
Electronic multidimensional health assessment questionnaire (eMDHAQ): past, present and future of a proposed single data management system for clinical care, research, quality improvement, and monitoring of long-term outcomes

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ABSTRACT

An MDHAQ/RAPID3 (multidimensional health assessment questionnaire/routine assessment of patient index data) was developed from the HAQ over 25 years, based on observations made from completion by every patient (with all diagnoses) at every routine rheumatology visit since 1980. Modification of the HAQ was viewed as similar to improving a laboratory test, with a primary focus on clinical value for diagnosis, prognosis, and/or management, as well as feasibility for minimal effect on clinical workflow. Rigorous attention, was also directed to validity, reliability, other methodologic and technological considerations, but after clinical value and feasibility were established. A longer “intake” MDHAQ was introduced for new patients to record a complete past medical history - illnesses, hospitalisations, surgeries, allergies, family history, social history and medications. MDHAQ scales not found on the HAQ record complex activities, sleep quality, anxiety, depression, self-report joint count, fatigue, symptom checklist, morning stiffness, exercise status, recent medical history, social history and demographic data within 2 pages on one sheet of paper. An electronic eMDHAQ/RAPID3 provides a similar platform to pool data from multiple sites. A patient may be offered a patient-administered, password-protected, secure, web site, to store the medical history completed on the eMDHAQ. This eMDHAQ would allow a patient to complete a single general medical history questionnaire rather than different intake questionnaires in different medical settings. The eMDHAQ would be available for updates and correction by the patient for future visits, regardless of electronic medical record (EMR). The eMDHAQ is

designed to interface with an EMR using HL7 (health level seven) and SMART (Substitutable Medical Apps, Reusable Technology) on FHIR (Fast Healthcare Interoperability Resources), although implementation requires collaboration with the EMR vendor. Advanced features include reports for the physician formatted as a medical record note of past medical history for entry into any EMR without typing or dictation, and a periodic “tickler” function to monitor long-term outcomes with minimal effort of the physician and staff. Nonetheless, clinical use of an eMDHAQ should be guided primarily not by the latest technology, but by value and feasibility in clinical care, the same principles that guided development of the pencil-and-paper MDHAQ/RAPID3.

Introduction

A major milestone in rheumatology was publication in 1980 of two patient self-report questionnaires, the health assessment questionnaire (HAQ) (1) and arthritis impact measurement scales (AIMS) (2), sequentially in the same issue of *Arthritis and Rheumatism* (now *Arthritis and Rheumatology*). In the same year, 1980, the author assumed a new academic position with considerably greater clinical responsibilities than any previous position. An interest in clinical measurement had been kindled a decade earlier in development of a radioimmunoassay for DNA antibodies in systemic lupus erythematosus (SLE) for routine laboratories (3), which had been performed only in research settings at the time. Further serological research (4-6) resulted in a position as director of a clinical immunology laboratory. The HAQ and AIMS appeared of possible value to improve routine clinical

care and outcomes, analogous to laboratory tests. The clinic receptionist was instructed to ask each patient to complete a HAQ or AIMS in the waiting area before seeing the rheumatologist. The receptionist was oriented to explain to patients that the questionnaire was to help the doctor provide the best care possible, not for “research” or to serve as an “intake” questionnaire to record a medical history, the primary previous experiences of patients, doctors, and staff with patient questionnaires.

The HAQ was found more user-friendly. The only feasible method to avoid complicating workflow was for every patient, regardless of diagnosis, to complete a HAQ at every visit, rather than any effort to select certain patients to complete different questionnaires (or no HAQ) according to diagnosis or any criterion. Fortunately, the HAQ was informative in most patients with all diagnoses.

The explanation that the purpose of the questionnaire was to help the doctor provide the best care has been readily accepted by more than 20 receptionists over the years, who then explained this purpose to patients, almost all of whom completed the questionnaire. The doctor reviewed the questionnaire carefully, which requires only about 15 seconds, but provides considerable information concerning patient physical function, pain, and patient global estimate in far less time than a clinical interview. Patient questionnaire scores are quantitative, standard measures, similar to laboratory tests, extending components of a patient history from “subjective” (7) narrative descriptions to meet criteria for “scientific” data (8).

Availability of HAQ or AIMS data to the physician in the examination room facilitates doctor-patient communication to be directed to matters of greatest interest to the patient and/or the doctor. In general, if the staff and patients recognise that anything is important to the doctor, it is not difficult to implement, including a patient questionnaire. By contrast, if a patient is told that a questionnaire in routine care is collected for “research,” documentation, or any purpose other than to improve clinical care, most patients and staff members lose interest.

It should be emphasised that patient

questionnaire data are not regarded as a substitute for conversation between the doctor and the patient. On the contrary, questionnaire responses have always been regarded as a providing guidance to add considerable value to the conversation. For example, a pain score on a 0–10 visual analogue scale (VAS) of “1” *versus* “8” suggests different queries about pain intensity and character (9). Although the doctor knows considerably more about pathophysiology and treatment than the patient, the patient has more accurate knowledge concerning patient-experienced problems. Furthermore, of course, patient data require interpretation by the doctor, as with laboratory tests, as discussed below (10, 11).

Quantitative measures have been central to advances in diagnosis, prognosis, assessment of status, management, and description of outcomes of many chronic diseases over the last century, primarily from the laboratory and other high-technology sources (12). RA differs from many chronic diseases in that medical history information is regarded as far more prominent in diagnosis and management decisions in RA than laboratory tests or ancillary studies, according to a survey of 313 physicians (154 rheumatologists and 159 non-rheumatologists) (13). By contrast, clinical decisions in 7 other prevalent chronic diseases are dominated by other components of a clinical encounter, *e.g.* vital signs in hypertension, laboratory tests in diabetes, or ancillary studies in ulcerative colitis (13). RA was the only one of the 8 diseases in which a patient history accounted for more than 50% of clinical decisions in diagnosis and management (13).

Inclusion of patient questionnaires in routine care was given great impetus by an observation in 1982 that premature mortality rates in RA (14), with a natural history similar to hypertension and diabetes (15), were predicted significantly by functional disability on a patient questionnaire (14). Further, formal prospective studies indicated that patient questionnaire data were far more significant than any laboratory or imaging test in the prognosis of RA mortality (16), confirmed in many set-

tings over the years (17). Recognition of the significance of physical function in the prognosis of severe RA outcomes of premature mortality (14, 17, 18) and work disability (14, 19) suggested that a patient questionnaire was not only a clinical tool for a better encounter, but also provided a target to improve prognosis, analogous to blood pressure in hypertension or serum haemoglobin A1C in diabetes (20). Completion of a HAQ by patients in the waiting area in routine care appeared as important as laboratory tests (21–23).

Modifications to improve the clinical value of the HAQ for patients and doctors were introduced on the basis of observations from regular completion in routine care by patients in the waiting area over 25 years, between 1980 and 2005, to develop a multidimensional HAQ (MDHAQ) (21) (Fig. 1). The strategy for modification reflected the author’s background in laboratory science, with a primary focus on clinical utility for diagnosis, prognosis, and/or management (4), analogous to development of laboratory tests (3), in which minor changes in, say, the pH or ionic strength of a buffer were not unusual without formal reports (5, 24). Modification of the HAQ to an MDHAQ is viewed in retrospect as an effort to implement continuous quality improvement (CQI) into routine clinical care, rather than a research agenda (21, 25, 26), introducing changes according to principles of a CQI “plan-do-study-act” strategy (21, 25–28) (Fig. 2).

This article updates previous reviews concerning the MDHAQ: the past - development of the MDHAQ from the HAQ in 1980–2005 (12, 29–32); the present - results supporting a rationale for the MDHAQ/RAPID3 (routine assessment of patient index data) at every visit in routine clinical care (22, 26, 33–37), and the future - available and projected features of an electronic MDHAQ/RAPID3 (eMDHAQ/RAPID3).

