

## CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

### General Description of the Questionnaire:

The childhood HAQ has been adapted from the Stanford Health Assessment Questionnaire. The Stanford HAQ assesses four outcome dimensions: disability, discomfort and pain, drug side effects, and dollar costs. At the present time, only the sections on disability and discomfort and pain have been adapted for use in children. We are working on the modification of the other outcome dimensions. Disability is measured in the categories of dressing, arising, eating, walking, hygiene, grip, and activities. Discomfort is determined by the presence of pain and its severity.

### Administration of the Questionnaire:

The HAQ is either parent- or self-administered. We have shown that parents are reliable proxy-reporters for their child's functional status, and are now using only the parent-administered format. Parents are given the questionnaire and asked to complete it without additional instructions.

### DAILY FUNCTION (Disability Index) Pages 1 & 2

#### General Description:

This section is designed to assess the patient's functional ability over the past week. It is composed of eight categories, each of which has at least two component questions. Parents are also asked to indicate the use of any aids or devices or if the child needs help from another person for any of these activities.

#### Specifics:

The eight categories are: dressing & grooming, arising, eating, walking, hygiene, reach, grip, and activities. For each of these categories parents are asked to record the amount of difficulty their child may have. Parents are requested to note only those difficulties that are caused by arthritis. Do not define terms such as SOME, MUCH or USUAL for the parents. Let them use their own frame of reference. For example, if you are asked what "SOME" means, you can say "Whatever you think of as 'SOME'."

The time frame is OVER THE PAST WEEK. Some parents question whether we are interested in a particularly good or bad time which is out of this time frame. We are not. Parents sometimes are concerned that we are missing those times when their child's functional ability changes. By repeating the questionnaire at specific time periods we can look at the patterns of function. If we asked parents to complete this section only when their children were feeling particularly good or bad, then we would be getting a false picture.

We are interested in the patients' USUAL abilities using their usual equipment. The score is not increased if the patients have difficulties sometimes or occasionally require help.

Parents sometimes wonder how to answer the questions for various reasons.

1. If the child does not do things out of preference (shampooing hair, taking a tub bath), then they should leave them blank since we want to know what the child can do.

2. If they have adapted or modified things (clothing, faucets, cars), then they should answer the questions based on their child's usual equipment. If their child has no difficulty using the adapted equipment, then the parents would mark the "no difficulty" column.
3. If the patients can open their own car doors but not others, then the parents should respond considering their usual equipment and encounters.
4. Parents should make their own decisions concerning distance in answering the question about walking.
5. Parents should also make their own decisions as to whether their child is unable to perform a certain activity because of age (developmental immaturity) or because he/she is restricted by arthritis.

Scoring and Coding:

Possible responses for the component questions are:

Without ANY difficulty	= 0
With SOME difficulty	= 1
With MUCH difficulty	= 2
UNABLE to do	= 3

The highest score for any component question determines the score for that category. If a component question is left blank or the response is too ambiguous to assign a score, then the score for that category is determined by the remaining completed question(s). If all component questions are blank, then the category is left blank.

If the parent's mark is between the response columns, then move it to the closest one. If it's directly between the two, move it to the higher one.

If either devices and/or help from another person is checked for a category, the score = 2. This may determine the score unless the score on any other component question = 3. For example, the response to "Dress yourself..." is with SOME difficulty (score = 1). The parent has checked the use of a device for dressing, thereby increasing the score to 2. The response to "Shampoo your hair" is UNABLE to do (score = 3). Therefore, the score for the DRESSING category is 3.

Devices associated with each category:

DRESSING & GROOMING	- Devices used for dressing (button hook, zipper pull, long handled shoe horn, etc.)
ARISING	- Built up or special chair
EATING	- Built up or special utensils
WALKING	- Cane, walker, crutches
HYGIENE	- Raised toilet seat Bath tub seat Bath tub bar Long-handled appliances in bathroom
REACH	- Long-handled appliances for reach
GRIP	- Jar opener (for jars previously opened)

Devices written in the "Other" sections are considered only if they would be used for any of the stated categories.

Disability Index Calculation:

The index is calculated by adding the scores for each of the categories and dividing by the number of categories answered. This gives a score in the 0 to 3.0 range.

PAIN (Page 3)

General Description:

This question is designed to obtain information about the presence or absence of ARTHRITIS-related pain and its severity. The time frame is IN THE PAST WEEK.

Specifics:

Some parents say that their child's pain varies during the day and from day to day so it is hard to answer this question. Ask them to answer it thinking of how the pain has USUALLY been over the past week.

Scoring and Coding:

Pain is measured on a visual analog scale (a horizontal line where each end represents opposite ends of a continuum), 15 cm long, with "no pain" or 0 at one end and "very severe pain" or 100 at the other.

A score from 0 to 3.0 is determined based on the location of the respondent's mark. Some parents put more than one mark on the line. If that is the case, take the midpoint.

Using a metric rule, measure the distance from the left hand side of the line to the mark (0 to 15.0 cm) and multiply by .2 to obtain a value from 0 to 3.0. Round to the even number of cms if the mark falls between two points. For example, if the mark is between 4.2 and 4.3 cm, use 4.2. There is a pain severity coding sheet (which follows) for your use. It converts the number of cm into the appropriate score.

Some parents put a mark on the line and write a number (eg., 50%) with it as well. In that case, the score is determined by the number (eg., 50% means 1.5).

**\*\* PAIN \*\***  
**SEVERITY CODING**  
**(USING THE VISUAL ANALOG SCALE)**

MEASUREMENT (CM) = SCORE

0 = 0  
0.1 - 0.7 = 0.1  
0.8 - 1.2 = 0.2  
1.3 - 1.7 = 0.3  
1.8 - 2.2 = 0.4  
2.3 - 2.7 = 0.5  
2.8 - 3.2 = 0.6  
3.3 - 3.7 = 0.7  
3.8 - 4.2 = 0.8  
4.3 - 4.7 = 0.9  
4.8 - 5.2 = 1.0  
5.3 - 5.7 = 1.1  
5.8 - 6.2 = 1.2  
6.3 - 6.7 = 1.3  
6.8 - 7.2 = 1.4  
7.3 - 7.7 = 1.5

MEASUREMENT (CM) = SCORE

7.8 - 8.2 = 1.6  
8.3 - 8.7 = 1.7  
8.8 - 9.2 = 1.8  
9.3 - 9.7 = 1.9  
9.8 - 10.2 = 2.0  
10.3 - 10.7 = 2.1  
10.8 - 11.2 = 2.2  
11.3 - 11.7 = 2.3  
11.8 - 12.2 = 2.4  
12.3 - 12.7 = 2.5  
12.8 - 13.2 = 2.6  
13.3 - 13.7 = 2.7  
13.8 - 14.2 = 2.8  
14.3 - 14.7 = 2.9  
14.8 - 15.0 = 3.0

Further information and scoring rules will be furnished upon request.