

**THE HEALTH ASSESSMENT QUESTIONNAIRE (HAQ) DISABILITY INDEX (DI) OF THE
CLINICAL HEALTH ASSESSMENT QUESTIONNAIRE (VERSION 96.4):**

There are 8 sections: *dressing, arising, eating, walking, hygiene, reach, grip, and activities*. There are 2 or 3 questions for each section. Scoring within each section is from 0 (without any difficulty) to 3 (unable to do). For each section the score given to that section is the worst score within the section, i.e. if one question is scored 1 and another 2, then the score for the section is 2. In addition, if an aide or device is used or if help is required from another individual, then the minimum score for that section is 2. If the section score is already 2 or more then no modification is made.

The Aides and Devices are assigned to the specific HAQ sections as follows:

Dressing and Grooming: Devices used for dressing (button hook, zipper pull, shoe horn, etc.)

Arising: Special or built up chair

Eating: Built up or special utensils

Walking: Cane, Walker, Crutches, Wheelchair

Hygiene: Bathtub bar, Long-handled appliances in bathroom, Raised toilet seat

Reach: Long-handled appliances for reach

Grip: Jar opener for jars previously opened

The 8 scores of the 8 sections are summed and divided by 8. The result is the DI or FDI, the disability index or functional disability index. In the event that one section is not completed by a subject then the summed score would be divided by 7. For your convenience a calculator for the HAQ is provided on page 4. This will divide the sum score by 8 for you.

The other sections of the CLINHAQ are not provided here.

Journal References.

Wolfe F. A brief clinical health assessment instrument: CLINHAQ. *Arthritis Rheum.* 1989; 32 (suppl): S9

Wolfe F. Data collection and utilization: a methodology for clinical practice and clinical research. In: Wolfe F, Pincus T, Dekker M, eds. *Rheumatoid arthritis: pathogenesis, assessment, outcome and treatment*. New York: Marcel Dekker, 1994: 463-514.

**Note: The IMACS Clinical Trial/Study Outcomes Data Repository uses the scoring of the
HAQ Disability Index of the CLINHAQ.**

THE HEALTH ASSESSMENT QUESTIONNAIRE
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INTRODUCTION

The Health Assessment Questionnaire (HAQ) was originally developed in 1978 by James F. Fries, MD, and colleagues at Stanford University. It was one of the first self-report functional status (disability) measures and has become the dominant instrument in many disease areas, including arthritis. It is widely used throughout the world and has become a mandated outcome measure for clinical trials in rheumatoid arthritis and some other diseases.

The initial paper, published in 1980 (see key journal references at end of this document), has been the most cited article in the rheumatology literature. A 1995 review discusses more than 200 publications on the reliability, validity, and its applicability in multiple settings and languages. The present number of citations (see website-to be completed in September, 2000) is in excess of 400.

Purpose

The HAQ was developed as a comprehensive measure of outcome in patients with a wide variety of rheumatic diseases, including rheumatoid arthritis, osteoarthritis, juvenile rheumatoid arthritis, lupus, scleroderma, ankylosing spondylitis, fibromyalgia, and psoriatic arthritis. It has also been applied to patients with HIV/AIDS and in studies of normal aging. It should be considered a generic rather than a disease-specific instrument. Its focus is on self-reported patient-oriented outcome measures, rather than process measures.

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General Questionnaire Description

While the HAQ disability and pain scales are often referred to as “The HAQ”, long term outcome assessment best includes the Full Five-Dimension HAQ, which is a comprehensive outcome measure that assesses a hierarchy of patient outcomes in four domains: 1) disability, 2) discomfort and pain, 3) drug side effects (toxicity) and 4) dollar costs. Death, while obviously not a self-report outcome, is a requisite part of the conceptual model of patient outcome. In the United States, this is usually accomplished using the National Death Index. Alternatively, the first two domains, which comprise the HAQ Disability Index and Pain Scale can be used independently and frequently are. The drug toxicity sections and the economic impact sections undergo periodic changes; the disability, pain, and patient global areas have been maintained as constant since 1983.

The domain of disability is assessed by the eight categories of dressing, arising, eating, walking, hygiene, reach, grip, and common activities. Discomfort is determined by the presence of pain and its severity. Specific drug-associated side effects are classified according to their severity and whether the drug was stopped. Dollar costs are divided into direct and indirect costs. Direct costs include hospitalization, surgery, nursing home care, physician and health worker visits, medications, laboratory tests, x-rays, aids and devices, non-traditional treatments, assistance with personal care, housework and such, transportation and any additional cost related to medical care. Utilization of these services is determined and converted into dollar costs. Indirect costs are those associated with productive days lost for the employed, housewives, students and retired persons, and changes in lifestyle and activities for the patient and family. Items address normal daily activities, employment status, marital status, and living arrangements.

The time frames differ among the various sections in the full HAQ. Data on disability and discomfort and pain is based on the PAST WEEK; for medications, symptoms, side effects and costs, data is based on the PAST SIX MONTHS.