The Past: Development of MDHAQ with a focus on clinical value and feasibility within clinic workflow unlike usual patient questionnaire development

Development of the MDHAQ (21) in routine care with changes to improve

its value differed in many ways from development of most reported questionnaires in the rheumatology, general medical, and psychology literature (Table I). This information is presented in part to emphasise a guiding focus on clinical value and feasibility, as summarised below:

1. The primary goal of modifying the HAQ was to improve the encounter in routine care and outcomes, rather than to develop and report a new questionnaire for clinical research or clinical trials as seen for rheumatoid arthritis (RA) (38), osteoarthritis (39), psoriatic arthritis (40-44), systemic lupus erythematosus (SLE) (45-54), ankylosing spondylitis (55-61), vasculitis (62, 63), fibromyalgia (64), and others. Nonetheless, versions of the MDHAQ have been used in clinical trials (65, 66), and MDHAQ components of physical function, pain and patient global estimate were analysed in clinical trial data in order to validate a RAPID3 index to distinguish active from control treatments (67-72).

2. As noted, development of the MDHAQ is recognised as an effort to implement CQI into routine care, rather than a research agenda (21, 25, 26). The primary consideration was clinical value of information provided by the patient to the doctor that would affect clinical management and save time for both doctor and patient in shared decisions, analogous to laboratory tests. Nonetheless, many research observations have emerged from use of the MDHAQ, as availability of quantitative data in a long-term database facilitates many research studies and reports (8, 26, 36, 37, 73).

3. The CQI approach (27, 28), with attention to clinical value of content, feasibility and acceptability to patients and health professionals in addition to validity and reliability (38-43), by definition resulted in many changes over a 25 year period (from 1980-2005) according to a “plan-do-study-act” strategy (21, 25-28) (Fig. 2), which continues at this time. By contrast, the HAQ has remained unchanged over 36 years, although various modifications have been published (29-31, 74, 75).

Table I. Development of multi-dimensional health assessment questionnaire (MDHAQ):

	Differences from development of most rheumatology questionnaires.
1	Development in routine care rather than in research setting, to facilitate doctor-patient communication and save time for both doctor and patient.
2	Implement continuous quality improvement (CQI) using “plan-do-study-act” strategy (21, 25, 26) rather than research design, although data may be of great value for research.
3	Many changes over 25-years from 1980-2005 (21, 25-28), based on clinical value to assess and manage patient care, rather than only on validity and reliability (38-43).
4	Rigorous analyses to document psychometric validity and reliability <u>after</u> recognition of clinical value and feasibility by doctor and acceptability by patient for routine care (30, 31).
5	Scores for physical function, pain, and patient global estimate viewed as analogous to laboratory tests - “vital signs” for care of people with chronic diseases (78-80), depicted in a flow sheet which also includes laboratory tests and medical data.
6	Requirement for feasibility and minimal interference with clinic workflow by having patient complete MDHAQ in waiting area, rather than in examination room or after visit, with minimal staff support needed for most patients (23), as self-report is most reliable (1).
7	Analyse, rather than dismiss, data that are discordant between patient and physician, as possible clues to diagnosis and management, <i>e.g.</i> distinguish fibromyalgia from RA (92, 96, 97).
8	Maintain MDHAQ on 2-sides of one piece of paper – addition of new measures for possible incremental clinical value, <i>e.g.</i> self-report joint count (90), fatigue (91), required deletion of valid and reliable measures of patient satisfaction (29), helplessness (94, 95).
9	Develop 4-page version in new patient intake questionnaire for past history - illnesses, surgeries, allergies, family history, social history, medications, etc. in standard format (26, 98).
10	Patient-friendly report to the patient, for review and so she/he may amend, correct, and update new information concerning medical history at encounter or for future encounters (99). (Note: <u>A medical record is a legal document that cannot be altered; however, a medical history database can be amended by the patient for the next and future visits.</u>)
11	Entry of patient medical history information into database to improve documentation, with minimal effort on the part of the physician (77).
12	Report to physician of patient self-reported past-history in a medical record format, available for possible entry into a medical record as entered data rather than narrative transcription (99).

4. All changes that were introduced and maintained on the basis of providing clinical information that contributed to better clinical decisions ultimately were analysed rigorously for psychometric validity and reliability (30, 31, 76, 77), although this testing generally occurred after use in routine care, unlike usual development of questionnaires.

5. Scores for physical function, pain and global status were viewed as “vital signs” for management of chronic rheumatic diseases (78-80). Scores were recorded in flow sheets (Fig. 4) which also include laboratory tests and medical data. Physical function scores are highly significant in the prognosis of mortality (14, 17, 18, 81-84) and work disability (14, 19, 85-88). Collection of physical function scores is regarded as analogous to collecting blood pressure or serum cholesterol in cardiovascular disease (15, 18, 89).

6. The second major consideration was feasibility, with minimal interference

with clinic workflow, by having each patient complete the same questionnaire in the waiting area, with minimal staff support for most patients. Requests for help may be answered with the instruction on the questionnaire, “there are no right or wrong answers, please answer exactly as you think or feel,” (31). The MDHAQ should be available to the rheumatologist in the examination room, rather than completed by the patient in the examination room or after the visit, when the patient is anxious to leave, and the questionnaire would have no impact on care (23).

7. Attention to feasibility included maintenance of the questionnaire on two-sides of one piece of paper, so that when a new feature was added, such as a rheumatoid arthritis self-report joint count (RADAI) (90), fatigue visual analogue scale (VAS) (91) or symptom checklist (92, 93), some scales were deleted, such as queries about pain and satisfaction in daily activities (29) and an Arthritis Helplessness Scale of 15 items

Multi-Dimensional Health Assessment Questionnaire (MDHAQ™) (R926-NP4R)

This questionnaire includes information not available from blood tests, X-rays, or any source other than you. Please try to answer each question, even if you do not think it is related to you at this time. Try to complete as much as you can yourself, but if you need help, please ask. There are no right or wrong answers. Please answer exactly as you think or feel. Thank you.

1. Please check (✓) the ONE best answer for your abilities at this time:

OVER THE PAST WEEK, were you able to: a. Dress yourself, including tying shoelaces and doing buttons? b. Get in and out of bed? c. Lift a full cup or glass to your mouth? d. Walk outdoors on flat ground? e. Wash and dry your entire body? f. Bend down to pick up clothing from the floor? g. Turn regular faucets on and off? h. Get in and out of a car, bus, train, or airplane? i. Walk two miles or three kilometers, if you wish? j. Participate in recreational activities and sports as you wish? k. Get a good night's sleep? l. Deal with feelings of anxiety or being nervous? m. Deal with feelings of depression or feeling blue?

FOR OFFICE USE ONLY: 1-61 FR (0-10):

2-PM (0-10):

4-PTGL (0-10):

3-PM (0-10):

4-PTGL (0-10):

RAPID™ (0-20):

Cat:

HS > 12

MS = 6.1-12

LS = 3.1-6

R = <

2. How much pain have you had because of your condition OVER THE PAST WEEK? Please indicate below how severe your pain has been:

NO PAIN AS BAD AS PAIN 0 0.5 1.0 1.5 2.0 2.5 3.0 3.5 4.0 4.5 5.0 5.5 6.0 6.5 7.0 7.5 8.0 8.5 9.0 9.5 10 IT COULD BE

3. Please place a check (✓) in the appropriate spot to indicate the amount of pain you are having today in each of the joint areas listed below:

No. Mild Moderate Severe a. LEFT FINGERS b. LEFT WRIST c. LEFT ELBOW d. LEFT SHOULDER e. LEFT HIP f. LEFT KNEE g. LEFT ANKLE h. LEFT TOES a. NECK i. RIGHT FINGERS j. RIGHT WRIST k. RIGHT ELBOW l. RIGHT SHOULDER m. RIGHT HIP n. RIGHT KNEE o. RIGHT ANKLE p. RIGHT TOES r. BACK

4. Considering all the ways in which illness and health conditions may affect you at this time, please indicate below how you are doing:

VERY WELL 0 0.5 1.0 1.5 2.0 2.5 3.0 3.5 4.0 4.5 5.0 5.5 6.0 6.5 7.0 7.5 8.0 8.5 9.0 9.5 10 POORLY

13. Please check (✓) either "No" or "Yes" to indicate whether or not you have any of the conditions below: Have you ever had: AGE or YEARS

High Blood Pressure or Hypertension No Yes or Gynecological (Female)/Prostate (Male) problem No Yes or Severe allergies No Yes or Rheumatoid arthritis No Yes or Osteoarthritis No Yes or Lupus No Yes or Back or spine problems No Yes or Fibromyalgia (Fibrositis) No Yes or Osteoporosis No Yes or Broken bones after age 50 No Yes or Dry mouth No Yes or Dry eyes No Yes or Cataracts No Yes or Parkinson's disease No Yes or Depression No Yes or Mental illness No Yes or Alcoholism No Yes or Other (Please name) or Other (Please name) or

14. Please list below all operations you have ever had. Please check (✓) here if none:

Operation Year Surgeon Hospital, City, State 1. 2. 3. 4.

