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# OPAL: a clinician driven point of care observational data management consortium

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Received on August 1, 2014; accepted in  
revised form on September 10, 2014.

*Clin Exp Rheumatol* 2014; 32 (Suppl. 85):  
S150-S152.

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EXPERIMENTAL RHEUMATOLOGY 2014.

**Key words:** rheumatoid arthritis,  
OPAL, registry database

## ABSTRACT

*A vast amount of important information on the various rheumatic diseases that the rheumatologist treats is available in the medical records derived from the patient consultation. Until recently, it has been difficult to assemble and interpret this data. Moreover, the 'everyday' rheumatologist seeing the 'everyday' patient often does not contribute data to better understanding of 'everyday' clinical issues. We discuss an approach to this problem by describing a blending of a customised electronic medical record with a consortium of like-minded clinicians. We feel that this approach demonstrates the powerful potential for targeted point of care data collection in rheumatology research and patient management.*

Optimising Patient outcomes in Australian rheumatology (OPAL), a Quality Use of Medicines Initiative (QUMI), is point of care-derived observational registry database. Currently, over 14,000 rheumatoid arthritis (RA) patients are being followed. The OPAL consortium uses Audit 4, (Software for Specialists, Sydney, Australia) which is an electronic patient management programme. This was adopted as the platform for a QUMI by Roche Products Pty Limited (Australia) in 2009, with the development of focused data collection workbooks embedded into the programme. As of March 2014, 64 Australian rheumatologists use this same electronic medical record as part of OPAL, with patient- and disease-specific details captured during the routine physician-patient consultation. This information thus represents real-life data and reflects all aspects of everyday care of the patient. An example of an Audit 4 worksheet for RA joint score evaluation is shown in Figure 1.

As the rheumatologist examines the patient, he/she enters on the homunculus,

one click for tender joint, two clicks for swollen joints and three clicks for tender and swollen joints. The "Gather" button is then pressed which electronically collates the latest ESR and CRP pathology results within 30 days of the point of care entry. The rheumatologist then makes a manual entry for physician and patient global, patient pain (which the patient has already completed in the waiting room along with a HAQ-II/MDHAQ for RAPID3 scoring). The software automatically calculates the composite disease activity scores DAS28 ESR, DAS28 CRP, CDAI and SDAI at the time of assessment with charting of activity. Discussion of these results with the patient relevant to decision making then occurs during the consultation.

All other relevant pathology and investigations are downloaded as required. Drug start and stop dates, reasons for discontinuation are recorded. Prescription printing and other standard features of an electronic medical record are available.

The Audit 4 software used by members of the OPAL consortium also includes application forms that are required by Australian government regulatory authorities for subsidised biologic DMARD prescriptions in RA, psoriatic arthritis, ankylosing spondylitis and juvenile idiopathic arthritis.

The individual rheumatologist retains their own patient data on their local server and is able to independently audit their own clinical practice data at any time.

OPAL being an observational registry database, is also designed to conduct large multi-centre clinical audits to answer Australian rheumatological practice research questions. Data (de-identified by patient, clinic and clinician) can be exported from each of the OPAL members local server to a central server for analysis based on a pre-defined ethics-approved protocol.

