REUMA.PT/LES: THE PORTUGUESE LUPUS REGISTER



Registo Nacional de Doentes Reumáticos Rheumatic Diseases Portuguese 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.

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

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

2013

The Portuguese registry of lupus patients - Reuma.pt/LES					
	N.º of participating centers	N.º of patients registered	Number visits/patient:		
December	50	1510	2.06±2.28		

Reuma.pt/LES description

o Access protected by username and password;

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

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

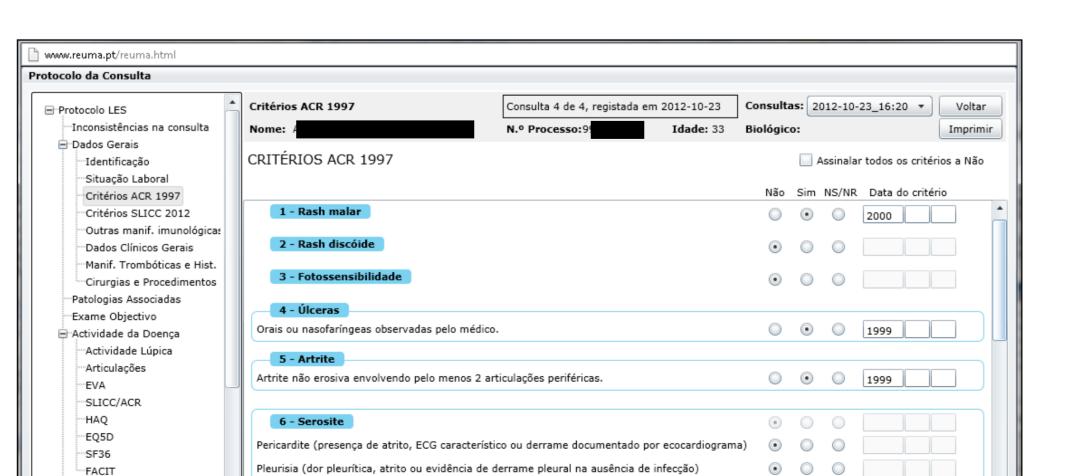
o **Common screens across all databases:** identification, demographic data, work status, life styles, body mass index, previous medical history, co-morbidities, laboratorial results form, past and current therapies, adverse events, tuberculosis screening, observations/notes;

o **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)

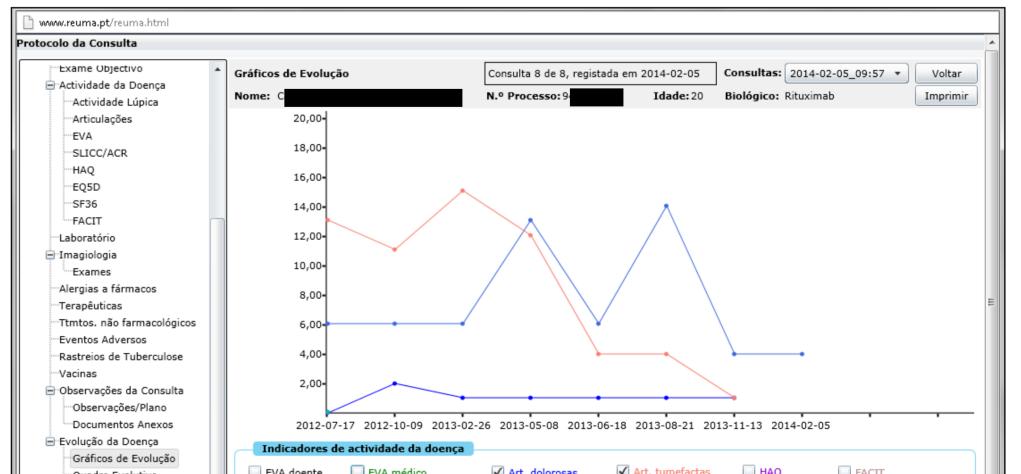
o **Summary data report:** After data collection, Reuma.pt can generate a preformatted report, integrating all information and also an evolution framework; (Figure 3)

Sit. Data Médic

Fechar sessão



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%)



Acesso a formulários de auto-preenchimento Checklist para biológicos Inconsistências			
Registar Guardar doente Guardar doente doente doente doente	Filtrar pelo nome	Filtrar pelo n.º processo	Corrigir dados Apagar consulta Editar consulta consulta

COM O APOIO DE

B MSD (Roche

⊡ Imagiologia Exames -	7 - Envolvimento Renal	•		-
	Guardar			
Expandir Colapsar				

Quadro Evolutivo	EVA doente	EVA médico SLEDAI modificado	 ✓ Art. dolorosas ✓ SLICC 	✓ Art. tumefactas ■ ECLAM	HAQ	FACIT	
Expandir Colapsar							

Figure 1 – Main menu of Reuma.pt database

Reumapt

Rheumatic Diseases Portuguese Regist

Todos os protocolo

Espondilartrites com Biológico

Artrite Psoriática com Biológicos

Espondilartrites sem Biológicos

Artrite Psoriática sem Biológicos

Outros diagnósticos juvenis

úpus eritematoso sistémico

Outros diagnósticos (adultos)

Artrite Reumatóide sem Biológicos

Artrite Idiopática Juvenil sem Biológico

Artrite Reumatóide com Biológicos

Artrite Idiopática Juvenil com Biológico

Artrites iniciais

Figure 2 – Reuma.pt screen for SLE patients

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

Conclusions

www.reuma.pt/reu

Sociedade

Portuguesa de

lospital Garcia de Orta

Médico

Modificar

Sandra Sousa

dados pessoais

Doente

N.º Interno BD:

N.º Processo Clínico

N.º Cartão Utente

Data de Nascimento

Nome

Apelido

Sexo

tagens, relatórios, pedidos de partilha de dados, et

Registar outro Apagar outro

ectificar Diagnóstico

Masculino 🔘 Feminin

Partilhar

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.

Reuma.pt was developed with the support of Abbvie, Merck Sharp & Dohme, Pfizer, Roche and UCB

