

# Does the perspective of SLE patients match the expert opinion and definitions of remission and low disease activity state?

## Prospective analysis of 500 patients from a Spanish multicenter cohort.

Coral Mourino Rodriguez<sup>1,2</sup>, Jose Maria Pego Reigosa<sup>1,2</sup>, Inigo Rua Figueroa<sup>3</sup>, Francisco Rubino<sup>3</sup>, Inigo Hernandez Rodriguez<sup>1</sup>, Raul Menor Almagro<sup>4</sup>, Esther Uriarte Isacelaya<sup>5</sup>, Eva Tomero<sup>6</sup>, Tarek Saleman Montes<sup>7</sup>, Maria Irene Carrion Barbera<sup>7</sup>, Maria Galindo<sup>8</sup>, Esther Rodriguez Almaraz<sup>8</sup>, Norman Jimenez<sup>2</sup>, Luis Ines<sup>9</sup>, Irene Altabas Gonzalez<sup>1,2</sup>.  
1.Complejo Hospitalario Universitario de Vigo; 2.IRIDIS (Investigation in Rheumatology and Immune-Mediated Diseases) Group, Galicia Sur Health Research Institute; 3.Hospital Universitario de Gran Canaria Dr. Negrín; 4.Hospital Universitario de Jerez de la Frontera; 5.Hospital Universitario de Donostia; 6.Hospital Universitario de La Princesa, Madrid; 7.Hospital del Mar/Parc de Salut Mar-IMIM, Barcelona; 8.Hospital Universitario 12 de Octubre, Madrid; 9.Centro Hospitalar e Universitario de Coimbra, Portugal.

### INTRODUCTION

There is no information available regarding whether the **patient's perception** of disease activity aligns with current definitions of DORIS 2021 remission and Lupus Low Disease Activity State (LLDAS), nor whether there is concordance between the patient's perception and that of the physician.

**Aim:** To compare the SLE activity perceived by the patient using the Patient Acceptable Symptom State (PASS) question with the global assessment of activity by the physician, as well as with the definitions of LLDAS/DORIS2021.

### METHODS

**Cross-sectional multicenter study of SLE patients from seven Spanish Rheumatology Departments.** **DORIS 2021** remission definition and **LLDAS** were applied and the rheumatologists were asked to classify the **activity of the disease** (remission, SACQ, low, moderate or high activity). Patients answered the **PASS question**: “Considering all the different ways your disease is affecting you, if you were to stay in this state for the next few months, do you consider your current state satisfactory?”: PASS yes/PASS no, and the patient global assessment (PtGA) in a scale of 0-100 scale.

### RESULTS

A total of 503 patients were included in the study (92% female, mean age 50.4 years). 386 (77.4%) had an **acceptable symptom state** according to the PASS question. Mean ( $\pm$ SD) PtGA was 29.62 ( $\pm$ 24.38) and mean physician global assessment (PGA) in a scale of 0-3 was 0.46 ( $\pm$ 0.59). A total of 236 (47.6%) patients met **DORIS 2021** remission and 289 (59%) met **LLDAS (Table 1)**.

Among the patients who answered **"yes" to the PASS question**, 245 (65.5%) were in LLDAS and 220 (57.9%) were in remission according to the DORIS 2021 criteria. Mean PtGA in these patients was 19.7 ( $\pm$ 18) and PGA 0.29 ( $\pm$ 0.4). On the other hand, among **non-PASS group**, 71 (62.8%) patients were not in the LLDAS and 99 (87.6%) did not meet the criteria for DORIS 2021 remission state. Mean PtGA in these patients was 58 ( $\pm$ 19) and PGA 1 ( $\pm$ 0.7) (**Table 2**)

Overall **level of agreement** between PASS question and categorical classification by the rheumatologist was 82% (IC95%: 79.9, 82.9) with a Cohen’s kappa of 0.43.

Table 2. LLDAS and DORIS 2021 remission states according to PASS yes/no perspective by patient.

PASS (n, %)				non-PASS (n, %)			
LLDAS		DORIS		LLDAS		DORIS	
YES	NO	YES	NO	YES	NO	YES	NO
245 (65.5%)	129 (34.5%)	220 (57.9%)	160 (42.1%)	42 (37.2%)	71 (62.8%)	14 (12.4%)	99 (87.6%)
PtGA, mean, SD 19.76 ( $\pm$ 18)				PtGA, mean, SD 58.04 ( $\pm$ 19)			
PGA, mean, SD 0.29 ( $\pm$ 0.4)				PGA, mean, SD 1.01 ( $\pm$ 0.72)			

Abbreviations: PASS: Patient acceptable symptoms state; LLDAS: lupus low disease activity state; PGA: physician global assessment; PtGA: patient global assessment.

Table 1. SLE activity: patient and expert’s perspective

Number (%) or mean ( $\pm$ SD) (n = 503 patients)	
SLE disease state classification by expert	
Remission of SLE	205 (40.9%)
Serologically active, clinically inactive	74 (14.8%)
Low SLE activity	156 (31.1%)
Moderate SLE activity	56 (11.2%)
Severe SLE activity	10 (2%)
PGA at enrolment	0.46 ( $\pm$ 0.59)
Positive PASS question	386 (77.4%)
PtGA at enrolment	29.62 ( $\pm$ 24.38)

Abbreviations: SLE: systemic lupus erythematosus; PGA: physician global assessment; PASS: Patient acceptable symptoms state; PtGA: patient global assessment.

### CONCLUSIONS

The majority of SLE patients reported being in an **acceptable symptom state** according to the PASS question. More than a third of patients in the PASS group were not in remission/LLDAS and approximately 10-35% of the non-PASS group were in a state of remission/LLDAS. It seems that **patient perspective is similar to the physician perspective** in terms of subjective classification, but there are some **differences in terms of LLDAS and DORIS**.