The use of databases for quality assessment in rheumatoid arthritis

T.A. Stamm¹, D. Aletaha¹, S. Pflugbeil², T. Kapral¹, K. Montag², K.P. Machold¹, J.S. Smolen¹²

ABSTRACT
As resources in health care systems become increasingly scarce, rheumatologists may need to provide evidence that their quality of care uses the allocated resources effectively by achieving a good outcome for patients with rheumatoid arthritis (RA). In order to assess quality, it has been recommended in other areas of medicine to gather data according to appropriate outcome measures, preferably in electronic databases, enabling identification of benchmarks to compare the outcome quality of different clinical settings.

Available electronic applications commonly comprise a database for data processing and storage, as well as a tool for regularly measuring and following disease activity in individual patients. Access to aggregated data makes it possible to monitor disease activity in individual patients over time in relation to treatment. In addition, electronic applications should allow the extraction of patient data according to special characteristics for analysis. In this way, such electronic applications can provide a central database that can be used for monitoring patients in routine care, case studies or general research, as well as facilitating comparisons of quality of care in different centres or in different countries for reference purposes.

Introduction
Rheumatoid arthritis (RA) is a chronic inflammatory disease that is known to result in pain, disability and joint destruction. It has already been recognized for many years that a poor prognosis, whether based on an evaluation of joint destruction, long-term functional disability or mortality, is associated with the degree of the cumulative inflammatory response (1-11). More recently, it has been suggested that acute phase reactant levels or swollen joint counts even at the time of initiation of disease modifying anti-rheumatic drugs (DMARD), or 3 months thereafter, are highly predictive of subsequent joint damage (12). Over time, increasing joint damage leads to increasing disability (13, 14).

As a consequence of these insights, the primary aim in treating patients with active RA is the rapid reduction of disease activity, the optimal goal being the achievement of remission. The success of tight control of the disease status in conjunction with the adjustment of therapy based on the results of control examinations has been clearly documented in three recent investigations (15-17). Therefore, to achieve optimal therapeutic effects in all RA patients, regular quantitative evaluation of disease activity must be regarded a necessity even in clinical practice.

A recent Europe-wide survey indicated that patients in different countries appear to exhibit distinct clinical activity and disability index values despite the use of similar therapies (18), but the reasons underlying these differences have not been evaluated. They may be linked to differences in baseline characteristics and/or the treatment response in specific patient populations (19) or to differences in the quality of patient care, including adherence to more or less intensive treatment strategies (15, 20). With dynamic treatment strategies and the optimal use of currently available therapies, low disease activity or remission should be an achievable goal in the majority of our patients (21).

Monitoring disease activity
Inherent in the strategy of intensive treatment with DMARDs (including biological agents) with the goal of preventing or slowing permanent structural joint damage and long-term disability in RA is the accurate monitoring

¹Division of Rheumatology, Department of Internal Medicine III, Medical University of Vienna; ²2nd Department of Medicine, Centre for Rheumatic Diseases, Hietzing Hospital, Vienna, Austria.
Tanja Stamm, PhD, MSc, MBA, MagPhil, OTR; Daniel Aletaha, MD; Stephan Pflugbeil, MD; Theresa Kapral, MD; Karin Montag, MD; Klaus Machold, MD; Josef Smolen, MD.
Please address correspondence to:
Dr. Tanja Stamm, Division of Rheumatology, Department of Internal Medicine III, Medical University of Vienna, Waehringer Guertel 18-20, A-1090 Vienna, Austria.
E-mail: Tanja.Stamm@meduniwien.ac.at
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of disease activity (22, 23). Both the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR) have defined core sets of disease activity measures for RA (22, 24) with the goal of providing a certain uniformity in the assessment of outcome (25-31).

Both in daily clinical practice and in clinical trials, many variables are recorded to monitor the course of the disease. A variety of factors can confound the process of measuring disease activity, however, including the unpredictable course of RA, the varied clinical presentation of the disease in different patients, and the variability and potential bias of individual measures. Because of these factors, it was suggested that monitoring disease activity in the form of a composite evaluation of core set variables might be more valid than the evaluation of single variables (2-4). In this respect, continuous composite scores for assessing disease activity in RA have been developed and validated, using more complex or simplified means of calculation and comprising core sets with the inclusion of an acute phase reactant (APR) such as the Disease Activity Score (DAS)28 (28), SDAI (30) or CDAI (6) values (23, 32-34), as they comprise core set variables with the inclusion of an acute phase reactant (APR) such as the Disease Activity Score (DAS)28 (28) and the Simplified Disease Activity Index (SDAI) (30), with or without the addition of an APR measure such as the Clinical Disease Activity Index (CDAI) (6). These composite indices are preferable to measuring single variables (23, 32-34), as they comprise both the physician’s as well as the patient’s perspectives.