15. Please list below all major illnesses or hospital admissions (other than for operations). Please check (✓) here if none:

Illness or Reason for hospitalization Year Hospital, City, State 1. 2. 3. 4.

16. The questions below concern your family medical history:

Birth Year or Age Any Major Medical Conditions Year or Age at death Cause(s) of death Father Mother Brother(s) Sister(s) Son(s) Daughter(s)

17. Any blood relative (parent, child, brother, sister, aunt, uncle) with: If "Yes", give relationship.

Rheumatoid Arthritis No Yes Relation(s) Lupus or SLE No Yes Relation(s)

18. Any illnesses which run in the family?

1. 2. 3. 4.

5. Please check (✓) if you have experienced any of the following since the last month:

Fever Lump in your throat Paralysis of arms or legs Weight gain (>10 lbs) Cough Numbness or tingling of arms or legs Weight loss (>10 lbs) Shortness of breath Fainting spells Feeling sick Wheezing Swelling of hands Headaches Pain in the chest Swelling of ankles Unusual fatigue Heart pounding (palpitations) Swelling in other joints Swollen glands Trouble swallowing Joint pain Loss of appetite Heartburn or stomach gas Back pain Skin rash or hives Stomach pain or cramps Neck pain Unusual bruising or bleeding Nausea Use of drugs not sold in stores Other skin problems Vomiting Smoking cigarettes Loss of hair Constipation More than 2 alcoholic drinks per day Dry eyes Diarrhea Depression - feeling blue Other eye problems Dark or bloody stools Anxiety - feeling nervous Problems with hearing Problems with urination Problems with thinking Ringing in the ears Gynecological (female) problems Problems with memory Stuffy nose Dizziness Problems with sleeping Sores in the mouth Losing your balance Sexual problems Dry mouth Muscle pain, aches, or cramps Burning in sex organs Problems with small or taste Muscle weakness Problems with social activities

FOR OFFICE USE ONLY: S. RDC:

Please check (✓) here if you have had none of the above over the last month:

6. When you awakened in the morning OVER THE LAST WEEK, did you feel stiff? No Yes

If "No," please go to Item 7. If "Yes," please indicate the number of minutes or hours until you are as limber as you will be for the day.

7. How do you feel TODAY compared to ONE WEEK AGO? Please check (✓) only one.

Much Better (1), Better (2), the Same (3), Worse (4), Much Worse (5) than one week ago

8. How often do you exercise aerobically (sweating, increased heart rate, shortness of breath) for at least one-half hour (30 minutes)? Please check (✓) only one.

3 or more times a week (1) 1-2 times per month (1) Cannot exercise due to disability/ handicap (9) 1-2 times per week (2) Do not exercise regularly (0)

9. How much of a problem has UNUSUAL fatigue or tiredness been for you OVER THE PAST WEEK? FATIGUE IS NO PROBLEM 0 0.5 1.0 1.5 2.0 2.5 3.0 3.5 4.0 4.5 5.0 5.5 6.0 6.5 7.0 7.5 8.0 8.5 9.0 9.5 10 FATIGUE IS A MAJOR PROBLEM

10. Over the last 6 months have you had: [Please check (✓)]

Di No Yes Change(s) of arthritis or other medication Di No Yes Change(s) of address Di No Yes Change(s) of marital status Di No Yes Change job or work duties, quit work, retired Di No Yes Side effect(s) of any medication or drug Di No Yes Change of medical insurance, Medicare, etc. Di No Yes Smoke cigarettes regularly Di No Yes Change of primary care or other doctor

Please explain any "Yes" answer below, or indicate any other health matter that affects you:

11. Please list below any medications which you cannot take because you are allergic to them:

12. Please list below anything else (grass, molds, pollens, etc.) you might be allergic to:

19. Please write below all pills that you took over the last TWO WEEKS, with or without a prescription. Include aspirin, birth control pills, pain pills, alternative therapy, health supplements, pills sold in health food stores:

NAME OF DRUG, MEDICINE DOSE How Many per day or week? OR ALTERNATIVE THERAPY (if known) NAME OF DRUG, MEDICINE DOSE How Many per day or week? 1. 2. 3. 4. 5. 6.

20. What is your current occupation? (If you are not working now, what was your past occupation?)

Working full time Retired Working part time Student Homemaker-full time Disabled Seeking work Other (describe)

21. At this time, are you? (Please check (✓) all that apply.)

Working full time Retired Working part time Student Homemaker-full time Disabled Seeking work Other (describe)

22. How many other people live at home with you? (Please check (✓) who lives with you.)

Spouse/partner Parents Sons or daughters I live alone Others (describe)

23. How many years of school have you completed? Please circle the number of years of school:

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

24. Your weight: lbs, height: in, waist: in.

Your Name Today's Date Time of Day AM/PM Street Address City State ZIP Telephone Social Security # Date of Birth

SEX: Female ETHNIC: Asian Hispanic Other MARITAL STATUS: Single Married Divorced Male GROUP: Black White Widowed Separated

Please check if this questionnaire is completed entirely by patient OR with help from (name)

WE ASK YOU FOR CONSENT TO REVIEW YOUR RECORDS FOR MEDICAL RESEARCH AND TO CONTACT YOU IN THE FUTURE. YOUR CARE WILL NOT BE AFFECTED IF YOU ANSWER "NO."

I agree to allow information from my medical record to be reviewed for medical research by selected colleagues of my doctor, and for you to send me similar questionnaires in the future, which I am not required to answer. I understand that this information will remain confidential with my doctor and his or her research associates only. Please check (✓) in one box. Thank you!

I understand and agree that my doctor may share this information with colleagues at other medical research centers, in order to learn more about best treatments for my condition. Please check (✓) in one box. Thank you!

Please list the name, address, and telephone number of your primary care physician:

Name Address City, State ZIP Telephone

Please list the name of your rheumatologist and insurance center:

Rheumatologist Insurance

Please list the name, address, and telephone number of someone who lives at a different address from you, and who will be likely to know your whereabouts if we are unable to reach you:

Name Address City, State ZIP Telephone Relationship

Fig. 3. 4-page new patient MDHAQ/RAPID3 intake questionnaire for past history - illnesses, surgeries, allergies, family history, social history, medications, etc. in standard format (26, 98)

pages 3 and 4 of the MDHAQ in a medical record format for entry into a medical record (99) (Fig. 6), which saves 10–15 minutes for each new patient (26, 99). Information concerning mechanisms for pain, fatigue, and other problems experienced by patients is not provided the MDHAQ, but by more detailed and lengthy research questionnaires, which are not feasible in routine clinical care. Nonetheless, despite many published reports of excellent questionnaires in rheumatology noted above (1, 2, 29, 38–64), the only quantitative data in the medical records of most rheumatology patients often are laboratory tests (103). Therefore, possible benefits of major advances in quantitative clinical measurement of rheumatic diseases to guide physicians' decisions are available for only a minority of patients seen in regular care. Availability of 80% of the data in 100% of patients appears preferable to 100% of the data in 5% or less of patients (104), particularly with a database reporting flow-sheets to monitor patient status over long periods.

The MDHAQ compared to the HAQ

As noted above, modification of the HAQ (1) to the MDHAQ (30, 31) is now recognised as a continuous quality improvement (CQI) program in routine care, rather than a research program (21, 25, 26). Both the HAQ and MDHAQ are simple 2-page questionnaires on one sheet of paper which score physical function, pain and patient global estimate, the 3 patient self-report measures among the 7 measures in the RA core data set (105), as quantitative data rather than as narrative descriptions. Both questionnaires (Table II) are completed by a patient in 5–10 minutes, and both have templates for quantitative scores. The HAQ includes 20 activities, in 8 categories of 2 or 3 activities each, for a total of 20 activities. The MDHAQ initially included 8 activities, 1 from each of the 8 HAQ categories, which was found to provide similar information to the HAQ, but allow space for additional scales (29). In the 1990s, it was noted that many patients had scores of “zero” on the HAQ and modified HAQ (MHAQ) (29), suggesting “normal” physical function, despite reporting on-

going limitations to perform more difficult physical activities (floor effects) (31). Therefore additional complex activities were added as an MDHAQ (31), ultimately 2 activities, “walk 2 miles or 3 kilometers” and “participate in sports and recreation as you would like,” for a total of 10, which facilitated scoring and provided values similar to the HAQ (30, 31, 106). The VAS for pain and patient global estimate on the MDHAQ are in a 21-circle format, rather than a 10-cm line as on the HAQ (107) (Fig. 1), which facilitates completion by patients and scoring by doctors and staff.

