The total JAQQ score is computed as the mean of the four dimensions. A pain scale is included but scored separately. English, French and Dutch versions are available.

The JAQQ has been developed in a detailed fashion, resulting in excellent validity and responsiveness, and, because of this, it might be the ideal instrument for clinical trials.

**The Childhood Arthritis Health Profile (CAHP).**
This instrument was developed to capture the broad range of health states in children with JIA, including physical functioning, psychosocial functioning and family impact of disease. The CAHP was developed in parallel with a generic instrument, the Childhood Health Questionnaire (CHQ). There is a parent-reported version as well as a teen-reported version for adolescents (13+ years of age).

The CAHP is self-administered and consists of three modules: generic health status measured by the CHQ, JIA-specific scales and patient characteristics. The initial report focused on the development, validity and reliability of the functional scales (both JIA-specific and generic).
The CAHP is a promising instrument. Despite its complexity, it can be filled out in the clinical setting in less than 15 minutes by parents and children. A user-friendly data-entry database has been developed to improve the ease of use in a standard clinical situation, and work is underway to simplify the scoring system.

CONCLUSION
The focus of this overview has been predominantly the six outcome measures that have been developed for JIA, and the attempt to measure functional status and/or HRQoL. These six instruments differ significantly from one another, and have been developed with different objectives in mind, giving each its own unique qualities.

The CHAIMS has been less well-studied and its measurement properties are not good; thus it is unlikely to have a continuing role.

The CHAQ and JAFAR have excellent measurement properties and have seen the greatest widespread use; they are simple to use and can be completed within a brief period of time. While the CHAQ and the JAFAR are of value as research tools, their greatest value is probably in the clinical setting. The CHAQ, by virtue of its applicability to all age groups, has a distinct advantage over the JAFAR.

The JASI has excellent measurement properties—although, because it takes considerable time to complete, it is probably best used as a research tool, rather than as a tool for clinical use.

The JAQQ also is comprehensive, although it can be completed more quickly than the JASI. The JAQQ can be administered to all age groups and is highly responsive; its most appropriate role is in clinical trials—the specific purpose for which it was designed.

The CAHP also has excellent measurement properties, particularly in its discriminative ability. It is comprehensive and cannot be completed quickly, so its role most likely will be as a research tool for longitudinal studies. It is important to note that both the JAQQ and the CAHP measure HRQoL and may thus be important for inclusion in long-term outcome studies in JIA.

With the expansion of the network of collaboration for clinical trials, it has been necessary to adapt instruments for use in several countries. To this end, PRINTO is encouraging both the adaptation and translation of both the CHAQ and CHQ to several languages, given the widespread participation in the trials that the organization is coordinating. As the work of PRINTO evolves, it will be interesting to see how these instruments perform in the broader international arena.

References