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EDITORIAL

Reuma.pt – a dynamic registry supporting clinical practice and research in rheumatology

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[#]Scientific Committee of Reuma.pt for the bienium 2024-2026
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Reuma.pt is the national research platform of Portuguese rheumatology. Created in 2008 as an integrated electronic clinical record based on structured data and designed as a real-world database for people living with rheumatic and musculoskeletal diseases, it has successfully fulfilled its original objectives[1,2]. Its broad disease coverage – comprising 14 disease-specific and two generic protocols for other rheumatic diagnoses in adults and children – together with an easy online access and a governance model that ensures direct data access for contributing centers, has established Reuma.pt as one of the flagship initiatives of the Portuguese Society of Rheumatology (SPR).

As of December 2025, 71 Portuguese and seven Brazilian centers were actively contributing data to Reuma.pt (defined as having entered new data within the previous three years), from a historical maximum of 112 participating centers. The registry currently includes more than 42,000 patients and 360,000 clinical visits. Approximately 29% of patients are receiving biologic or targeted synthetic disease-modifying antirheumatic drugs (b/tsDMARDs) – 27% on bDMARDs and 2% on tsDMARDs – according to 2024 data. The registry shows an average annual growth of approximately 10% in the total number of registered patients. The largest disease cohorts are rheumatoid arthritis (RA) (n = 12,006), spondyloarthritis (SpA) (n = 7,219), psoriatic arthritis (PsA) (n = 4,388), osteoporosis (n = 2,771), and systemic lupus erythematosus (n = 2,721), as of June 2025[3].

Over time, Reuma.pt has expanded both in size and data quality, reflecting the progressive maturation of the registry (Figure 1). Its governance model now includes a national coordinator and a Coordination and Scientific Commission composed of eight additional members (including a deputy coordinator, a dedicated pre-award member, and project-specific leads, as applicable). The platform is supported by a full-time project manager and study coordinator working in close collaboration with the SPR secretariat, a system analyst liaising with outsourced web design, healthcare data technology, and artificial intelligence companies, and a designated Data Protection Officer. Reuma.pt operates under a structured regulatory framework that includes: (1) the regulation of the Coordination and Scientific Commission; (2) the regulation for access, use, and disclosure of data registered in Reuma.pt; and (3) the regulation for the implementation of new protocols and platform features. The Reuma.pt ecosystem has progressively expanded beyond rheumatologists and patients to include other health professionals, patient organizations, and academic institutions.

Since 2013, a fully dedicated patient interface has enabled the systematic collection of patient-reported outcomes (PROs) across all protocols. These include measures of disease activity, quality of life, physical function, physical activity, and work productivity (absenteeism and presenteeism). In 2023, this interface was redesigned into a mobile-friendly version through close collaboration with patient organizations, healthcare professionals, researchers, and software engineers. The Reuma.pt Patient Area was reconceptualized to serve as a self-management support tool, strengthening the collection of PROs, improving communication between people living with RMDs and healthcare professionals, and fostering health literacy and patient empowerment.

Reuma.pt has facilitated and promoted investigator-initiated clinical trials. This was achieved through the integration of a purpose-built randomization module functioning as an interactive web response system for blinded patient allocation in randomized controlled

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trials, together with interoperability with a pharmacy-dedicated platform for investigational product management (Reuma.pharmacies). Acting simultaneously as an electronic case report form, protocol-specific data capture screens with restricted access were successfully used in the GO-DACT, ViscOA, and Bioefficacy trials[4].

In response to the COVID-19 pandemic, Reuma.pt joined the European Alliance of Associations for Rheumatology (EULAR) COVID-19 Database initiative in 2020. A dedicated module was rapidly developed to collect clinical data on SARS-CoV-2 infection in patients with rheumatic diseases. In 2021, an additional protocol was launched to evaluate the effectiveness and safety of COVID-19 vaccination in this population, illustrating the registry's adaptability and responsiveness to emerging public health challenges[5,6].

Reuma.pt has also expanded beyond the field of rheumatology. Over the years, SPR supported other Portuguese scientific societies in the development of similar research platforms. In collaboration with the Portuguese Society of Dermatology, Derma.pt was created for patients with psoriasis[7,8]. Subsequently, Liver.pt was established in partnership with the *Associação Portuguesa para o Estudo do Fígado*, covering a wide range of liver diseases, including viral hepatitis, hemochromatosis, alcoholic liver disease, Wilson disease, non-alcoholic fatty liver disease, and primary biliary cholangitis, among others[9]. More recently, in 2020, Uveite.pt was developed in collaboration with the Portuguese Ocular Inflammation Group of the Portuguese Society of Ophthalmology[10]. While technical development relied on the Reuma.pt team, scientific input and field definition were provided by the respective specialty societies. Formal inter-societal agreements were established, with some platforms evolving toward independent governance models and others maintaining technical support from the SPR.

In parallel, Reuma.pt has established strong collaborations with governmental bodies, including INFARMED and the Direcção Geral de Saúde (DGS). Safety data recorded in Reuma.pt are communicated monthly to INFARMED and include adverse event descriptions, onset dates, severity, organ/system classification, causality assessment, clinical evolution, and therapeutic interventions, allowing for direct pharmacovigilance notification. These data are aligned with national pharmacovigilance requirements and allow INFARMED to directly contact responsible physicians to complete any additional regulatory information.