The Disability Index and Pain Scale

The HAQ Disability Index and Pain Scale have been widely used for research purposes in both experimental and observational studies, as well as in clinical settings. The additional domains included in the full HAQ (e.g., drug side effects [toxicity], dollar costs, plus other ancillary items such as demographics and health care utilization) have primarily been used for research purposes. These have over the years been tailored for specific hypotheses or research questions by ARAMIS (Arthritis, Rheumatism, and Aging Medical Information System).

The Disability Index is sensitive to change and is a good predictor of future disability costs. It has been shown to be reliable and valid in different languages and contexts. Test-retest correlations have ranged from 0.87 to 0.99. Correlations between interview and questionnaire format have ranged from 0.85 to 0.95. Validity has been demonstrated in literally hundreds of studies. There is consensus that the HAQ Disability Index possesses face and content validity. Correlations between questionnaire or interview scores and task performance have ranged from 0.71 to 0.95 demonstrating criterion validity. The construct/convergent validity, predictive validity and sensitivity to change have also been established in numerous observational studies and clinical trials. The HAQ Disability Index has also demonstrated a high level of convergent validity based on the pattern of correlations with other clinical and laboratory measures.

Questionnaire Administration

The HAQ is usually self-administered, but can also be given face-to-face in a clinical setting or in a telephone interview format by trained outcome assessors, and has been validated in these settings. The questionnaire is typically mailed to patients every six months, and they are asked to complete it without additional instructions. Follow-up phone calls are sometimes needed to obtain missing data or to clarify ambiguous responses in the high-quality research data applications. The HAQ Disability Index and Pain Scale can be completed in approximately five minutes. The full HAQ takes 20 to 30 minutes to complete.

The Disability Index

The eight categories assessed by the Disability Index are 1) dressing and grooming, 2) arising, 3) eating, 4) walking, 5) hygiene, 6) reach, 7) grip, and 8) common daily activities. For each of these categories, patients report the amount of difficulty they have in performing two or three specific activities. Patients usually find the HAQ Disability Index entirely self-explanatory, and clarifications are seldom required.

Ratings such as SOME, MUCH, or USUAL are deliberately not defined for the patients; patients are instructed to respond idiomatically, using their own frame of reference. For example, if a patient asks what “SOME” means, an appropriate response would be “Whatever you think ‘SOME’ means to you”.

The time frame for the disability questions is the PAST WEEK. The Disability Index is designed to assess patients’ USUAL abilities using their usual equipment. Some patients have questioned whether their response should reflect a particularly good or bad time, which is out of the time frame requested, because they feel that their response may be missing those times when their functional ability changes. However, by repeating the HAQ at specific and regular time intervals, patterns of function can be examined. Inquiring about these activities only when patients are feeling particularly good or bad would result in inaccurate and biased data. The score is not modified if they have difficulties sometimes or required help only occasionally. Some of the following discussion is taken from materials used by ARAMIS outcome assessors.

Addressing some scenarios which occasionally arise:

- If an item does not apply to an individual, e.g., they don’t shampoo their hair, take tub baths, or reach for a heavy object above their heads, then they should leave the item(s) blank since the purpose is to obtain data about what they can do.

- If a patient uses adapted or modified aids or devices (e.g., clothing, faucets, cars), then they should answer the questions based on their usual equipment. If they have no difficulty using the adapted equipment, then they would mark the “no difficulty” column. The adapted equipment (aids and devices) will be taken into account in the assistance variables (see below).
- If an individual can open their own door but not for others, then they should respond in consideration of their own requirements.
- Relative to inquiries about distances in responding to the item about walking, patients should be advised to make their own decisions.

Scoring Conventions for the Disability Index

There are four possible responses for the Disability Index questions:

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

- The highest score reported by the patient for any component question of the eight categories 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 or if more than one answer is given, then follow up with the respondent is required.
- If the respondent’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.

Each of the disability items on the HAQ has a companion aids/devices variable that is used to record what type(s) of assistance, if any, the participant uses for his/her usual activities. These variables (see below) are coded as follows:

- 0 = No assistance is needed.
- 1 = A special device is used by the patient in his/her usual activities.
- 2 = The patient usually needs help from another person.
- 3 = The patient usually needs BOTH a special device AND help from another person.

Devices that are associated with each category:

Note that this assignment of devices to particular disability categories assumes that the devices are used only for the purpose for which they are designed. For example, if an individual indicates that he/she uses a cane, it is presumed that they use the cane as an aid in walking. However, it is possible for that patient to use that cane as an aid in performing other activities. For example, the patient may check off the cane listed at the bottom of the page 1 (or write “cane” under the “other” slot) and then write a little note in the margin stating that the cane is also used on a regular basis as an aid in helping them rise out of a chair and to rise off of the toilet. In such a case, the variables should be coded as “1” to reflect the patient’s use of a cane in these three areas of daily functioning. If unsure whether the patient is using one of the devices specified above for the purpose for which it is designed, call the patient to inquire about specific uses.

