REUMA.PT/LES: THE EXPERIENCE OF TWO CENTRAL HOSPITALS IN LISBON

S. Sousa[1], M. J. Gonçalves[2,3], R. Roque[1], F. Vinagre[1], A. Cordeiro[1], F. Godinho[1], M. J. Saavedra[2], F. Ramos[2], C. Macieira[2], H. Canhão[2,3], J. E. Fonseca[2,3], C. da Silva[1], J. A. Pereira da Silva[2], M. J. Santos[1,3]

[1] Department of Rheumatology, Hospital Garcia de Orta, Almada; [2] Department of Rheumatology and Bone Metabolic Diseases, Hospital de Santa Maria, Lisboa; [3] Rheumatology Research Unit, Instituto de Medicina Molecular, Faculdade de Medicina da Universidade de Lisboa, PORTUGAL

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Introduction

Reuma.pt, the Rheumatic Diseases Register from the Portuguese Society of Rheumatology has recently expanded its coverage to Systemic Lupus Erythematous (SLE) patients, the Reuma.pt/LES.

Reuma.pt/LES is a web-based platform launched in September 2012 that simultaneously serves as a nationwide longitudinal registry and as an electronic medical record.

Its aim is to prospectively collect clinical and laboratory data, in a standard way, from a large number of SLE patients in order to increase the knowledge of the disease, while improving the quality of clinical care.

Objectives and Methods

○ To present the structure and functioning of the application Reuma.pt / LES

○ To describe SLE patients from two participating centers of the Lisbon area - Hospital Garcia de Orta (HGO) and Hospital Santa Maria (HSM) – followed in the Reuma.pt/LES

○ Patients fulfilling ACR classification criteria for SLE and registered until 31th January 2013 were included in the analysis

Results

The Portuguese registry of lupus patients - Reuma.pt/LES

	Nº of participating centers	Nº of patients registered	Nº of visits
June 2013	48	1440	2148

Reuma.pt/LES description

○ Access protected by username and password;

○ **First menu**: create a new patient, new visit, edit previous visits and choose different protocols; (Figure 1)

○ **Common screens across all databases:** identification, demographic data, work status, life styles, body mass index, previous medical history, co-morbidities, laboratorial results form, past and current therapies, adverse events, tuberculosis screening, observations/notes;

○ **SLE specific screens:** ACR and SLICC 2012 classification criteria, thrombotic and obstetric manifestations, SLE disease activity at each visit, fatigue scale, health related quality of life measures, irreversible damage; (Figure 2)

○ **Summary data report:** After data collection, Reuma.pt can generate a pre-formatted report, integrating all information and also an evolutionary framework; (Figure 3)

○ All screens are printable.

Figure 1 – Main menu of Reuma.pt database

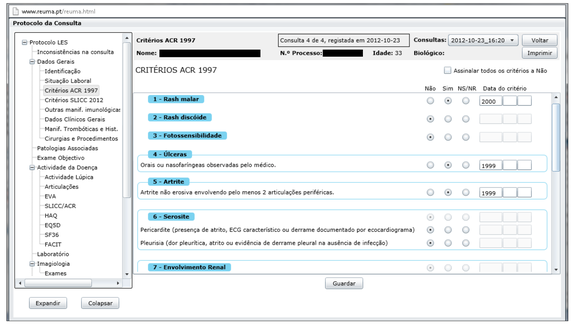

Figure 2 – Reuma.pt screen for SLE patients

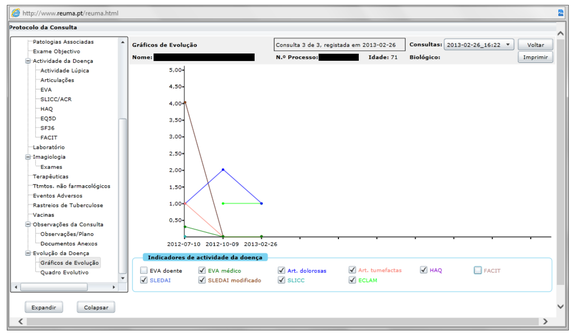

Figure 3 – Reuma.pt screen for evolutionary framework

Demographic and clinical characteristics of SLE patients from HGO/HSM

- 305 patients, 95.1% Women, 80% Caucasians
- Number visits/patient: 2,06 +- 2,96
- Mean age at diagnosis: 35.9 ± 14.9 years
- Disease duration at enrollment into Reuma.pt/LES:10.3 ± 7.3 years
- SLE Disease Activity Index (SLEDAI): 3.4 ± 3
- Damage (SLICC): 0.7 ± 1.1
- Comorbidities: Hypertension 27.2%, Diabetes mellitus 8.9%, Hypercholesterolemia 3.9%; Cardiovascular diseases 8.9%; Malignancies (except lymphoma) 6.7%

SLE Classification Criteria ACR 1997	Criteria Satisfied
1. Malar rash	**45,2%**
2. Discoid rash	**8,6%**
3. Photosensitivity	**46,5%**
4. Oral ulcers	**38,6%**
5. Arthritis	**82,6%**
6. Pleuritis or pericarditis - Pericarditis - Pleuritis	**31,8%** 23,1% 23,5%
7. Renal Disorder - Persistent proteinuria > 0.5 grams /day or > than 3+ - Cellular casts	**37,1%** 36,1% 10,5%
8. Neurologic disorder - Seizures - Psychosis	**9,9%** 6,8% 5,3%
9. Hematologic disorder - Hemolytic anemia - Leukopenia - Lyphopenia - Thrombocytopenia	**67,9%** 11,1% 38,1% 45,7% 33,6%
10. Immunologic disorder - Anti-DNA in abnormal titer - Antiphospholipid antibodies	**88,6%** 86,4% 33,6%
11. Positive antinuclear antibodies	**96,2%**

Most Common Therapeutic Options	% Patients
Hydroxychloroquine	93.9%
Corticosteroids	75.1%
Immunosuppressive drugs **. Azathioprine / Methotrexate / Cyclophosphamide / Mycophenolate mofetil / Cyclosporine / Leflunomide**	27% / 15.5% / 7.4% / 4.8% / 3.4% / 1.4%
Biological therapies **. Rituximab / Belimumab**	5.9% / 0.98%

Safety Data- Adverse events reported	Number
Infections	5
Ocular disorders	4
Blood and lymphatic system disorders	3
Nervous system disorders	3
Gastrointestinal disorders	2
Immune system disorders	2
Vasculopathy	1

7 SERIOUS ADVERSE EVENTS

Rituximab – seizures (1) and severe infusion reaction (1)

Cyclophosphamide - seizures (1), bacterial pneumonia (1) and septicemia(1)

Azathioprine: cytopenia (2)

Conclusions

Our preliminary data support the important role of Reuma.pt/LES in the evaluation and follow-up of lupus patients. Reuma.pt/LES allows standardized prospective data collection, storage and analysis, with the ultimate objective of improving the quality of care and patient outcomes. At the same time, this registry is a useful tool for scientific research in the field of SLE.

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Sandra Sousa, sandrainsousa@gmail.com