RAPID3 is an index of only the 3 RA Core Data Set patient self-report measures of physical function, pain and patient global estimate (69, 108). RAPID3 is calculated easily on the pencil and paper MDHAQ, using a scoring template for physical function (FN) to convert the sum of ten 0–3 scores (range 0–30) to a 0–10 physical function score through division by 3, and small boxes to record the FN score, and VAS scores for pain (PN) and patient global estimate of status (PATGL) (each scored 0–10). The sum of these three variables is the composite RAPID3 score (0–30). RAPID3 on an MDHAQ requires about 5 seconds to score, compared to 42 seconds for the HAQ, and almost 2 minutes for a DAS28 or CDAI (109).

Four categories of RAPID3 scores – for high, moderate, low disease severity, and remission in RA – are correlated significantly with similar categories according to DAS28 and CDAI (70, 108, 109). Thus RAPID3 can be useful in implementing a treat-to-target strategy in usual clinical care (22, 37), analogous to DAS28 (110) or CDAI (111) while offering a number of pragmatic advantages over the other indices (37, 68), primarily that all measures are provided by the patient.

The MDHAQ includes 3 psychological items concerning sleep quality, anxiety and depression in the patient-friendly HAQ format (Table II, Fig. 1); the depression query is correlated significantly with the Beck Depression inventory (31), and provides a useful screening query. Also included is a rheumatoid arthritis disease activity index (RA-DAI) self-report joint count (52), which

is correlated significantly with tender joint count ($r=0.55$) and swollen joint count ($r=0.42$), in the same range as ESR with CRP ($r=0.50$) (109).

The MDHAQ includes a 60 symptom checklist (Table II), introduced initially to serve as a review of systems, which provides a useful screen for non-inflammatory problems of distress, such as fibromyalgia or depression, in patients who check more than 16–20 of 60 symptoms. This finding may be particularly helpful in patients who may also meet formal criteria for RA, systemic lupus erythematosus (SLE) osteoarthritis (OA) or other rheumatic disease, and have secondary fibromyalgia (92, 97), which may affect negatively responses to therapy.

The MDHAQ includes a 0–10 VAS for fatigue, regarded by many patients as a prominent problem affecting RA (112), SLE and other rheumatic diseases. A query concerning the frequency of exercise also is included; limited exercise is as significant as smoking in the prognosis of 5-year mortality in normal older individuals (113).

The patient also records responses to 12 queries concerning recent medical history (Table II) – surgeries, illnesses, hospitalisation, new medications, adverse effects of medications, etc. At most visits, responses to these queries are all “no”; availability of self-report information from the patient can save a physician 2–3 minutes. If a response is “yes,” that information should be known at the visit. Finally, demographic data, including date of birth, gender, ethnic group, marital status, occupation, and formal education level are queried, so a database can be developed directly from the questionnaire.

As noted above, a 4-page MDHAQ on 2 sheets of paper provides a standard new patient intake questionnaire (26, 98). The first 2 pages are the 2-page MDHAQ; the 3rd page contains a traditional “past history;” the 4th page includes a review of medications, consents for future monitoring and sharing of data with colleagues of the physician. The 3rd and 4th pages can be developed into a report for a physician for entry into a medical record, which saves considerable time at each new patient encoun-

Table II. Comparison of health assessment questionnaire (HAQ) and multidimensional health assessment questionnaire (MDHAQ).

	HAQ	MDHAQ
First report	1980 (1)	1999 (31)
Patient completion	5-10 minutes	5-10 minutes
Physician to scan (“eyeball”)	30 seconds	10 seconds
Time to score	42 seconds	5 seconds
Index	HAQ-DI	RAPID3
# Activities of daily living	20	10
# Complex activity	None	2- walk 3 km, recreation
Pain visual analogue scale (VAS)	10 cm line	21 circles
Patient global VAS	10 cm line	21 circles
Psychological variables: sleep, anxiety, depression	No	HAQ format for sleep, anxiety, depression
Symptom checklist	No	60 symptoms
Fatigue VAS	No	21 circles
Morning stiffness	No	Yes
Exercise status	No	Yes
Change in status	No	Yes
Medical history	No	Surgery, illnesses, falls, side effects, etc.
Demographic data	No	Yes
Social history	No	Yes
Scoring templates	No	Yes
BMI: weight, height	No	Yes

ter, and a patient-friendly report for the patient to update, correct and amend information concerning her/his medical history (26, 98).

The Present: Pragmatic and scientific rationale for MDHAQ/RAPID3 at every rheumatology visit

Many pragmatic and scientific features of the MDHAQ/RAPID3 support its use at all rheumatology visits (Table III). The “pragmatic” value of MDHAQ/RAPID3 (Table III) includes:

1. The patient does 99% of the work, with minimal effort on the part of the staff or rheumatologist. About 20% of patients do require help, but help from a health professional should be minimal, as self-report generally is more reliable than scoring by a health professional (1).

2. The MDHAQ allows a health professional to review information in 5–10 seconds that otherwise would require 10-15 minutes of conversation. Nonetheless, self-report of medical history information always requires conversation between patient and doctor and interpretation by a knowledgeable health professional, as is the case with any laboratory test such as ESR or CRP, or ancillary study such as ultrasound or biopsy report (22).

3. The data inform doctor-patient communication, facilitating a focus on issues of greatest interest to the patient and doctor (77).

4. The “new patient” 4-page intake version of MDHAQ for new patients includes a traditional “past history,” including illnesses, hospitalisations, surgeries, allergies, family history, social history, and medications, for entry into a medical record and a request for patient consent to be monitored periodically (every 3, 6 or 12 months), if the patient does not return to the same clinical setting, as well as for sharing her/his data to with colleagues of the patient’s physician for medical research (26, 98).

5. A report for the patient in a patient-friendly format for the patient to amend, correct, and update new information concerning demographic data, medical history and medications, to be available to health professionals at the next visit.

6. A report for the physician in a medical record format for entry into a medical record (99), which saves 10-15 minutes at each new patient visit (26, 99).

The “scientific” value of MDHAQ/RAPID3 (Table III) includes:

1. Physical function scores on a patient

self-report questionnaire are more significant than laboratory tests or radiographs to predict most severe long-term outcomes of RA, including premature mortality (14, 81, 83, 84), as well as work disability (14, 19, 86, 87, 114), costs of care (115, 116), and joint replacement surgery (117). Five-year survival of RA patients with poor physical function was in the range of 50%, similar to Stage IV Hodgkin’s disease and 3-vessel coronary artery disease (118).

2. Individual patient self-report measures of physical function, pain, and patient global estimate of status are as efficient as joint counts and laboratory tests to distinguish active from control treatments in clinical trials involving adalimumab (119), abatacept (69, 70), certolizumab (71), and infliximab (72). Physician and patient global estimates tend to have the highest relative efficiencies, followed by SJC, physical function and pain on a patient questionnaire, while ESR or CRP and TJC are generally the least efficient among the seven core Data Set measures (72).

3. RAPID3 gives similar results to DAS28 and CDAI to distinguish active from control treatments in clinical trials of leflunomide (120), methotrexate (120), adalimumab (67), abatacept (69) and certolizumab (71).

4. RAPID3 is correlated significantly with DAS28 and CDAI in clinical trials (67, 69, 71, 120) and clinical care (108, 109), including categories for high, moderate, low disease severity and remission (70, 71, 108, 109).

5. RAPID3 also provides criteria for remission in RA in the ESPOIR cohort of patients who received usual care in France, as the prevalence of remission according to RAPID3 \leq 3+ SJ \leq 1 (RAPID3 \leq 3 and \leq 1 swollen joint) was similar to ACR/EULAR Boolean criteria, SDAI (simplified disease activity index), and CDAI (clinical disease activity index) (121).