Devices written in the “Other” sections or notes written next to any component questions are considered if they would be used for any stated categories. Permanent adaptations of the person’s environment (e.g., changing faucets in the bedroom or kitchen, using Velcro closures on clothing) should also be counted as aids and devices.

Computed Variables:

The scoring variables and scoring rules permit the computation of two disability indices, the Standard Disability Index and the Alternative Disability Index. For either of these, a disability index cannot be computed if the patient does not have scores for at least six (6) categories.

1) The Standard Disability Index. “What is the Disability level of this Person?”

This question results in a new set of category scores that are computed by adjusting the score for each category, if necessary, based on the patient’s use of an aid or device or assistance for that category. If either devices and/or help from another person are checked for a category, the score is set to “2”, unless the score is already “3” (i.e., scores of “0” or “1” are increased to “2”). For example, if the highest score for the dressing category is “1”, and the patient says they use a device for dressing, the computed category score would be “2”. The sum of the computed categories scores is then calculated and divided by the number of categories answered. This gives a score in the 0 to 3 range.

2) The Alternative Disability Index. “What is the Disability level of this patient when using aids and devices to compensate for disability?”

The aid and device variables are not used to calculate the alternative disability index; it 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 range.

The Pain Scale

The pain scale is designed to obtain data relative to the presence or absence of arthritis-related pain and its severity. The reference time frame is THE PAST WEEK. The objective is to obtain information from patients on how their pain has USUALLY been over the past week, even though pain may be reported to vary over the course of a day or from day to day.

Scoring Conventions for the Pain Scale

Pain is measured on a doubly –anchored visual analog scale (a horizontal line where each end represents opposite ends of a continuum) that is standardized to 15 centimeters in length is convenient for the page and for the patient. It is labeled with “no pain” (with a score of 0) at one end and “very severe pain” (with a score of 100) at the other. Patients are instructed to place a vertical mark on the line to indicate the severity of their pain. A score from 0 to 3 is obtained based on the location of the respondent’s mark. In some applications, the 0-100 scale is used, which is perfectly permissible.

To obtain the individual’s score, with a metric ruler, measure the distance from the left side (at base zero) of the line up to the mark and multiply by 0.2. This converts the number of centimeters into the appropriate score and will yield a value from 0 to 3.

Some Potential Scenarios:

- If the patient writes in a number on the pain scale, or writes a number in addition to making a mark, you need only take the number, converting it to the corresponding score. In this case, do not measure the mark. For example, if the patient writes “50” on the line, this should be coded as 1.5.
- If an individual records a percentage, multiply the percentage by 3. Pain severity coding translations follow below: If a patient puts more than one mark, the midpoint is used.

- If a patient makes a horizontal line below the pain scale, instead of vertical one, the midpoint of that line is taken. If the line starts at the beginning of the scale, measure to the end of the line not the middle.

PAIN SEVERITY CODING TRANSLATIONS

<u>Measurement (Cm) = Score</u>	<u>Measurement (Cm) = Score</u>
0 = 0	7.8 – 8.2 = 1.6
0.1 – 0.7 = 0.1	8.3 – 8.7 = 1.7
0.8 – 1.2 = 0.2	8.8 – 9.2 = 1.8
1.3 – 1.7 = 0.3	9.3 – 9.7 = 1.9
1.8 – 2.2 = 0.4	9.8 – 10.2 = 2.0
2.3 – 2.7 = 0.5	10.3 – 10.7 = 2.1
2.8 – 3.2 = 0.6	10.8 – 11.2 = 2.2
3.3 – 3.7 = 0.7	11.3 – 11.7 = 2.3
3.8 – 4.2 = 0.8	11.8 – 12.2 = 2.4
4.3 – 4.7 = 0.9	12.3 – 12.7 = 2.5
4.8 – 5.2 = 1.0	12.8 – 13.2 = 2.6
5.3 – 5.7 = 1.1	13.3 – 13.7 = 2.7
5.8 – 6.2 = 1.2	13.8 – 14.2 = 2.8
6.3 – 6.7 = 1.3	14.3 – 14.7 = 2.9
6.8 – 7.2 = 1.4	14.8 – 15.0 = 3.0

Drug Side Effects [Toxicity]

A prevalence of symptom frequency is obtained by inquiring about symptoms, conditions, and side effects that have occurred in the past six months. Data on side effects associated with specific drugs includes severity of side effects, whether or not the drug was stopped, and importance of the side effects to the patient. These items about patient-attributed drug side effects provide the six-month incidence figures.

Scoring and Coding: For additional information, please contact us.

Dollar Cost and Other Items – For additional information, please contact us.

KEY JOURNAL REFERENCES

Ramey Dr, Fries JF, Singh G. in B. Spilker *Quality of Life and Pharmacoeconomics in Clinical Trials*, 2nd ed, The Health Assessment Questionnaire 1995 -- Status and Review. Philadelphia: Lippincott-Raven Pub., 1996, p 227 – 237.

Fries JF, Spitz P, Kraines G, Holman H. Measurement of Patient Outcome in Arthritis, Arthritis and Rheumatism, 1980, 23:137-145.