

THE PORTUGUESE REGISTRY OF RHEUMATIC DISEASES:

THE STRATEGY BEHIND MERGING THE ELECTRONIC MEDICAL RECORD, RESEARCH DATABASES AND PATIENTS' REGISTRIES

Paulo J. Nicola¹, Fernando Martins¹, João Tedim¹, Helena Canhão², João E. Fonseca²

¹ Epidemiology Unit, Institute for Preventive Medicine, University of Lisbon Medical School, Portugal

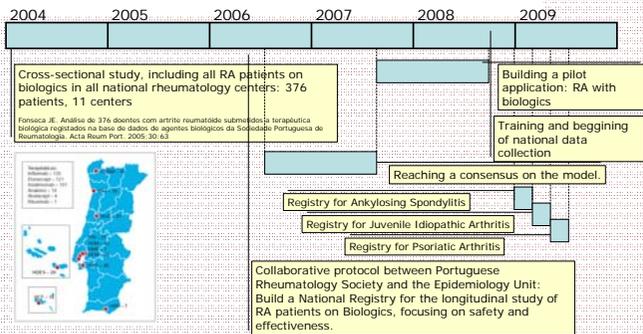
² Institute of Molecular Medicine and Department of Rheumatology, University of Lisbon Medical School, Portugal

OBJECTIVES

To present the **model**, the **requirements** and **strategic approaches** of the **Portuguese Registry of Rheumatic Diseases**, aiming to integrate an **Electronic Medical Record (EMR)**, with **research data collection** and **national patient registry** capability.

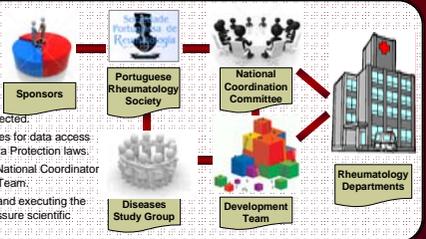
BACKGROUND

- The number of national patient' registries has been increasing for rheumatic diseases, as elsewhere, with growing number of participants, time under observation, and research publications.
- While registries are a powerful tool for research, they are also demanding in terms of human, financial and institutional resources, requiring strategies to deal with these challenges.
- We propose a strategy which has been built in research and institutional experience since 2004. These have been the project phases:



GOVERNANCE

- The Portuguese Rheumatology Society owns the Registry.
- The Study Groups provide recommendations regarding variables to be collected, data definition and classification, as well as minimum data to be collected.
- The National Coordinator Committee is to assure rules for data access and the compliance with Ethical Permissions and Data Protection laws.
- Rheumatology Departments are represented in the National Coordinator Group and also relate directly with the Development Team.
- The Development Team is responsible for planning and executing the technical development of the registry, as well as to assure scientific quality of its data.



METHODS I

A DEDICATED ELECTRONIC MEDICAL RECORD AS A SUPPORT TO THE NATIONAL REGISTRY

- 1) Patient management**
 - Security access, password validation, Registration of new doctors.
 - Data export
 - Print the patients appointment report
 - Unique national identification number, which allow linking to death certificate
 - Customization according to the Medical Department choices
 - Quick search for patients
 - List of appointments from the selected patient
- 2) Calendar/Plan of appointments, and drug administrations**
 - Calendar of appointments and drug administrations
- 3) Patient synopsis and activity profile**
 - Data collection forms during the appointment, which are different for each disease, patients going biologics, and patients in special research protocols
 - Patient's report of clinical problems, drug history, surgeries, etc.
 - Calendar overlap of disease activity scores and lab values
 - Creating an appointment report, which may be edited and printed

- 4) Longitudinal update of clinical data**
 - Messaging of errors and alerts
 - For each appointment, there is only need to update data (clinical problems, drug changes, etc.)
- 5) Registration of drug adverse events**
 - Registration of drug adverse events
- 6) Activity scores**
 - Calculating the ACR response

In close collaboration with the Portuguese Society of Rheumatology Arthritis Study Group and the Ankylosing Spondylitis Study Group

CONTACTS:
Paulo Nicola <pnicola@fm.ul.pt>

www.bioreportar.org

METHODS II

CLINICAL RESEARCH ASPECTS ASSOCIATED TO THE ELECTRONIC MEDICAL RECORD / NATIONAL REGISTRY

- 1) Missing data**
 - Calculation of risk factors scores and burden
 - List of missing data indicated before closing the appointment
 - Denying conditions
- 2) Use of questionnaires**
 - Health Assessment Questionnaire (HAQ)
- 3) Use of standard classifications**
 - For instance, diseases are classified using the MedDRA, supported by search functionalities.
- 4) Including research protocols**
 - Modified Sharp Classification

CONCLUSIONS

After extensive tests, a model for the Portuguese Registry of Rheumatic Diseases has been reached. The next aim is to maximize its utility, measured by data introduction by rheumatologists, use during appointments, and research use.

The EMR included a total of 560 variables and 70 classifications. As of May 2009, the ongoing data collection added to 441 patients.

FUTURE PERSPECTIVES

Currently, the team is developing the web version of the electronic medical record, which will greatly facilitate updating the software, keeping the central data base updated and provide access to national statistics for comparison.

The application will develop further to allow clinical alerts and clinical protocols of quality assurance.