

EpiDoC Unit – a clinical research unit open to the rheumatology community

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EpiDoC is an epidemiology and outcomes research unit, with a main focus in Rheumatology clinical research but also in other non-communicable chronic diseases. Established in 2016, it is located at NOVA Medical School¹ – CEDOC, and integrates the Comprehensive Health Research Center (CHRC)², a clinical and public health research unit, scored Excellent by Fundação Ciência e Tecnologia (FCT) 2019's evaluation.

In Portugal, clinical and public health research have been developed in primary care units and hospitals but often with low support of specialized offices such as research funding office, biostatistics and data management office, clinical research units, etc.

To attend to this unmet need, we established EpiDoC unit aiming at providing scientific information of excellence, gathering health and diseases issues and covering clinical, social, economic and population aspects.

EpiReumaPt (EpiDoC 1)^{3,4}, a large epidemiological study of rheumatic diseases, collected information of a national representative sample of 10,661 participants in Mainland and Islands, retrieving the prevalence of the most relevant rheumatic diseases as well as demographic, socio-economics and clinical data associated with them. This study was performed in collaboration with Portuguese Society of Rheumatology, NOVA University, National Directorate of Health (DGS) and Universidade Católica Portuguesa and was conducted between 2011-2013. Blood samples, DXA and x-Rays imaging were also collected. Two new waves were performed in 2013-2015 (EpiDoC 2) and 2015-2016 (EpiDoC 3), evaluating the same participants, and building up the EpiDoC Cohort study⁵. In 2021, ten years after

the first evaluation, we will evaluate for the last time these participants (EpiDoC 4).

Importantly, all data are available for researchers by submitting research projects to the scientific committee. Data access form can be found at <http://cedoc.unl.pt/epidoc-unit/>. We encourage all the rheumatology fellows and rheumatologists to work with EpiDoC team to advance clinical research in rheumatology and find the support of a multidisciplinary team involving different medical specialties, nutritionists, psychologists, statisticians and biomedical sciences' researchers.

Currently, we are also carrying out the project “B-active: a training protocol for patients with paediatric rheumatic diseases”, which aims to evaluate the motor competence of Portuguese children with rheumatic diseases, and to develop a training protocol that can be easily practiced by these children. The propensity of patients with paediatric rheumatic diseases to be hypoprotective - often due to social self-isolation, overprotection, and fear and/or ignorance on the part of parents, teachers and health practitioners - can be detrimental to general disease symptoms and function. In Child and Adolescent Rheumatology Department (CARD) of EpiDoC we are also developing an app in which patients with juvenile rheumatic diseases have suggestions for healthy style programs, videos and stress management strategies. It is also our aim to develop training actions in schools, in order to increase the awareness of juvenile rheumatic diseases in the school community.

EpiDoC Unit team has expertise in surveys, chronic disease registries, observational studies and management of large databases including a wide range of data: demographic, life habits, clinical, pharmacological, socio-economic, labor, quality of life (QoL), imaging, genetic and laboratorial data. Training and mentoring of master, doctoral and post-doctoral students are also a Unit's major activity.

Besides adult and pediatric rheumatic diseases and other chronic diseases research, EpiDoC is also dedi-

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cated to help patients and vulnerable population groups to improve their health. We are committed on promoting educational and training strategies using information and communications technology (ICT, internet, apps and smart TV tools). The Unit has also experience in conducting interventional studies using these new ICTs⁶. With this, we expect to contribute to patient empowerment, to reduce inequities in health and to provide evidence for public health policies. Ongoing projects include the development of new technologies (internet, apps, smart TV) as tools to improve health and to monitor disease. We are designing and applying online platforms, apps and TV programs to collect objective measures and clinical monitoring refining individual follow-up of chronic disease patients. These tools are also applied as educational and motivation tools as well as in interventional studies namely to promote life healthy habits. The collaborations with national and international partners as well as the participation in several networks and international projects are a key advantage.

Projects which we are involved now and for that invite rheumatologists and fellows are:

- Develop, test and apply innovative forms of “measure” health condition in patients with rheumatic and other chronic diseases through new technologies such as internet, apps, smart TV, using patient oriented strategies;
- Identify health access and health consumption inequalities among patients with rheumatic diseases and citizens in general;
- Identify predictors of morbidity and mortality among rheumatic and other non-communicable chronic diseases;
- Study the influence of clinical and socio-demographic and life style characteristics (nutrition, physical activity) in health outcomes in the Portuguese population;
- Determine the burden of different rheumatic and other non-communicable chronic diseases on the functional capability, work status, social and economic outcomes;
- Monitor the effectiveness and safety of rheumatic and other chronic diseases’ treatments in a "real-world" setting;
- Provide community services in the prevention, detection and treatment of rheumatic and other chronic diseases and in the education of the population;
- Characterize SARS COV2 exposure among EpiDoC participants and in a longitudinal study of previously infected people;
- Different projects where we are using artificial intelligence and new ICTs to study frail elderly, disorders associated to work, therapy adherence and COVID features (cough patterns recognition).

Our ultimate goal is to provide tools and support to students, fellows and researchers, to develop, boost and elevate clinical research in rheumatology and, in the end, to better serve the clinical care and policies in rheumatology.

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