

REUMA.PT/LES: THE PORTUGUESE LUPUS REGISTER

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Introduction

The Rheumatic Diseases Register from the Portuguese Society of Rheumatology has expanded its coverage to Systemic Lupus Erythematosus (SLE) - Reuma.pt/LES. It is a web-based platform launched in September 2012 that simultaneously serves as a nationwide registry and as an electronic medical record. Its aim is to register all patients with SLE and follow them up in a standard manner in order to improve the monitoring and clinical care for patients with SLE while increasing the knowledge of this disease.

Objectives and Methods

- To present the structure and functioning of the application Reuma.pt/LES
- To characterize Portuguese SLE patients
- All SLE patients registered in Reuma.pt/LES until 31th December 2013 and fulfilling ACR classification criteria were included in the cross-sectional analysis at the last visit

Results

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

	N.º of participating centers	N.º of patients registered	Number visits/patient:
December 2013	50	1510	2.06±2.28

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, comorbidities, 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 evolution framework; (Figure 3)

Demographic and clinical characteristics of SLE patients	n (%)
Women	1388 (92%)
Age (years)	47.7 ± 14.9
Ethnicity	1427(94.5%) Caucasian; 69(4.6%) Black; 14(0.9%) Other
Education (years)	9.35 ± 4.9
Disease duration (years)	13.8 ± 8.9
Malar rash	560 (41.4%)
Discoid rash	103 (7.6%)
Photosensitivity	656 (48.5%)
Oral ulcers	415 (30.7%)
Arthritis	971 (71.7%)
Serositis	272 (20.0%)
Renal involvement	393 (29.4%)
Neurologic disorder	65 (4.8%)
Hematologic disorder	851 (63.2%)
Anti-DNA positivity	1025 (75.6%)
Anti-Sm positivity	149 (11.4%)
Anti-cardiolipin positivity	361 (28.5%)
ANA positivity	1321 (97.3%)
Anti-SSA/Anti-SSB positivity	284 (38.3%) / 139 (18.9%)
Anti-RNP positivity	161 (22.7%)
Low complement	843 (67.7%)
Anti-phospholipid syndrome	49 (7.6%)
SLEDAI-2K (last visit)	2.53 ± 3.18
SLICC/ACR Damage Index	0.7 ± 1.23

Comorbidities	n (%)
Hypertension	202 (31.5%)
Thyroid disease	69 (10.8%)
Sjögren's syndrome	68 (10.6%)
Diabetes Mellitus	46 (7.2%)

Medication used for SLE	n (%)
Antimalarials (ever)	957 (63.3%)
Corticosteroids (ever)	756 (50%)
Other immunosuppressants (ever)	
Azathioprine	284 (18.8%)
Methotrexate	128 (8.5%)
Cyclophosphamide	37 (2.5%)
Cyclosporine	17 (1.1%)
Mycophenolate mophetil	112 (7.4%)
Biological therapies (ever)	41 (2.7%)