6. Patient questionnaire scores are more reproducible than formal joint counts (122-128) by physicians, a phenom-

Table III. Pragmatic and scientific rationales for MDHAQ/RAPID3 at each patient visit.

Pragmatic rationale

- 1 Patient does 99% of the work, with minimal impact on workflow or staff or rheumatologist for about 80% of patients, although about 20% need some help.
- 2 The MDHAQ allows a health professional to review information in 5-10 seconds that otherwise would require 10-15 minutes of conversation, but requires interpretation by a knowledgeable health professional, as is the case with laboratory tests (22).
- 3 Data inform doctor-patient communication, facilitating a focus on issues of greatest interest to the patient and doctor (77).
- 4 4-page intake MDHAQ for new patients includes a traditional "past history" for databases (26, 98).
- 5 Report for the patient in patient-friendly format for her/him to amend, correct, and update medical history information to be available to health professional at next visit. (Note: A medical record is a legal document that cannot be altered; however, a medical history database can be amended by the patient for the next and future visits.)
- 6 A report for the physician formatted for entry into a medical record (99), which saves 10-15 minutes at most new patient visits (26, 99).

Scientific rationale

- 1 Physical function scores on a patient self-report questionnaire are more significant than laboratory tests or radiographs to predict most severe long-term outcomes of RA, including premature mortality (14, 81, 83, 84), as well as work disability (14, 19, 86, 87, 114), costs of care (115, 116), and joint replacement surgery (117).
- 2 In clinical trials, active treatment is distinguished from control treatment by individual patient self-report measures of physical function, pain, and patient global estimate, and RAPID3 (67, 69, 71, 120), as efficiently as joint counts, laboratory tests (119, 150-152).
- 3 RAPID3 gives similar results to DAS28 and CDAI to distinguish active from control treatments in clinical trials of leflunomide (120), methotrexate (120), adalimumab (67), abatacept (69) and certolizumab (71).
- 4 RAPID3 is correlated significantly with DAS28 and CDAI in clinical trials (67, 69, 71, 120) and clinical care (108, 109), including categories for high, moderate, low disease severity and remission (70, 71, 108, 109).
- 5 RAPID3 also provides criteria for remission in RA similar to ACR/EULAR Boolean criteria, SDAI, and CDAI (121).
- 6 Patient questionnaire scores are more reproducible than joint counts by physicians (122-128).
- 7 RAPID3 is more likely to be abnormal in new RA patients than ESR (37), and RAPID3 identifies incomplete responses to methotrexate and initiation of a biological agent while ESR does not (102).
- 8 RAPID3 is effective to document change in clinical status in all rheumatic diseases (129).
- 9 Continuation of courses of DMARDs is more accurately described by observational data from clinical care than by data from clinical trials (136).
- 10 A medical history is far more prominent in diagnosis and management decisions in RA than laboratory tests or ancillary studies, in contrast to other chronic diseases, according to a survey of rheumatologists and non-rheumatologists (13).

enon that may be explained, in part, because a single observer (in this case the patient) is likely more consistent than 2 observers (a joint count has input from both doctor and patient) (128).

7. RAPID3 is more likely to be abnormal in new RA patients than ESR (37), and RAPID3 identifies incomplete responses to methotrexate and initiation of a biological agent while ESR does not (102).

8. MDHAQ/RAPID3 is informative to recognise change of patient status over time in many rheumatic diseases beyond

RA (129), including systemic lupus erythematosus (129, 130), osteoarthritis (129), ankylosing spondylitis (129, 131-134), psoriatic arthritis (129), gout (129), vasculitis (135) and others (76, 129).

9. Effectiveness of DMARDs in RA may be described more accurately by observational data from clinical care than by data from clinical trials (136). For example, a meta-analysis of 117 treatment groups in 66 clinical trials reported in 1990, indicated no significant differences between 4 disease-modifying antirheumatic drugs (DMARDs), sulfasalazine, d-penicillamine, methotrexate, and

injectable gold (1) (137). By contrast, estimated duration of continuation of 1,083 courses of 6 DMARDs over 60 months in 477 RA patients at 5 years was approximately 60% for methotrexate, *versus* approximately 20% of hydroxy-chloroquine, d-penicillamine, parenteral gold, and azathioprine courses (136).

10. A medical history is far more prominent in clinical decisions concerning diagnosis and management in RA than laboratory tests or ancillary studies, unlike 7 other chronic diseases, according to a survey of rheumatologists and non-rheumatologists (13). Other components of a patient encounter such as vital signs (*e.g.* hypertension), laboratory tests (*e.g.* diabetes), or ancillary studies (*e.g.* ulcerative colitis) (13) were more prominent in other diseases (13).

The future: Electronic MDHAQ/RAPID3 (eMDHAQ) designed to interface with Electronic Medical Record (EMR)

The HAQ and MDHAQ/RAPID3 introduced quantitation and standardisation of scores for physical function, pain and patient global estimate into rheumatology clinical trials and care.

Nonetheless, almost each site and clinical trial in which the HAQ or MDHAQ are collected from patients has used a different format for entering data into a computer, with different names for variables, coding of responses, etc. Therefore, efforts to pool very similar databases with HAQ or MDHAQ/RAPID3 scores and other RA core data set measures are quite labour-intensive.

An interesting example of the disadvantages of different computer platforms for identical or similar data can be seen in the 9 European early arthritis cohorts analysed to establish new classification criteria for RA. These criteria were based on analyses of 3,115 patients in the 9 databases which distinguished patients who developed RA from those who did not develop RA (138). Although the 9 databases were about 80% identical, pooling the data was a labour-intensive process that required more than a year (138). This process could have been performed with minimal effort if the data structures had been identical.

Table IV. Electronic MDHAQ (eMDHAQ): Proposed advantages to doctor and patient.

- 1 May be completed at home on the day before a visit, including 4 page MDHAQ to record illnesses, hospitalisations, surgeries, allergies, family history, social history, medications, to facilitate workflow in the clinic and have data available in database.
- 2 May be completed anywhere, including other doctor's offices, vacation setting, etc. to record quantitative data for informed clinical decisions.
- 3 All data in same computer platform at all sites which use same electronic MDHAQ system, for ease of pooling and collaborative research, for all rheumatic diseases, particularly rare diseases such as polymyositis, vasculitis, etc. for analyses of course and outcomes.
- 4 SPERA – Standard Protocol to Evaluate RA - Patient-generated standard history of comorbidities, extra-articular disease, surgeries, medications, etc. recorded in standard database structure, available for pooling of data from different clinical and research sites.
- 5 Patient option for patient-administered, password-protected, secure, HIPAA compliant web site to store past medical history - illnesses, hospitalisations, surgeries, allergies, family history, medications (26, 98), so patient completes only a single general medical history questionnaire for any doctor, regardless of EMR.
- 6 Report to patient in patient-friendly format at patient-administered, password-protected, secure, website for patient to amend, correct errors, and update history for future visits. (Note: A medical record is a legal document that cannot be altered; however, a medical history database can be amended by the patient for the next and future visits.)
- 7 Option for patient to request and store at patient-administered, password protected website any medical record information (such as visit note, operation note, discharge summary), regardless of EMR in which the information is recorded, as PDF, if HL7, SMART on FHIR available not, to be available for care of patient at any facility.
- 8 Periodic list with "tickler" function of those with no contact after 3, 6, or 12 months (at discretion of the site, with no extra work of the part of the site) for automatic email and questionnaire to be sent to those consented patients.
- 9 MDHAQ data available for seamless data interface with electronic medical record (EMR), using HL7, SMART on FHIR – requires collaboration with EMR vendor, which could enhance seamless transfer to any EMR of items 3-8 above.
- 10 Report to physician in formatted as a medical record note of past medical history - illnesses, surgeries, hospitalisations, allergies, family history, social history, medications (26, 98), available for entry into any EMR without typing or dictation by physician or transcription by scribe, if HL7, SMART on FHIR available.

