

Reuma.pt – structure and innovation

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The importance of registries for knowledge of the natural history of diseases, and for the identification of rare adverse events or those that arise late and are not captured in clinical trials, is widely recognized. Aware of this importance, back in 2008 the Portuguese Society of Rheumatology (SPR) developed and launched the Rheumatic Diseases Portuguese Register or *Registo Português de Doenças Reumáticas* (Reuma.pt), an innovative instrument whose characteristics are unique in our country. The introduction of biological therapies as part of clinical practice has only strengthened this proposal, as it was already a consensus among rheumatologists that the deployment of such new therapies warranted appropriate monitoring, to ensure the use thereof under conditions with a favourable risk-benefit balance. However, the potential of Reuma.pt has very much exceeded these aspects. For example, Reuma.pt allows the standardization and improvement of clinical practice in the field of rheumatology, captures the impact of disease and treatments in various domains of patient health and well-being, or acts as support for decision-makers.

Many rheumatology centres had taken up standardised procedures, compliant with the monitoring protocols and SPR recommendations for the use of biological therapies; as a result, participation in Reuma.pt was a natural consequence of this fact.

Ever since first created, Reuma.pt has posted a constant and consistent growth. Indeed, what started out as a registry aimed at patients diagnosed with Rheumatoid Arthritis, Ankylosing Spondylitis, Psoriatic Arthritis and Juvenile Idiopathic Arthritis treated with biotechnological therapies was later gradually widened in scope, to include patients treated with classic immunomodulatory therapies and to include other rheumatic diseases. Ten years on, Reuma.pt includes pathologies as varied as Osteoarthritis, Systemic Lupus Ery-

thematosus, Systemic Sclerosis, Sjögren's Syndrome, Systemic Vasculitis, Early Arthritis, and Auto-Inflammatory Diseases. The number of centres actively contributing to the registry has increased steadily and now stands at 82. The number of patients being monitored now stands at over 18,250 and the number of visits has reached 150,000. Every year, an execution report containing essential data about the effectiveness and safety of therapies is drawn up and made publicly available.

At the end of 2012, the online version (at www.reuma.pt) became available, enabling standardised following and also real-time registration of all patients, meaning that Reuma.pt in fact works as a fully structured electronic medical record. The English version was set up in 2014, and since then several new features have been developed, making it easier to register and monitor the patients in real-time, and also to help with clinical decisions. Examples of such features include lists of inconsistencies; search through filters; sharing of patients between different centres; checklists with the procedures to be carried out before the start of biotechnological therapies; automatic calculation of composite disease activity scores and response criteria; graphs showing disease evolution through follow-up; summary charts showing the patient's clinical situation and the final report on the medical appointment, which may be printed, or copied to a different type of electronic support mechanism, thus avoiding duplicated work; and supplying clinical data and metrics that enable response to administrative issues, as well as being a support mechanism for making clinical decisions.

Reuma.pt also seeks to proactively get the patients involved in the handling of their diseases. Indeed, the patients may take part by accessing the "Patient's Area" and filling in the questionnaires prior to the medical appointment (HAQ, BASDAI, BASFI, SF36, EQ5D, HADS, FACIT, etc). For this, the assistant doctor just needs to grant them access rights, to access the self-completing questionnaires, on the face page of the patient's area. During the appointment, such questionnaires are kept available for the physician to see, which

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speeds up and facilitates the appraisal process.

The management of Reuma.pt is the responsibility of the Coordination and Scientific Committee (*Comissão Coordenadora e Científica - CCC*). The main mission of this team is to maintain and develop the registry, to improve its quality, and to manage the access and use of the collected data. Each participating centre shall have at least one representative on the National Committee, that is also the contact element with the CCC.

The use of Reuma.pt and the insertion of data is done on an entirely voluntary basis. Any rheumatologist or rheumatology fellow may use this tool, provided he or she is registered by another physician or sends in a joining request form, which is available on the Reuma.pt website. The register is also available for colleagues from other specialities who follow rheumatic patients, as is the case of paediatrics.

Some years ago, Reuma.pt surpassed the national borders and is now available not only in several Brazilian centres specialised in paediatric rheumatology, but also in the United Kingdom.

The data included are property of each participating centre, which has access to this information at any time. Access to anonymised global data can be obtained by submitting a scientific project, whose pertinence and relevance are appraised by the CCC.

The number of projects submitted and under way have increased recently, and this has given rise to multiple presentations at scientific meetings and to publications in national and international scientific journals.

Reuma.pt has established protocols for collaboration with other scientific societies, with universities, and also with regulatory authorities within the scope

of pharmacovigilance and monitoring of prescriptions. More recently, a protocol was signed, with the aim of applying artificial intelligence and automatic learning techniques to the processing of non-structured fields of Reuma.pt, in order to infer new and relevant knowledge.

Additionally, collaboration networks were established with registers from other countries, allowing the analysis of an enormous amount of information.

The success of Reuma.pt was only possible thanks to the wide consensus and to the unifying nature of this Project. The management structure was consolidated, and currently comprises an informatics engineer, a biostatistician, and a project manager.

With the growth and the development of Reuma.pt, there was also an increase in responsibilities and challenges. The quality and accuracy of the data must be controlled on an ongoing basis, strategies to avoid omissions in data, ensure that the patients are retained had to be implemented, and, at the same time, the sustainability of the project must be assured.

In short, what started out as a registry for the efficacy and safety of biologic medication later became an agent promoting an improvement in health care provided to rheumatic patients and, simultaneously, a boost in the knowledge and investigation of Rheumatology, now being the jewel of the crown at the Portuguese Society of Rheumatology, and also being absolutely essential for growing scientific affirmation.

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