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Acta Med Port 2016 Feb;29(2):83-84 • <http://dx.doi.org/10.20344/amp.7243>

Keywords: Portugal; Registries; Rheumatic Diseases.

Palavras-chave: Doenças Reumáticas; Portugal; Sistemas de Registos.

Registries provide vital information for long-term observational studies by collecting data on individuals with a specific disease or condition. For healthcare professionals these are key instruments aimed not only at a better understanding of the natural history of diseases, but also at the results of therapeutic interventions and their effectiveness and safety in daily clinical practice. Registries use observational study methods, and have the advantage of providing information from the real world, which may overcome some limitations of randomized clinical trials (RCT). As they include both a large number of patients and long-term follow-up, registries can capture information on particular patient groups under-represented or not included in RCTs, as well as on rare clinical events or outcomes.

Patient registries and databases for rheumatic diseases have been established worldwide, but not all of them have the same purpose: some are drug-centred, others are centred on patient-reported outcomes, some aim to obtain safety data, while others collect mainly efficacy information. Behind all these projects is the idea that registries can help understand disease – its course, outcomes and burden – in a real life setting.

Being aware of the importance of registries, one of the strategic objectives of the Portuguese Society of Rheumatology a decade ago was the development of the Rheumatic Diseases Portuguese Register, named Reuma.pt. The availability of biological therapies fuelled this idea since it was consensual among rheumatologists that the use of these new, very effective but also expensive medications justified close monitoring. Standardization of procedures among rheumatology departments was already underway, such as the adoption of patient monitoring protocols,¹⁻³ and the publication of recommendations for the use of biological therapies in inflammatory rheumatic diseases.⁴ Thus, the initial aim of Reuma.pt was the monitoring of safety and efficacy of biological therapies.

The first module of Reuma.pt, the registry for patients with rheumatoid arthritis (RA) treated with biotechnological agents, was completed and became active in 2008. Since

then, other protocols that include validated instruments for other rheumatic conditions were developed. Besides the registry of RA patients, specific protocols for monitoring patients with ankylosing spondylitis (AS), psoriatic arthritis (PsA), juvenile idiopathic arthritis (JIA), systemic lupus erythematosus (SLE), early arthritis, osteoarthritis (OA), autoinflammatory syndromes, vasculitis and scleroderma became available.⁵ Several screens are identical across all databases, such as identification, demographics, work status, lifestyle, comorbidities, patient reported outcomes, laboratorial results, medication, adverse events, tuberculosis screening and observations, while others are disease-specific. The information is stored in a common IT platform and patients can migrate from one protocol to another without losing information, e.g. early arthritis to RA or from synthetic to biological DMARDs. The overall goal is to prospectively record data on rheumatic patients from all rheumatology departments (public and private practices in mainland Portugal, Madeira and Azores Islands), treated with biotechnological therapies as well as with synthetic disease modifying anti-rheumatic drugs (sDMARD) and other therapeutic strategies, so as to determine the efficacy and safety of treatments and associated long-term comorbidities and outcomes. The online version has been available since April 2012 (at www.reuma.pt), which has resulted in exponential growth. An English version is also available. There are currently 76 participating centres, more than 13 700 patients included and more than 100 000 visits registered. Reuma.pt has obtained the approval of the Portuguese Data Protection Authority and of the Ethics Committees of participating institutions.

Reuma.pt is intended for use as an electronic medical record, thus the frequency of patient visits is entered according to clinical practice. Patients may access their own area and complete the patient reported outcomes before the medical visit. Other functionalities facilitate follow-up and monitoring and support clinical decision: checklists of procedures to be performed prior to initiating biological therapy, preformatted reports and letters for the primary

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Recebido: 24 de novembro de 2015 - Aceite: 18 de dezembro de 2015 | Copyright © Ordem dos Médicos 2016



care physician, automatic calculation of disease activity scores and response criteria, evolution graphs, summary tables of patient status, and a final report of each visit that can be printed out or copied to another electronic support avoiding duplication or work. The regular use of validated instruments for monitoring disease activity in clinical practice is a way of improving and maintaining the quality of care of rheumatic patients.

Most importantly, Reuma.pt is an invaluable resource for clinical research in Rheumatology. Data can be exported and analysed in specific statistical software. Exportation can be performed individually at each centre, or centrally encompassing anonymised data sets from multiple centres. Several scientific projects based on the analysis of data from Reuma.pt have resulted in presentations in major rheumatology meetings and publications in national and international peer-reviewed journals.

Collaborations with other registries (METEOR, RELESSER, CERRERA, EUROFEVER, PHARMACHILD, PANABA), with national authorities (INFARMED, DGS), with other national medical scientific societies (such as Dermatology and Association for Study of the Liver) and with other countries (such as UK and Brazil) have been established and continue to contribute to the expansion of Reuma.pt.

After eight years of existence we can conclude that Reuma.pt is an example of success not only as a scientific and clinical tool, but most importantly as a unifying project of Portuguese rheumatologists. Nevertheless, as Reuma.pt growth, the responsibilities and challenges increase. The quality and accuracy of data must be continuously controlled, and strategies to avoid missing data and to assure patient retention developed, all while ensuring funding and the sustainability of this project.

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