Introduction of electronic medical records (EMRs) has retained the heterogeneity of electronic versions of the HAQ, MDHAQ/RAPID3, and other informative patient questionnaires. More than 100 EMRs are used in different settings in the United States, which are incompatible with one another for electronic data transfer (139). Available EMRs at present do not take great advantage of capacities of computers, and function more as simply stored paper records (139). Therefore, a mandate has been established for an interface termed "health level 7" (HL7) to link all EMRs, though a set of international standards for transfer of clinical and administrative data. HL7 and programs such as SMART (Substitutable Medical Apps, Reusable Technology) on FHIR (Fast Healthcare Interoperability Resources), the latest standard to be developed under the HL7 organisation (140, 141), allow exchange of electronic data with any EMR, as of August 2016. Implementation of these interfaces to date

has been relatively slow, however, and unavailable at most sites.

It is ironic that several features which were available 2 decades ago to improve clinical encounters and outcomes of routine care using MDHAQ (142-145) have not been incorporated into any EMR, as of August 2016. Such features as flowsheets to compare MDHAQ scores, laboratory test results and medications over time (Fig. 4), patient-friendly reports to allow the patient to amend, correct, and update new information concerning demographic data, medical history and medications (Fig. 5), and physician reports of the patient's self-reported past medical history in a medical record format (Fig. 6), which can save 10-15 minutes for each new patient (26, 99), are not yet available. An electronic MDHAQ/RAPID3 (eMDHAQ/RAPID3) is designed with the capacity to incorporate HL7 and SMART on FHIR thereby allowing exchange of electronic data with any EMR, and a number of additional advanced features

(Table IV). The eMDHAQ/RAPID3 may be completed in a clinic setting, at home on the day before a visit, or anywhere at any time for entry into a database at a HIPAA (Health Insurance Portability and Accountability Act)-secure website. All sites that use an identical platform for eMDHAQ/RAPID3 can pool all available data seamlessly to advance knowledge concerning rheumatology care and outcomes, particularly if simultaneous laboratory test results and medication data are available. Availability of these data would be greatly enhanced with implementation of HL7 and SMART on FHIR, but coordination of these data remains possible even with "old-fashioned" data entry.

An intake new patient eMDHAQ/RAPID3 similar to the 4-page paper version (Fig. 3), is now being pilot (beta) tested, so that a patient can record a complete and accurate general past medical history - illnesses, surgeries, hospitalisations, allergies to medications and other substances, family history, social history, medications, demographic data (19, 92). All these data can be entered into an EMR efficiently, particularly if HL7 and SMART on FHIR are available. Implementation of HL7 and SMART on FHIR would allow a note to be available for entry into any EMR without typing or dictation by physician or transcription by a scribe, saving considerable time for the physician.

The patient can be offered an option to save the medical history data completed on the new patient eMDHAQ/RAPID3 at a patient-administered, password-protected, secure HIPAA compliant web site, to be retrieved by the patient at any time or any site. When the patient completes the eMDHAQ, a query appears: "Would you like a report of the medical history questionnaire you have completed sent to a patient-administered, password-protected, secure, HIPAA compliant web site, which you can save, print, and provide electronically to any other physician or other agency that might ask you to complete a similar medical history questionnaire?" This option would allow the patient to complete only a single general medical history questionnaire for all sites at which she/he is under care, regardless

COMPLETED FLOWSHEET: 61 year old male with RA

PT Name _____ DX ICD9 710.9, Onset:(mo/yr) ___ Record# _____
 Rheumatologist _____, 1st Visit:(mo/yr) 4Nov03, RF: Pos / Neg If+, titer _____, ANA: Pos / Neg If+, titer _____
 Address _____ City, ST ZIP _____ Home tel _____
 SSN# _____, DOB _____, Sex M / F, Marital: _____, Race: _____
 Work st: _____, Occ: _____ #Yrs Educ _____, Consent given: Y / N, 1^o MD _____ MD Tel _____

DATE	4Nov03	13Jan04	20Jul04	28ep04	28Dec04	08Feb05	28Mar06
FUNCTIONAL STATUS (FN) [0-10]	3.3	0	0	0	0	0	0
M PAIN (PN) [0-10]	9.5	0.5	3.5	0.5	6.0	0	0.5
H PATIENT GLOBAL (PTGL) [0-10]	9.5	0.5	2.0	1.0	5.5	0	0.5
A Q RAPID 3 [0-30]	22.3	1.0	5.5	1.5	11.5/4.0	0/0	1.0/0.3
PT JOINT COUNT (JT CT) [0-10]					1.9	0	0
RAPID 4 [0-40]					13.4/3.5	0/0	1.0/0.3
PHYSICIAN GLOBAL (MDACT) [0-10]					6.5	1.0	0.5
RAPID 5 [0-50]					19.9/4.0	1.0/0.2	1.5/0.4
WEIGHT (lbs)	167	167	163.8	159	168	166	171
BLOOD PRESSURE (mm/Hg)	114/70	131/81	116/76	128/80	111/71	120/72	129/79
ESR (mm/hr) [M:0-20 / F:0-30]	43	8	11	10	14	14	14
L CRP (mg/dL) [0-10]	30	3		7	6	8	9.3
A WBC (thou/uL) [4-11]	6.3	7.9	7.1	8.1	9.1	9.6	9.4
O HGB(g/dL M:14/F:12) OR HCT(%) [M:42/ F:37]	16.8	17	15.9	16.1	16.6	17	15.3
A PLATELETS (thou/uL) [150-400]	179	207	184	203	207	177	193
O ALBUMIN (g/dL) [3.5-5.0]	3.9	4.1	4.4	4	4.4	4.6	4.1
R SGOT (U/L) [4-40] OR SGPT (U/L) [4-40]	18	17	22	18	20	32	21
Y CREATININE (mg/dL) [0.7-1.5]	1.1	0.8	0.9	0.9	0.9	1.1	1.0
MED CODES: N- new drug, O-on at visit, X-toxicity, C-change dose, D-discontinue, T-taper, R-resume, I-injection, V-only today							
M Naproxen	O-880 Q6H	440 BID	440 BID	440 BID	440 BID	D-440 BID	
D Ranitidine	O-150 BID	150 BID	150 BID	150 BID	150 BID	150 BID	75 BID
I Acetaminophen with Codeine	O-30 TID	30 TID	D-30 TID				
A Prednisone	N-3 QD	1 BID	C-4 BID	C-3 BID	T-3 BID	T-2 BID	C-5 QD
T Methotrexate	N-10 QWK	20 QWK	C-15 QWK	15 QWK	C-25 QWK	15 QWK	15 QWK
I Folic Acid	N-1 QD	1 QD	1 QD	1 QD	1 QD	1 QD	1 QD
O Adalimumab					N-40 QOW	40 QOW	40 QOW
N Depo-Medrol					V-80		

Fig. 4. Flowsheet of MDHAQ/RAPID3 data, laboratory tests, and medications in 61-year-old male patient with rheumatoid arthritis

of EMR, although unique medical history data for different specialties may then be competed at different sites. These capacities are possible even without HL7 and SMART on FHIR, although implementation could add considerable efficiency, with added value to the data. The stored data could generate a report to the patient in a simple, patient-friendly format, for the patient to amend, correct errors, and update history in 3 categories – demographic data, past medical history, and medications - for future visits (Fig. 5). The patient is queried: “Would you like an additional report of the information you have completed in an electronic or paper format for any future medical encounters, which you can amend, correct any errors, and add new information?” It should be noted that a

medical record is a legal document that cannot be altered, although a medical history database can be amended by the patient for the next and future visits. A further option for the patient is to request and store at the patient-administered, password protected secure eMDHAQ/RAPID3 website any medical record information, such as a visit note, laboratory test report, imaging study, operation note, discharge summary, etc. regardless of EMR. “Would you like to have all medical record visits to any doctor, health professional, hospital stay, etc., sent to this secure web site, so that you may collect all your own medical records, regardless of the EMR in which they exist (as most are incompatible), password protected and available for your care anytime at any facility?” The documents could be available for

care of the patient at any facility and any time, regardless of EMR. The patient could request that all information be sent “automatically” to the eMDHAQ website without further request, much as current EMRs allow automatic forwarding of EMR data to referring physicians. The eMDHAQ/RAPID3 includes a “tickler” function in the database, so that consented patients who have no entry in the database for, say, 3, 6, or 12 months (at discretion of the site), are sent an automatically-generated email and questionnaire, with no work on the part of the doctor or staff. This feature can be quite valuable to monitor the long-term course of chronic rheumatic diseases, data concerning which are sorely lacking. The eMDHAQ/RAPID3 platform also includes screens for rheumatologists to enter pertinent quantitative data. A user-friendly homunculus includes a single mannequin for both swollen and tender joint counts, for 28 or 42 joints. Also included is an entry form for a RheuMetric (formerly RHEUMDOC) checklist (Fig. 7), which includes a physician global estimate, and 3 sub-scale estimates for degree of reversible findings – inflammation, infection; irreversible signs – organ damage; and distress – fibromyalgia, depression, hypochondriasis, etc. (10, 11). The software provides automatic calculations of DAS28, CDAI, and SDAI, in addition to RAPID3, if the component measures are available. The eMDHAQ/RAPID3 might involve further implementation of a standard protocol to evaluate RA (SPERA), which initially was reported in 1999 (146-148). SPERA presents a standard, structured history of comorbidities, extra-articular disease, surgeries, medications, etc. All clinical sites that use the eMDHAQ/RAPID3 software could collect the same data in the same computer format in all patients with RA for a SPERA. This process would allow data in a standard database structure at participating sites to be available for pooling to conduct long-term observational research. All of the above functions of eMDHAQ/RAPID3 would be enhanced by

