International Journal of
Clinical Rheumatology

Special Report

Utilizing the METEOR initiative to improve rheumatoid arthritis patient care

Advances in the treatment of rheumatoid arthritis have made remission an achievable goal. Rheumatologists monitor disease activity continuously to assess patients' response to therapy and to make treatment decisions. Calculating and recording disease activity scores can be cumbersome; thus, calculators are often required. Various parameters must be assessed to follow disease activity over time, including joint examination, acute phase reactants and patient and physician global assessments. These must be correlated with the medication history. Measurement of Efficacy of Treatment in the 'Era of Outcome' in Rheumatology (METEOR) is a comprehensive international database that captures multiple dimensions of rheumatoid arthritis disease management, allowing rheumatologists to follow disease activity in the setting of routine care while providing opportunities for benchmarking and research.

Keywords: benchmark • database • disease activity scores • METEOR • patient reported outcomes • research • rheumatoid arthritis • treatment

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The treatment of rheumatoid arthritis (RA) has advanced significantly over the past two decades. The availability of multiple biologic therapies, which target various aspects of the immune system when used either alone or in combination with conventional disease modifying drugs, has made remission a realistic therapeutic goal [1]. Recommendations for the treatment of RA have been modified accordingly over time to reflect this higher standard of clinical response [2]. To this end, efforts have been undertaken to develop criteria for clinical remission in RA [3,4].

Several measures of disease activity have been proposed, although these do not necessarily correlate with structural remission, which implies halting progression of radiographic damage over time. In addition to measuring RA disease activity, rheumatologists must assess multiple aspects of disease on a regular basis to adjust treatment optimally.

Patient reported outcomes (PROs), such as the Health Assessment Questionnaire [5] or the Routine Assessment of Patient Index Data 3 (RAPID3) [6], assist rheumatologists to quantify a patient's functional status. Composite measures, such as the Disease Activity Score (DAS) [7], the DAS employing a 28 joint count (DAS28) [8], the Simplified Disease Activity Index (SDAI) [9] and the Clinical Disease Activity Index (CDAI) [10], quantify disease activity at any single point in time or longitudinally both in clinical trials and in daily practice. These composite measures include objective laboratory assessments (acute phase reactant levels), semiobjective assessments of joint pain and swelling and a subjective assessment by the patient of disease activity. The number of swollen joints and acute phase reactant levels, but not PROs, correlate with structural progression [11].

Although these PROs and composite measures of RA disease activity help rheumatologists monitor disease optimally and make appropriate treatment decisions, the time constraints that exist in outpatient clinic schedules make their incorporation into the clinical work flow challenging. Some physi-

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10.2217/ijr.15.44 © 2015 Future Medicine Ltd

ISSN 1758-4272

cians send patients a questionnaire for them to complete before their scheduled visit. A more economical strategy is to distribute the questionnaire to the patient upon their arrival at the clinic, so that she or he can complete it while waiting to be seen. However, this practice requires that the questionnaire be scored manually and the results be entered into the patient's record.

In some centers, patients complete an electronic questionnaire in the waiting room using touch screen technology. These data are then exported to a computer in the examination room, onto which additional information is entered by the clinician (e.g., swollen and tender joint counts, changes in medications, joint injections and orthopedic surgical procedures). These data are subsequently incorporated into the patient's medical record and may also be transferred to a registry or database [12]. However, these systems are not available to most rheumatologists.

Most disease activity scores require acute phase reactant laboratory test results. Calculating these scores at the time of the patient encounter is possible only if the patient comes in to have blood drawn several hours before the office visit or on an earlier day. Thus, it is challenging to calculate disease activity scores in real time in clinical practice. Newer methods to assess acute phase reactant levels offer test results in less time than before; however, these are not widely available. The accessibility of online systems to calculate and document these composite disease activity scores facilitates the incorporation of quantitative measures into clinical practice [13,14].

Since multiple variables must be assessed, recorded and followed to assess RA disease activity over time, there is a need for disease activity calculators and, even more, for comprehensive databases to facilitate rheumatologists' documentation of patient encounters. These databases should also allow rheumatologists to review multiple aspects of the disease process so as to have a sense of a patient's disease activity when making treatment decisions. Comprehensive databases provide opportunities for clinical research and are particularly useful to facilitate comparing patients across countries.

Registries and databases that gather data on patients with RA, such as the Danish Registry for Biologic Therapies in Rheumatology (DANBIO) [12], the British Society of Rheumatology Biologics Registers (BSRBR) [15] and the Rheumatic Diseases Portuguese Register (Reuma.pt) [16], exist in many countries and are used both in clinical practice and for research purposes. However, most of these databases are restricted to a single country or have specific inclusion criteria, such as entering data only from patients who are treated with biologic drugs. In contrast, Measurement of Efficacy of Treatment in the 'Era of Outcome' in Rheumatology (METEOR) is available internationally and offers clinicians in many countries the opportunity to enter patients. This, in turn, provides unique research opportunities.