*Competing interests: none declared.*

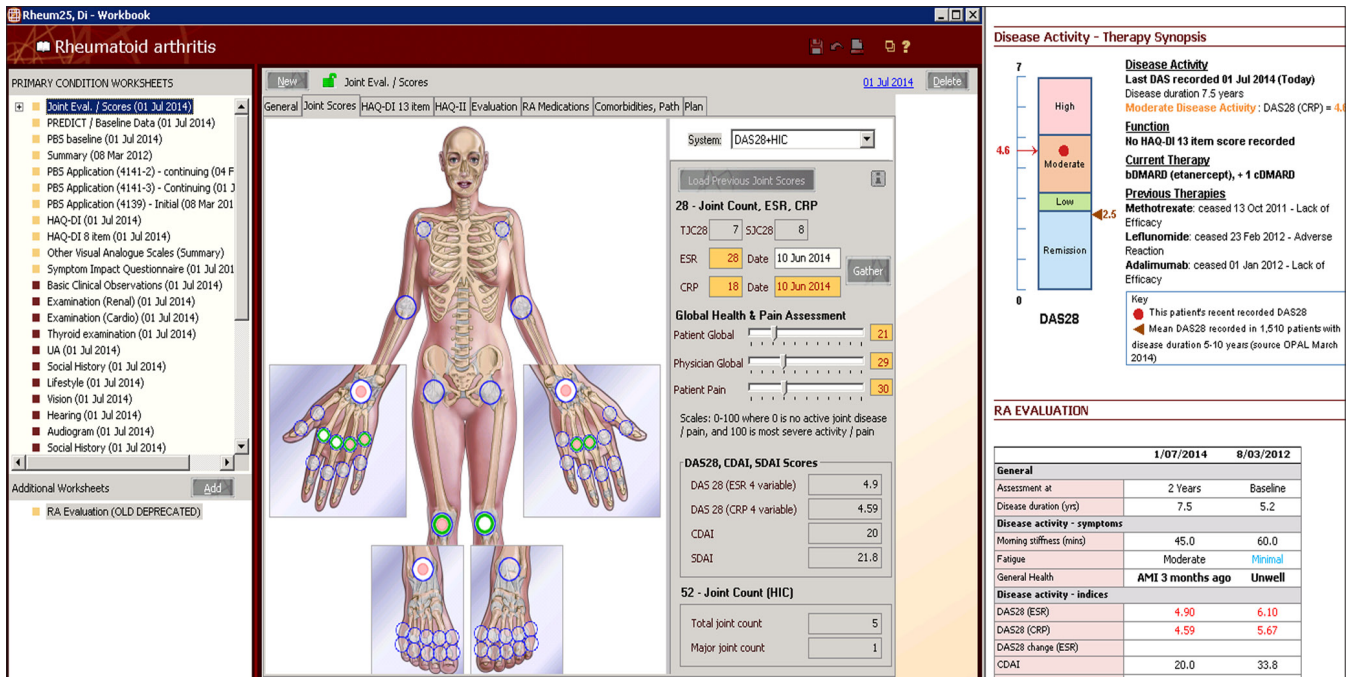


Fig. 1. An Audit 4 worksheet for RA joint evaluation.

To date, OPAL have conducted a number of studies to answer research questions from rheumatologists; these include:

- **SMILE** – This study assessed the safety of treating RA with a combination of methotrexate and leflunomide compared with methotrexate alone (a combination previously dictated by Australian government requirements prior to approval for subsidy for biologic accessibility) (1).
- **REMISSION 1** – This cross-sectional analysis of 2973 RA patients within the data base assessed current levels of disease activity. Within the cohort at that time 41.6% were in remission, 18.6% were in low disease activity (LDA), 31.6% were in moderate disease activity (MDA) and 8.2% were in high disease activity (HDA) (2).
- **MDA** – This study evaluated barriers to optimal disease control for RA patients with MDA or HDA in the clinical practice setting using the DAS28 ESR score. This study evaluated the reasons a rheumatologist elected to continue monitoring a patient with MDA or HDA rather than modify DMARD therapy to achieve LDA or DAS28 ESR remission. The study suggested patient self-reported characteristics of the DAS28 measure were influenced by irreversible joint

damage (19.7%) and non-inflammatory pain (9.2%), in addition to patient resistance and lack of physician-initiated change. As a consequence, we since believe there may well be a change in management strategy from rheumatologists within the OPAL group (3).

- **REMISSION 2** – This study evaluated the disease activity trends in 8458 Australian RA patients each year over a 5-year time frame. A significant trend to lower MDA (28.1%) and higher remission status (45%) was noted. Biological DMARD use within the cohort had increased from 22.8 to 37.9% (4).

We have noted a steady increase in the frequency of use of DAS and HAQ scores, as two measures of data quality, over the time frame of the OPAL project. We recognise that, as the available data is only that which is collected at the time of the clinical consultation, time constraints can limit entry of all possible data at every visit. Familiarity of the rheumatologist with the electronic record and ongoing improved *user-friendly* software are facilitating more complete data entry over time. The improvement in RA patient disease activity and rheumatologist recording of a disease activity measures

in this Australian cohort is likely to be attributed to two different but interrelated items. Firstly, there is increased focus on treat to target, increased availability of biologic DMARDs and more clarity in recognising remission as the goal in the general rheumatology community. Secondly, the availability of the OPAL Audit 4 software, which allows for calculation of disease activity scores at point of care assessment and discussion with the patient of their results and management plan, facilitates better quality of relevant patient management data.

We feel that all of this has improved individual patient and Australian rheumatology community health outcomes, which has been the aim and focus of the project. Our ongoing aim is to develop disease specific modules in other conditions, such as psoriatic arthritis, ankylosing spondylitis, systemic lupus erythematosus, among others, in order to better use the information that is accumulating on these disorders within the electronic medical record. The OPAL consortium has shown that observational data derived from everyday clinical care by community rheumatologists can generate large amounts of clinically useful data on aspects of care relevant to our patients' needs.

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