PATIENT INFORMATION REVIEW - Sample Patient #10003

Our commitment to excellent medical care includes maintaining an accurate record of your major health information. We ask your help to assure that the record is correct and up to date by reviewing it at this time. Please make any additions on the right side or the back of this page. If there are no corrections, please mark where indicated to acknowledge you have reviewed this information.

Basic Information Date of Last Update: 2008 If all correct, please check; if not, please note changes below

Patient: Sample Patient #10003
 Address 123 Anywhere Street
 Springfield, USA 00911-0911
 Phone: (555) 555-1212
 SSN: SSN-11-2222

Demographic Information If all correct, please check; if not, please note changes below

Sex: Male Date Of Birth: 7/4/1776
 Education (years) 10
 Occupation REAL ESTATE
 Work Status Part-Time
 Marital Status: Married

Contact Person If all correct, please check; if not, please note changes below

Someone at a different address in case we cannot find you but need to let you something such as abnormal lab test
 Name: Emergency Contact Name
 Address 789 Anywhere Road
 Springfield, USA 00911-0911
 Phone: (555) 555-0789
 Relation Daughter

Primary Care Physician If all correct, please check; if not, please note changes below

Name: John H. Smith, MD
 Address 011 Medical Center Drive
 Springfield, USA 00911-0911
 Phone: (017) 555-1212 Fax: (017) 555-1212

PATIENT INFORMATION REVIEW - Sample Patient #10003

MEDICAL CONDITIONS If all correct, please check; if not, please note changes below

Severe Allergies	YEAR	_____
Back or Spine Problems	YEAR	_____
Rheumatoid Arthritis	YEAR	_____
Stomach Ulcer	YEAR	_____
Heart Attack	YEAR	_____
Depression	YEAR	_____
Mental Illness	YEAR	_____
Bronchitis	YEAR	_____
Dry Eyes	YEAR	_____
Gastroesophageal Reflux	YEAR	_____

SURGERIES If all correct, please check; if not, please note changes below

Year	Hospital (City/State)	_____
Tonsillectomy	YEAR General Hospital, Somewhere USA	_____
Deviated Septum	YEAR General Hospital, Somewhere USA	_____
Hemorrhoid	YEAR General Hospital, Somewhere USA	_____
Hemorrhoid	YEAR General Hospital, Somewhere USA	_____
Deviated Septum	YEAR General Hospital, Somewhere USA	_____
Angioplasty	YEAR General Hospital, Somewhere USA	_____

HOSPITALIZATIONS If all correct, please check; if not, please note changes below

Year	Hospital (City/State)	_____
No Reported Hospitalizations	YEAR General Hospital, Somewhere USA	_____

FAMILY MEDICAL HISTORY If all correct, please check; if not, please note changes below

Family Member	Alive or Deceased	Date of Birth	Year of Death	Major Health Conditions
Father	Deceased	DOB	DOD	Stroke
Mother	Deceased	DOB	DOD	Heart Attack
Brother 1	Deceased	DOB	DOD	Heart Attack

MEDICATION ALLERGIES If all correct, please check; if not, please note changes below

Miacalcin lu/Spray
 Motrin
 Penicillin

OTHER ALLERGIES If all correct, please check; if not, please note changes below

Dust Mites
 Grasses
 Molds
 Pollens

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PT: Sample Patient #10003 MR#: SMP#10003
 Our records indicate that your last visit you were taking the medications listed below. Please review each medication and indicate whether you have taken or not over the last week. If you have taken the medication, please indicate how helpful the medication is and if you have any side effects from the medication.

Refill	Medication Name	Dosage	Number of Tabs Taken?	Taken How Often?	Taken at this Dose?	Taken-Other Dose?	Stopped	If taken, how helpful is it?				Any side effects?		
								Not	Somewhat	Very	Other			
<input type="checkbox"/>	Aspirin	81mg	1	Once Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Folic Acid	1mg	1	Once Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	methotrexate	2.5mg	1	Every Week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	prednisone	1mg	2	Once Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Multivitamin Tablets	1tab	1	Once Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Prevacid	30mg	1	Once Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Procardia XL	30mg	1	Once Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Tums	500mg	1	As Needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Tylenol	500mg	1	As Needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Zocor	20mg	1	Once Daily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please List Any New Medication

_____	<input type="checkbox"/>	<input type="checkbox"/>	_____
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____

Fig. 5. Patient-friendly report to the patient, for review and so she/he may amend, correct, and update new information concerning medical history at encounter or for future encounters (99).

seamless transfer with any EMR which has HL7, and SMART on FHIR. However, initial implementation does not require HL7 and SMART on FHIR. As noted, although implementation is mandatory, collaboration with the EMR vendor is required, and dissemination has been slow, though should become available over the years to enhance the value of the data.

Concluding thoughts
 Development of an eMDHAQ/RAPID3 presents a number of features that seek to overcome limitations of current use of pencil and paper. While simple in concept, implementation of many of these features present complexities to workflow that were experienced in the introduction of the EMR, which were unsettling in many clinical settings (139). Introduction of an eMDHAQ/RAPID3, which is not a legal document (until introduced into a medical record), appears to allow a more gradual introduction of each feature, some of which may never be implemented, over a decade or more. Each interested clinical

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DRUG CHANGES SINCE LAST VISIT (circle one): NO YES -- List all changes below

NEW DRUGS AND DOSAGE	CHANGE IN DOSAGE	DISCONTINUATION (BASIS)	DIC CODES
			NO efficacy TOXICITY LOSS of efficacy MD orders PT refused Administrative

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Past History Database - Sample-2 Patient

MR #: 0513931-6 Tel: (615) 383-4630 DOB: 5/30/40 Data Last Reviewed: 9/17/96
 MD: Theodore Pincus, M.D. Tel: (615) 936-2152 Fax: (615) 936-2159
 PC MD: Susan Doe, M.D. Tel: (615) 936-1014 Fax: (615) 936-1672

Illnesses	Year (Age)	Illnesses	Year (Age)
Prostate Problem	1965 (25)	Rheumatoid Arthritis	1984 (44)
Osteoarthritis	1972 (32)	Back or Spine Problem	1976 (36)
Depression	1976 (36)	Mental Illness	1960 (20)
Alcoholism	1965 (25)		

Operations	Date	Surgeon, Hospital, City
Tonsillectomy/Adenoidectomy	1942	Good Samaritan, Lexington, KY
Sutures for Dog Bite	1947	Dr. Reed's Office, Lexington, KY
Lymph node biopsy	1972	Dr. Rosenfeld, Vanderbilt Hospital, Nashville, TN
Ankle Fracture	1972	Dr. Brooks, Vanderbilt Hospital, Nashville, TN

Other Hospital Admissions

Bladder / Kidney Infection 1995 Vanderbilt Hospital, Nashville, TN

Drug Allergies Stelazine, Seconal, Mellaril

Other Allergies None

Family History	Status	Year of Birth	Age at Death	Illnesses or Cause of Death
Father	Dead		72	Massive Heart Attack, Diabetes II
Mother	Alive	1910 (87)		Osteoporosis
Brother	Alive	1943 (54)		Lumbar Disk, Tourette's Syndrome
Sister	Alive	1938 (61)		None
Son	Alive	1969 (28)		None
Son	Alive	1971 (26)		None

Social History

Marital Status: Married

Occupation: Professor / Astronomer

Education (Years): 20

Work Status: Working full time

Review of Systems:

General: No fever; No weight gain; No weight loss; Has unusual fatigue; No adenopathy; No anorexia.