The METEOR tool & database

In order to improve patient care by supporting and assisting rheumatologists on a day-to-day, as well as on a long-term basis, the METEOR initiative was started in 2006 by the Merit Foundation [17,18]. The METEOR tool has been developed as a stand-alone web-based program and has been available free of charge to all rheumatologists worldwide since 2008. Rheumatologists who are interested in using the METEOR tool can view demo versions and register online [19].

Patient data and clinical outcome measures are recorded over time and are displayed both numerically and graphically, allowing both the patient and treating physician to see trends in disease activity and physical function. Since data that contain patient identifiers are stored in the METEOR database in an encrypted manner, others can use these de-identified data to benchmark optimal treatment for quality improvement of routine patient care and for research purposes. This benchmarking feature allows users to compare their patient population to those of other rheumatologists at their site or within their country, or to the entire METEOR database.

Rheumatologists who submit patient information control their own data. Identifying data can be unencrypted only by the site that submitted the data. Thus, treating rheumatologists always have access to full details about their own patients and will always be able to download the data that they have submitted. Participating rheumatologists can always conduct research using their own data, which can be downloaded to an Excel file. Moreover, actively participating researchers can carry out research on the complete METEOR database [19].

At each site, one coordinator (either a rheumatologist or a research nurse) is granted administrative rights and, with these, the 'administrator' can create other individual user accounts for that site. Thus, within one center, several users can access the METEOR tool, each with his or her own account, and, if allowed by the administrator, may have access to all patients' data entered by their colleagues at the same center.

Currently, the METEOR database contains data from more than 175,000 visits of over 37,500 RA patients at 131 actively enrolling sites in 32 countries. At 89 sites, patients are entered into the METEOR database in real time by their rheumatologist, using the METEOR tool at the time of a visit. At another 42 sites, patient data is uploaded from existing databases into the METEOR database using the upload capability.

All patients with RA who are followed by a rheumatologist are eligible for entry into the METEOR database without restrictions on disease duration, age or other demographic parameters. Patients are evaluated during their usual clinical care, and data from subsequent visits are also entered. Among other variables, patient characteristics, such as age, gender, smoking habits, presence of rheumatoid factor or anti-citrullinated protein antibodies, presence or absence of erosions, and disease characteristics, such as tender and swollen joint counts and acute phase reactant levels, can be entered. The software automatically calculates the various disease activity scores (original DAS, DAS with 3 variables (DAS-3), DAS28, DAS28–3, CDAI, SDAI, RAPID3) [7–9,20]. In addition, details about medications can be entered (start and stop dates, iteration, interval and dosage) not only for the current drugs but also for previously used drugs. This allows rheumatologists a complete overview of past and present therapy and response to treatment, through the graphic depiction of a patient's disease activity and medication history (Figure 1) [21].

Upload capability

The METEOR tool can be a major asset for rheumatologists who are used to working with paper files in clinical practice. However, since the use of electronic health records (EHRs) has increased over the past several years, entering data into a separate tool (double entry) might be burdensome for a busy clinician.

The number of local and country-specific databases has also increased in the recent past. The leaders of some of these registries desire to compare their data to those of other registries by uploading their data into the METEOR database so as to benefit from the benchmarking and research capabilities of METEOR.

To overcome the annoyance of double entry, METEOR has developed a process to upload data into and download data from the METEOR database. The upload capability allows data stored in a local EHR or in local/country-specific databases to be uploaded into the METEOR database. The download capability allows all relevant data to be transferred from the METEOR database to a local EHR.

Since data can be stored in local registries in various different forms, which might not comply fully with how data is stored in the METEOR database, an intermediate procedure is required to convert these data into a form compatible with METEOR. To do this, METEOR has developed a standardized XML file, with a reference guide and additional documentation. Data from the local registry is extracted and stored in this XML file. This process is rather complicated and requires support from a local IT department. However, once the data in the XML file optimally match the specifications of METEOR, subsequent uploads can be integrated quickly and easily into the METEOR database.