Overall, Reuma.pt has profoundly transformed real-world rheumatology research in Portugal. Initially conceived as a registry focused on patients treated with biologic DMARDs, it has evolved into a highly flexible and dynamic platform supporting a wide range of scientific projects. Since 2011, a total of 119 research projects have been submitted to Reuma.pt[3]. The process for investigator-initiated studies has become progressively more structured and is now conducted through the Reuma.pt website. Each proposal undergoes an initial technical review addressing requested variables, ethical considerations, and authorship, followed by scientific appraisal by at least two members of the Coordination and Scientific Commission and the relevant interest group rapporteur. The national coordinator oversees all stages and provides final approval, while the Commission monitors project progress and reviews final outputs.

Reuma.pt has also extended beyond national borders through multiple international collaborations. The first international partnership was established in 2011 with the METEOR database, a multinational observational initiative capturing routine clinical practice in RA and later SpA,

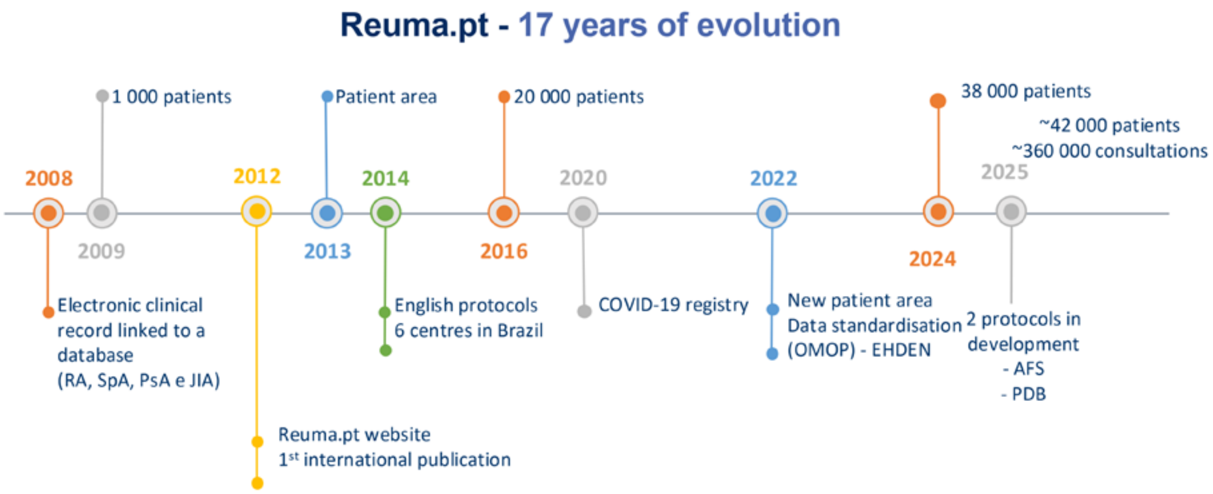

Figure 1. Reuma.pt relevant millestones over the last 17 years
RA: rheumatoid arthritis; SPA: spondyloarthritis; PsA: psoriatic arthritis; JIA: Juvenil Idiopatic Arthritis; AFS: Antiphospholipic syndrome; PDB: Paget's Disease of Bone

leading to the registry's first international publications[11-13]. Since then, Reuma.pt has participated in several collaborative initiatives, including CERERRA, PANABA, TOCERRA, RELESSER, EUROSpA, EDHEN, MeRITA and JAK-pot, among others. Through these collaborations and resulting publications, Reuma.pt has gained international recognition among rheumatology experts and scientific leaders.

This sustained scientific activity has resulted in 177 publications in national and international peer-reviewed journals and 169 presentations at scientific meetings. Research themes have frequently included disease characterization, treatment effectiveness and comparative effectiveness, predictors of disease activity and therapeutic response, comorbidities and genetic association studies[14]. Reuma.pt has also served as the research platform for numerous Master's and PhD theses in rheumatology.

Furthermore, while initially developed for the registration of RA, radiographic axial SpA, and PsA patients receiving biologic therapies, Reuma.pt has become a nationally recognized database and a reference model for other medical specialties, particularly in monitoring biologic prescriptions. It is now consensual among Portuguese rheumatologists that all patients initiating bDMARDs – and more recently tsDMARDs – should be registered and followed using standardized Reuma.pt protocols. In accordance with national regulations (Portarias no. 48/2016, no. 351/2017, and no. 261/2024), the Portuguese Government established the responsibility to maintain a national registry of patients treated under exceptional reimbursement regimes for RA, SpA, PsA, psoriasis, Crohn's disease, and ulcerative colitis. Reuma.pt fulfills this role by enabling assessment of treatment effectiveness, adherence, and safety, and by remaining available for regulatory inspections. A standardized "Registo Mínimo" report, compliant with the official requirements, provides essential information to the Pharmaceutical Services of the National Health Service and can be exported across all required Reuma.pt protocols.

Rigorous and continuous quality assurance, systematic strategies to minimize missing data, and measures to ensure long-term patient retention are essential to ensure Reuma.pt's sustainability and scientific credibility. What began as a platform for monitoring the safety and effectiveness of biologic therapies has evolved into a strategic driver of excellence in rheumatologic care and high-impact clinical research supported by the SPR. Given its contribution to scientific advancement, the harmonization of patient monitoring nationwide, its relevance to national health system performance, and its collaborations with scientific societies and regulatory authorities, we believe Reuma.pt has profoundly transformed rheumatology practice in Portugal and shaped national medical perspectives on the value of structured patient data collection and clinical registries.

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