THE PORTUGUESE REGISTRY OF RHEUMATIC DISEASES: THE STRATEGY BEHIND MERGING THE ELECTRONIC MEDICAL RECORD, RESEARCH DATABASES AND PATIENTS’ REGISTRIES

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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 in research and institutional experience since 2004. These have been the project phases:

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<th>Year</th>
<th>Project Phase</th>
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<tr>
<td>2004</td>
<td>Cross-sectional study, including all RA patients on biologics in all national rheumatology centers: 376 participants, 41 new centers and 117 new patients on biologics</td>
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<td>2005</td>
<td>Building a pilot EMR: RA with security access, cross-sectional study of all RA patients on biologics, starting and registering of national data collection, reaching a consensus on the model</td>
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<td>2006</td>
<td>Collaborative protocol between Portuguese Rheumatology Society and the Epidemiology Unit: Build a National Registry for the longitudinal study of RA patients on Biologics, focusing on safety and effectiveness</td>
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<td>2007</td>
<td>Training and beginning of national data collection</td>
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<td>2008</td>
<td>Calculating the ACR response</td>
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<td>2009</td>
<td>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.</td>
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METHODS I

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

1) Patient management
2) Calendar/Plan of appointments, and drug administrations
3) Patient synopsis and activity profile
4) Longitudinal update of clinical data
5) Registration of drug adverse events
6) Activity scores

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.

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.