Quality assessment in electronic databases

With the advent of biological therapies and the consequential increase in the direct costs of care (35, 36), a thorough assessment of disease activity is especially mandated to justify the use of expensive treatments. As resources in health care systems become increasingly scarce, rheumatologists may need to provide evidence that their quality of care makes use of the allocated resources effectively by achieving a good outcome for patients with RA. In order to assess outcome quality, it has been recommended in other areas of medicine to gather data according to appropriate outcome measures, preferably in electronic databases (37), which allow benchmarks to be set and the outcome quality of different units or organizations to be compared (38-42).

Variables recorded in electronic databases should include the following information on the patient: demographic data, disease duration, 28 to 64/66 tender (TJC) and swollen joint counts (SJC), patient VAS for pain (PPA) and global disease activity (PGA), physician VAS for global disease activity (MDGA), morning stiffness (MST), HAQ scores, the presence of rheumatoid factor (and, eventually, anti-CCP), APR (such as ESR and CRP), and medications used (including side effects) (Fig. 1). Clinical assessments should be performed by trained assessors.

Requirements for electronic applications

Available electronic applications commonly comprise a database for data processing and storage, as well as an electronic tool for regular measurement and to calculate the disease activity scores in individual patients. DAS28 (28), SDAI (30) or CDAI (6) values (Table I) may be calculated automatically by the electronic application and are then displayed to the rheumatologist. The advantage of using the CDAI is that values can be calculated at the time of the visit to the rheumatology clinic while the patient being seen by the rheumatologist, even if the laboratory test results, such as APR, are not yet available (Fig. 1).

Equally important is that aggregated data can be accessed in order to monitor disease activity in individual patients over time in relation to treatment (Fig. 2). This may help rheumatologists to set goals and chart treatment progress in a visual form that can be shared with the individual patient (43). In addition, electronic applications should be able to aggregate patient data based on specific characteristics and extract them for data analysis. Such electronic applications would provide a central database that can be used to organize patient information for routine follow-up, for case studies or research studies, or for the comparison of quality of care between centres and countries for reference purposes.

For the assessment of quality of care, data on RA patients is currently being compared between different settings and different countries in two ongoing projects. It is desirable to use either the same electronic application or to capture exactly the same variables at each centre. Variables should include at least...
the core set variables as detailed above and the use and side effects of medication. Preferably, the use of the same electronic application will provide an equal set of data without the need for adaptation, such as the recalculation of CRP values, because the units used may be different in different centres. In addition, one goal could be to standardise patient care and the measurement of variables in order to achieve the same process quality in different centres. In 2006 the ACR published a starter set of quality indicators for RA that has been applied in clinical studies (44, 45) to standardize and analyze the process of quality care for RA. In terms of the standardized measurement of variables, joint counts should preferably be carried out by the same assessor blinded to treatments. Measurement of the ESR, if performed on the rheumatology ward, must be standardized. Finally, it is important that the same patient populations are compared, based on routine care data or data from specific cohorts, such as early arthritis. In order to facilitate analysis, data should be stored anonymously with no need for informed consent or permission from the institutional review board (43). In addition, data storage needs to be safe and has to follow the legal requirements for processing patient data in each country.

**Outlook**

Table II provides an overview of the currently available electronic applications for monitoring disease activity in RA. Currently, a European initiative launched in 2007 – the Measurement of Efficacy of Treatment in the ‘Era of Outcome’ in Rheumatology (METEOR) – is undertaken to establish an international electronic application for patients with RA (43). In this project the same application, which can be slightly customized to the individual needs of each centre, will be used to produce comparable data. In Austria and The Netherlands, two ongoing projects are comparing data between 4 different centres. In Austria, the CARAbase application is used in some rheumatology centres. Rapid changes in available medications may lead to reductions in disease activity as well as the possibility of achieving remission in patients with RA. As resources in health care systems become increasingly scarce, rheumatologists may need to provide evidence that their quality of care exploits the allocated resources effectively by achieving well-documented outcomes for patients with RA. In order to facilitate data processing and comparisons between centers, electronic applications may be preferable. However, where electronic databases are not available, even such simple tools as the CDAI, which do not require any type of electronic device for their calculation, will be helpful for following patients in routine care, demonstrating the pertinent use of health care resources, informing patients on their disease status, and helping clinicians to adapt treatment in a dynamic manner based on state of the art knowledge.

**References**

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**Table I.** Formulas for calculating DAS28, CDAI and SDAI values.

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<thead>
<tr>
<th>Application</th>
<th>Year of launch</th>
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This table provides an overview of the currently available electronic applications to monitor disease activity over time in patients with RA. The METEOR foundation is an ongoing project in which rheumatologists from various different European countries are participating.

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**Table II.** Electronic applications currently available to monitor RA patients and assess the quality of treatment.

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**Fig. 2.** Monitoring of disease activity scores over time.

This screenshot from the CARAbase shows the DAS28 values for one patient over time. The ranges for remission, or low, moderate or high disease activity are provided in the left margin. Similar graphs are available for the CDAI and SDAI.