

CoReumaPt Project: The Portuguese Cohort of Rheumatic Diseases

BACKGROUND: Rheumatic diseases (RD) have a variety of clinical manifestations and their prognosis is influenced by several factors. Cohorts and registries have contributed to important epidemiologic knowledge about the disease course and the long-term outcomes of RD. The Portuguese Society of Rheumatology (SPR) developed a national register (Reuma.pt) for inflammatory RD (rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis and juvenile idiopathic arthritis), but so far no further nation-wide registries or cohort of patients with other relevant chronic RD have been established in Portugal, such as, osteoporosis, osteoarthritis, systemic lupus erythematosus, polymyalgia rheumatica, fibromyalgia, gout, periarticular diseases and non-specific low-back pain.

OBJECTIVES: CoReumaPt aims to be a national prospective cohort to further explore outcomes research of chronic RD and to assess factors influencing the development and progression of RD. CoReumaPt will also enable the evaluation of the economic impact and the burden of RD in Portugal.

METHODS: An open cohort is being created, initially composed by the randomly selected population of the ongoing cross-sectional National Epidemiological Rheumatic Diseases study (EpiReumaPt) and subsequently by other sources, namely through self- and physician's referral. Follow-up will be performed with annual self-administered questionnaires, in order to systematically collect and analyze outcomes of interest, mainly patient-reported outcomes. Data concerning less frequent assessments, such as radiographs and biomarkers, will also be assembled.

RESULTS: So far 2411 subjects were interviewed at home with a questionnaire to detect symptoms of RD. 1625 subjects with a positive screening (suspected RD) and 176 with no rheumatic symptoms were invited for the rheumatologist's assessment with standardized evaluations. 1053 subjects have accepted to participate in the CoReumaPt project and signed the Informed Consent. Out of these enrollees, 638 were already evaluated in a rheumatology baseline visit.

CONCLUSIONS: CoReumaPt will be a valuable resource for epidemiologic research and will deliver pivotal information to improve public health policies concerning the prevention and the management of RD in Portugal. Being nationwide, population-based and mainly derived from a random sampling technique are among the strongest aspects of our approach.