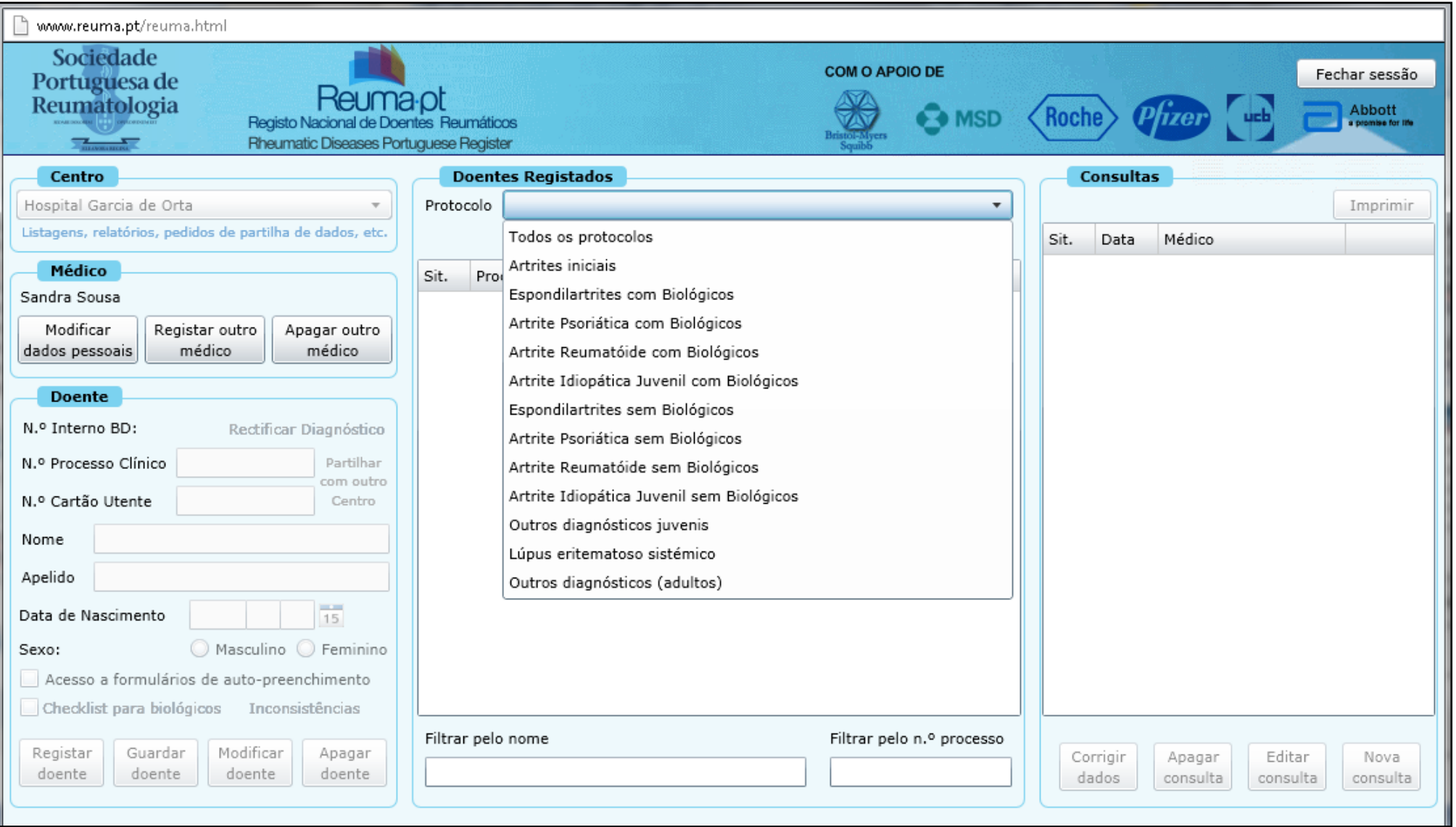


Figure 1 – Main menu of Reuma.pt database

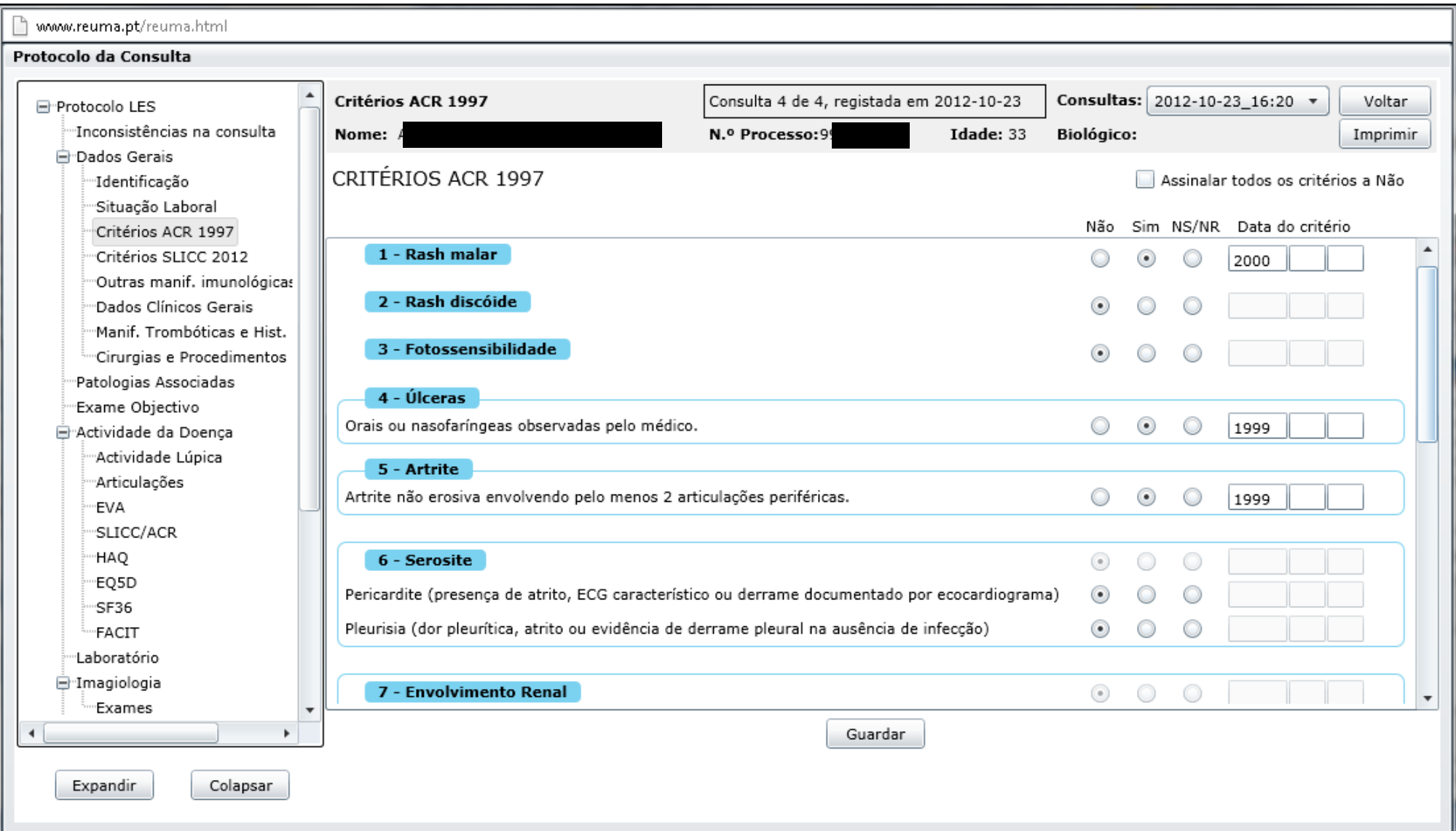


Figure 2 – Reuma.pt screen for SLE patients



Figure 3 – Reuma.pt screen for SLE evolution over time

Conclusions

Reuma.pt/LES is a very useful tool that allows a more efficient patient follow-up, and standardized data collection and analysis, with the ultimate objective of improving patient care and simultaneously scientific research in the field of SLE.