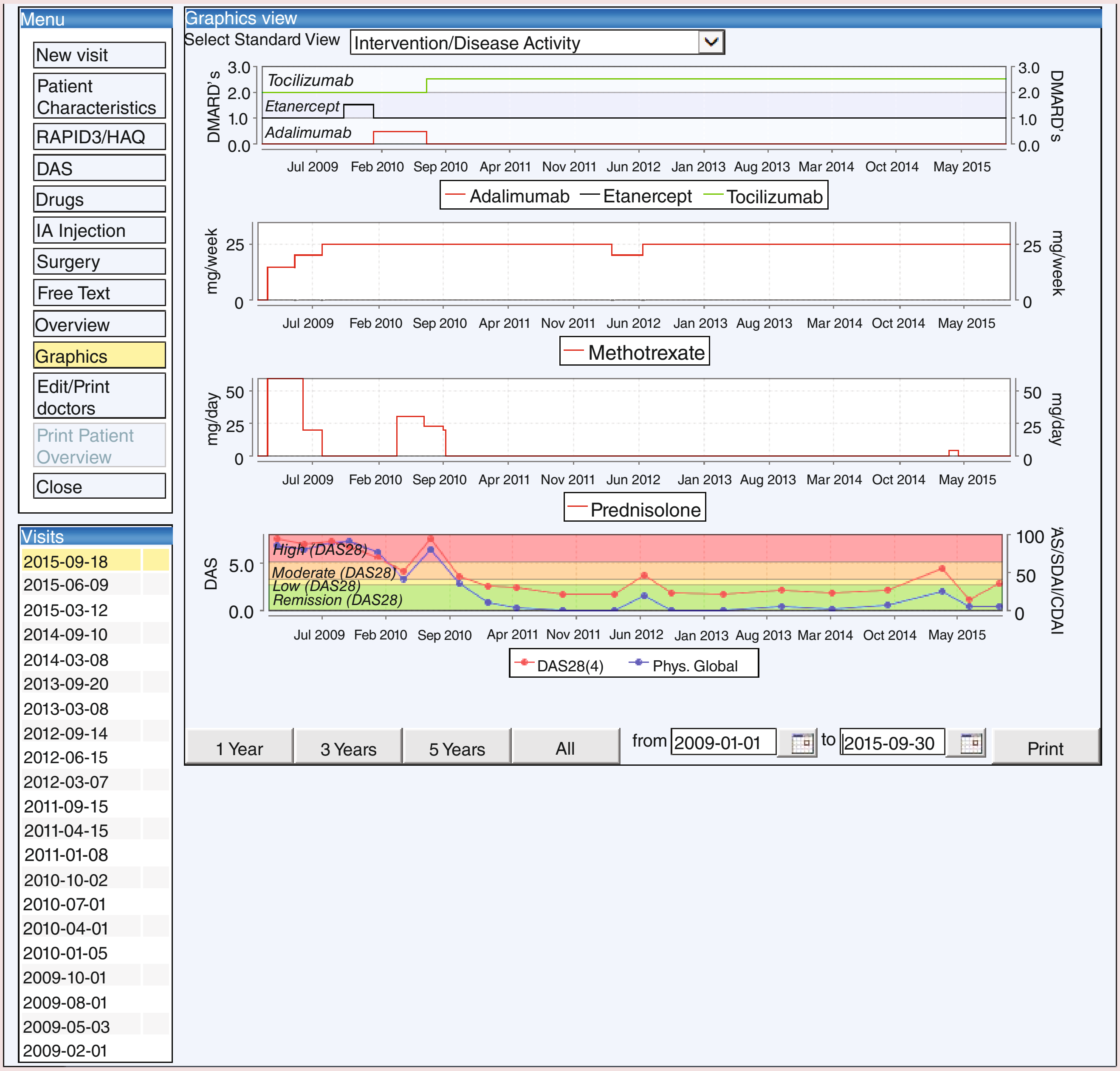
Research using the METEOR database

Real-life data entered into the METEOR database can be used to answer various research questions. This is of great value, since much clinical research is conducted within therapeutic trials that have inclusion and exclusion criteria, which result in the subjects not being representative of those RA patients who are seen in clinical practice.

Over the past decade, abstracts of studies based upon the METEOR database have been presented at the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR) annual scientific meetings and at other national meetings, and extended reports have been published in high impact rheumatology journals [17,18,21–30].

A recent publication by Gvozdenović *et. al.* compared individual patient's and physician's assessments of global disease activity (PtGDA and PhGDA, respectively) and demonstrated moderate agreement between PtGDA and PhGDA (intraclass correlation coefficient = 0.57). On a 100 mm visual analog scale, patients scored an average of 11 units higher (worse) than rheumatologists. Patients scored GDA higher than their physicians when the visual analog scale pain score was elevated, while physicians scored GDA higher than patients when the swollen joint count and ESR levels were elevated. Patients and physicians consider many similar factors when assessing GDA; however, they have a different focus. Patients base their judgment primarily on the level of pain (subjective factor), whereas physicians base their judgment primarily on the levels of swollen joint count and ESR (objective factors). Patients base their assessments on needs, priorities, experiences, expectations and attitudes, while physicians rely on the patient's physical health status. Overall, patients rate global disease activity consistently higher than their rheumatologists [29].