Skin: No new rash; No urticaria; No alopecia; No other skin problems.

HEENT: No dry eyes; No other eye problems; No hearing problems; No ringing in ears; No stuffy nose;

No sores in the mouth; No dry mouth; No problems with smell; No problems with taste.

Respiratory: No cough; No dyspnea; No wheezing.

Cardiac: No chest pain; No palpitations; No ankle edema.

Gastrointestinal: No dysphagia; No heartburn; No abdominal pain; No nausea; No vomiting;

No constipation; No diarrhea; No dark stools; No bloody stool.

Genitourinary: Has urinary frequency; Has dysuria; No abnormal vaginal bleeding; No facial edema;

No gynecological (female) problems; Has sexual problems.

Neurological: No headaches; No balance problems; No paralysis of arms or legs; No dysesthesia.

Musculoskeletal: Has muscle pain, aches, or cramps; No muscle weakness; Has hand swelling;

Has joint swelling; Has joint pain; No back pain; No neck pain.

Hematological: No unusual bleeding; No unusual bruising.

Psychiatric: No depression; No anxiety; No problems with thinking; No problems with memory;

Has problems with sleeping.

Habits: Doesn't use drugs not sold in stores; Doesn't smoke; No more than 2 alcoholic drinks per day.

Fig. 6. Report to physician of patient self-reported past-history in a medical record format, available for possible entry into a medical record as entered data rather than narrative transcription (99).

site may proceed at a level of comfort appropriate to the workflow of the setting, recognizing expertise in information technology, goals of the physician and staff, and possible requirements for documentation as they may develop.

A first step is to collect eMDHAQ/RAPID3 patient data and physician RheuMetric data electronically. This change may appear relatively simple if the transfer of information were from a desk of a patient to the desk of the physician, but introduces complexities to the workflow of the clinical setting. Indeed, pencil and paper may be an appropriate initial step in many clinical settings with no previous experience in the use of patient questionnaires. Other settings may choose to begin directly with an eMDHAQ/RAPID3, particularly if advanced skills are available. Pencil and paper may be maintained in

some settings at this time and for the foreseeable future, although ultimately it would appear that all information in medical care will be recorded in an electronic format.

A second step is to introduce seamless exchange of data from the eMDHAQ/RAPID3 and RheuMetric with an EMR using HL7 and SMART on FHIR. Again, this undertaking is not trivial, as collaboration with an EMR vendor is required, often involving additional intermediaries outside of solo- or rheumatology-only group practice settings. Implementation of HL7, although "mandatory," may involve months of planning, waiting for higher priorities of an institution or EMR vendor.

The advantages of HL7 and SMART on FHIR to have potentially "automatic" exchange of laboratory test results and medications from an EMR to a com-

mon database are not underestimated. Nonetheless, entry by a physician or assistant of eMDHAQ/RAPID3 scores for function, pain, patient global estimate, RAPID3, fatigue, and number of symptoms may appear a great burden, but can be accomplished in a few seconds, sometimes fewer than required to change screens for other functions. Introduction of an eMDHAQ/RAPID3 while anticipating later implementation of HL7 and SMART on FHIR to facilitate direct exchange with an EMR, may be appropriate in many rheumatology settings.

A common eMDHAQ/RAPID3 and RheuMetric would allow pooling of data from many rheumatology sites, facilitating the capacity of any rheumatology office site to contribute to important advances in rheumatology with no extra work on the part of the rheumatologists, staff, or patient, particularly for rare diseases such as polymyositis, vasculitis, etc. for analyses of course and outcomes. A patient option to save the data from a completed eMDHAQ/RAPID3 at a patient-administered, password-protected, HIPAA compliant web site to store past medical history, so the patient can complete only a single general medical history questionnaire for all encounters with health professionals, regardless of EMR, also does not require HL7 and SMART on FHIR.

A third or fourth step would introduce additional value-added features of an eMDHAQ/RAPID3 database (Table IV), including reports to the physician – formatted as a medical record note, reports to the patient – formatted in a patient-friendly format for the patient to amend, correct errors, and update history for future visits, option for patients to store any medical record information from any source or any EMR at a patient-administered, HIPAA-compliant, password-protected website, and "tickle" function for the rheumatology site to contact patients not seen for 6 or 12 months to monitor long-term outcomes, with minimal additional work for no doctors and staff. These features would appear to require seamless transfer involving HL7 and SMART on FHIR, and full implementation may involve decades.

R937.02 RheuMetric:™ PATIENT _____, MR # _____, DATE _____, P 1
 PHYSICIAN _____ Check if new Pt , If not: _____ Yr of 1st visit to this doctor
 INITIALS _____ _____ Yr of 1st visit to this site

1. a. PHYSICIAN GLOBAL ASSESSMENT (DOCGL) at this visit:
 EXCELLENT ○○○○○○○○○○○○○○○○○○○○○○ VERY POOR
 0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

2. DISEASE ACTIVITY, DAMAGE and DISTRESS:

b. Degree of INFLAMMATION or REVERSIBLE DISEASE (DOCINF) at this visit:
 NONE ○○○○○○○○○○○○○○○○○○○○○○ MOST SEVERE
 0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

c. Degree of joint or organ STRUCTURAL DAMAGE or IRREVERSIBLE DISEASE (DOC DAM) at this visit:
 NONE ○○○○○○○○○○○○○○○○○○○○○○ MOST SEVERE
 0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

d. Degree of DISTRESS (findings due to neither inflammation nor damage, eg, fibromyalgia)(DOCSTR):
 NONE ○○○○○○○○○○○○○○○○○○○○○○ MOST SEVERE
 0 0.5 1 1.5 2 2.5 3 3.5 4 4.5 5 5.5 6 6.5 7 7.5 8 8.5 9 9.5 10

e. If DOCGL>2, % of clinical decision based on (total=100%): _____ inflammation,
 _____ damage
 _____ distress

f. If DOCGL>2, proportion of clinical decision due to (total=100%): _____ rheumatic disease(s)
 _____ non-RD(s)

g. OVERALL CHANGE in clinical status compared to one week ago (DOCCHG) (please √ one):
 Much Better (1), Better (2), the Same (3), Worse (4), Much Worse (5)

3. PROGNOSIS

i. WITHOUT therapy (√ one): Excellent (1), Very Good (2), Good (3), Fair (4), Poor (5)

j. WITH therapy (√ one): Excellent (1), Very Good (2), Good (3), Fair (4), Poor (5)

4. DIAGNOSIS k. Primary (1°) Rheumatic diagnosis: (May be provisional): _____

l. Diagnostic certainty - 1° Rheumatic diagnosis: High (1), Moderate (2), Low (3), None (4).

m. Year of 1st symptoms: _____, Month, if <2 years: _____ Year of Diagnosis: _____

n. Other diagnoses a. _____, b. _____, c. _____

PATIENT ETHNICITY: Asian, Black, Hispanic, Indian, White, Other _____
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Fig. 7. RheuMetric physician checklist to record patient levels of inflammation, damage and distress as quantitative data rather than as narrative impressions (140)

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Finally, it is recognised that the pen and paper 2- and 4-page MDHAQ were facilitating clinical care, improving doctor-patient communication, saving time for patients and doctors, facilitating research concerning the natural history of disease, results of therapies and long term outcomes for more than 30 years (21, 22, 77, 106, 129, 149), and remains available for these purposes. An electronic version and even interchange with the EMR are not required, although these tools can add considerably to the value of the data collected with minimal additional work for a physician and staff. At the same time, the capacity for HL7

and SMART on FHIR to exchange of data with an EMR has been built into an eMDHAQ/RAPID3, to hopefully resolve a "tower of Babel" approach which characterises current implementation of many electronic versions of MDHAQ and RAPID3, which perpetuate electronic incompatibility similar to EMRs. However, none of these features need be used to implement the basic purpose of MDHAQ/RAPID3 to improve clinical care. The principles of value and feasibility as priorities over technology which have guided MDHAQ/RAPID3 over the years, might also guide eMDHAQ/RAPID3 in the coming years.

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