Another study that was published recently by Navarro-Compán *et al.* tested the feasibility of collecting, storing, retrieving and analyzing the information necessary to fulfill a preliminary set of ten quality indicators (QIs) that were proposed by an international task force. In this large multinational clinical practice database of patients with RA, they also looked at whether the country in which the patients are followed influences the feasibility of implementing these QIs. Time to diagnosis, frequency of visits and disease activity assessment



Select Standard View: Intervention/Disease Activity

from 2009-01-01 to 2015-09-30

Visits:
2015-09-18
2015-06-09
2015-03-12
2014-09-10
2014-03-08
2013-09-20
2013-03-08
2012-09-14
2012-06-15
2012-03-07
2011-09-15
2011-04-15
2011-01-08
2010-10-02
2010-07-01
2010-04-01
2010-01-05
2009-10-01
2009-08-01
2009-05-03
2009-02-01

Figure 1. Example of a graph automatically generated by the METEOR tool, helpful to rheumatologists while making treatment decisions.

at least once a year are examples of those ten QIs. For most of the QIs, it was demonstrated that it is feasible in clinical practice to collect and systematically record data in an electronic database and to retrieve these data to assess quality of care. This study had limitations, including wide variation between countries in the number of patients and visits recorded by rheumatologists. However, with the large number of patients recorded in the METEOR database, the authors were able to show that QIs can be used across countries, despite differences in approaches to practice across healthcare systems [30].

Conclusion

With the widespread adoption of EHRs in many countries, the time that physicians spend with patients is increasingly used to document these encounters. Maintaining a patient–physician interaction in the setting of EHRs presents a challenge for the practitioner. Tools, such as METEOR, assist in the collection of parameters that are useful in routine clinical care, as well as for research and benchmarking. By easing documentation of the physical examination, patient reported outcomes and calculated disease activity measures, such tools facilitate quantitatively driven management of RA and other diseases and will thereby help to improve treatment outcomes.

Future perspective

Objective demonstration of disease activity has become important in this era of ‘treat-to-target,’ as rheumatologists strive to achieve tight disease control and attain remission in their patients. Routine assessment of RA disease activity is beneficial to patient care, both to justify escalation of therapy and to document disease activity.

We expect this practice of quantitatively-driven management of RA to expand over the coming years and to become standard of care in clinical practice. In most European countries, documentation and reporting of RA disease activity measures is already required to justify the prescription of effective, but costly, medications and to demonstrate the quality of care provided to health insurance providers and government agencies. In contrast, in the USA, there is not yet a government mandate to report disease activity measures. However, demonstrating quality of care is becoming increasingly important and nongovernmental third party payers may request that rheumatologists provide disease activity scores, particularly during the approval process when initiating or continuing a biologic agent.

The METEOR initiative was developed to assist rheumatologists in calculating and recording measures of disease activity and physical function. Moreover, METEOR can play an important role in linking and comparing other registries. The METEOR database also serves as a useful resource with which rheumatologists can benchmark care: individual rheumatologists and/or centers can use METEOR to compare outcome measures of the care that they provide to their patients to those of care delivered to patients at other centers around the world.

Financial & competing interests disclosure

KI Salomon-Escoto is employed by the Merit Foundation as the METEOR national coordinator for the USA. R van den Berg is employed by the Merit Foundation as the METEOR international coordinator. J Kay is the METEOR country lead for the USA and is a member of the METEOR Executive Scientific Committee. D van der Heijde is a member of the Merit Foundation Board and the METEOR Executive Scientific Committee. The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

Executive summary

Background: value of following measures of disease activity in clinical practice

- The availability of biologic therapies for rheumatoid arthritis has made remission a realistic therapeutic goal.
- Tight control of rheumatoid arthritis disease activity can improve outcome.

The Measurement of Efficacy of Treatment in the ‘Era of Outcome’ in Rheumatology (METEOR) tool

- Stand-alone web-based tool, freely available for rheumatologists worldwide to monitor rheumatoid arthritis patients over time in daily practice.
- Helps both patient and physician to monitor disease activity by visualizing trends over time.
- The Measurement of Efficacy of Treatment in the ‘Era of Outcome’ in Rheumatology (METEOR) database
- Contains data from >37,500 patients and >175,000 visits of 32 countries that is available for benchmarking and research.
- A wide variety of research questions can be answered using data from the METEOR database.
- Research based on the Measurement of Efficacy of Treatment in the ‘Era of Outcome’ in Rheumatology (METEOR)
- database has been published.

Conclusion

- The need to monitor disease activity easily in clinical practice will increase and tools, such as METEOR, will assist rheumatologists in measuring and monitoring patients’ disease activity.

Future perspective

- Documentation and reporting of rheumatoid arthritis disease activity measures is important.
- Striving for clinical remission will become standard of care, over the next several years, and the need to register disease activity to justify therapy escalation/tapering will increase accordingly.

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