Characterization of SLE Patient Population from the FORWARD Lupus Registry in the US

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RWD61

OBJECTIVES

> The FORWARD Lupus Registry (FLR) is an online longitudinal patient-reported registry in the US, collected through FORWARD, The National Databank for Rheumatic Diseases.[1] Encompassing a broad spectrum of data such as socio-demographics, disease characteristics, Patient-Reported Outcomes (PROs), comorbidities, treatments, and lifestyle patterns, the FLR is a valuable source of patient experience insights. This study describes demographic and clinical characteristics of FLR participants.

METHODOLOGY

> FLR has an open enrollment, with data collected at enrollment and then every six months from patients via biannual surveys. A retrospective analysis was conducted on data from participants with physician-confirmed SLE who completed at least one biannual survey from 1999 through 2023. Participants with missing data for age or sex were excluded (n=131). Descriptive statistics for baseline observations and prevalence rates for comorbidities and hospitalizations across the study period were analyzed. Subgroup analyses on PROs were conducted based on the first response for every patient that have responded to SLAQ and BILD individually.

RESULTS

> Over the study period, patients completed an average of 9 (SD 9.3) biannual surveys (median 5 [IQR 2-13], maximum 47).

> The FLR cohort included 1,902 patients, 93.6% females. The baseline mean age was 50.1 (SD 13.6) years, with a racial/ethnicity distribution as follows: 73.2% White, 15.4% Black, and 11.4% other.

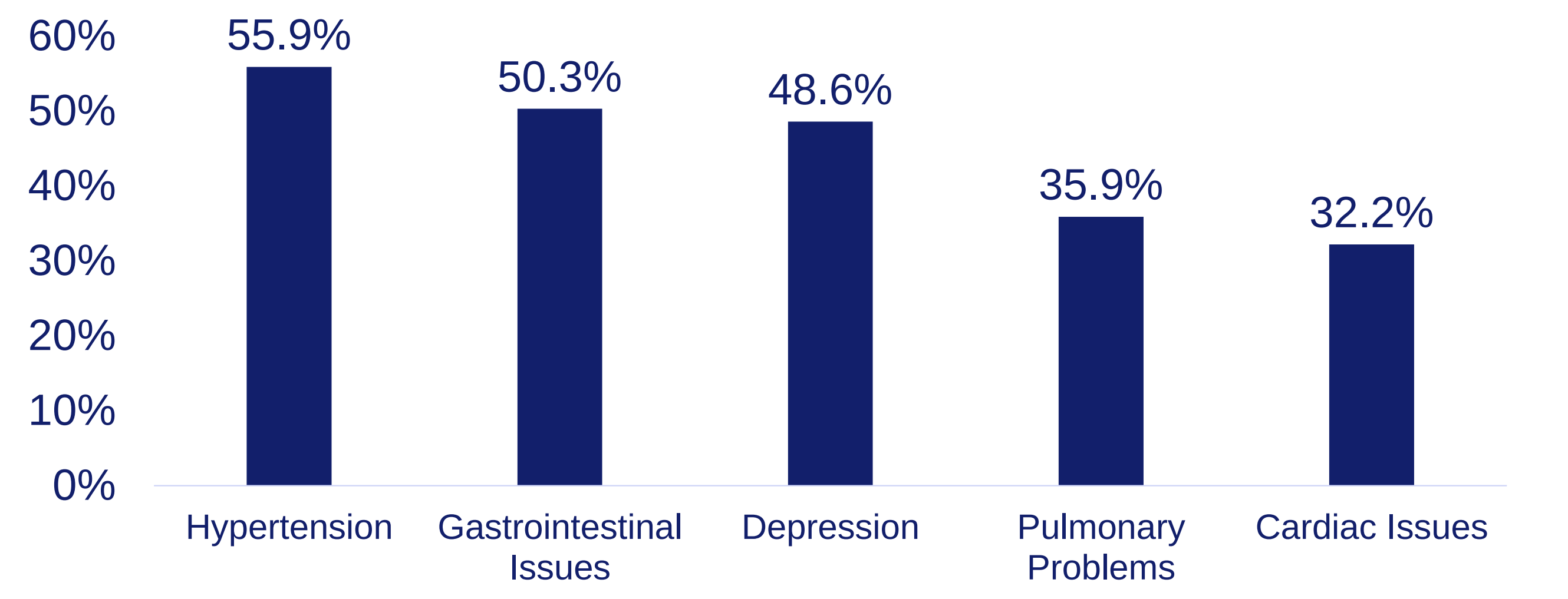
> **Table 1. Demographics at Baseline**

Variable, mean (SD) or %	Overall (n = 1,902)	Females (n = 1,781)
Age in years (SD)	50.1 (13.6)	49.7 (13.5)
Race breakdown (%)		
White	1,200 (73.2%)	1,118 (72.6%)
Black	252 (15.4%)	243 (15.8%)
Other[1]	187 (11.4%)	178 (11.6%)
Marital status (%)		
Married/remarried	1,108 (61.9%)	1,025 (61.1%)
Other[2]	682 (38.1%)	653 (38.9%)
Total annual income in USD (SD)	51,900 (33,500)	51,600 (33,600)
Employment status		
Employed	706 (40.9%)	665 (41.1%)
Other[3]	1021 (59.1%)	952 (58.9%)
Years of education (SD)	14.0 (2.4)	14.0 (2.4)
Insurance type (%)		
Private	601 (31.6%)	572 (32.1%)
Medicare	734 (38.6%)	671 (37.7%)
Medicaid	186 (9.8%)	174 (9.8%)
Others[4]	381 (20%)	364 (20.4%)

[1]Hispanic, Asian or Pacific Islander, American Indian or Alaskan Native
[2]Never married, divorced, separated, widowed
[3]Unemployed, retired, housework, student, disabled
[4]Preferred Provider Organization (PPO), Health Maintenance Organizations (HMO), no insurance

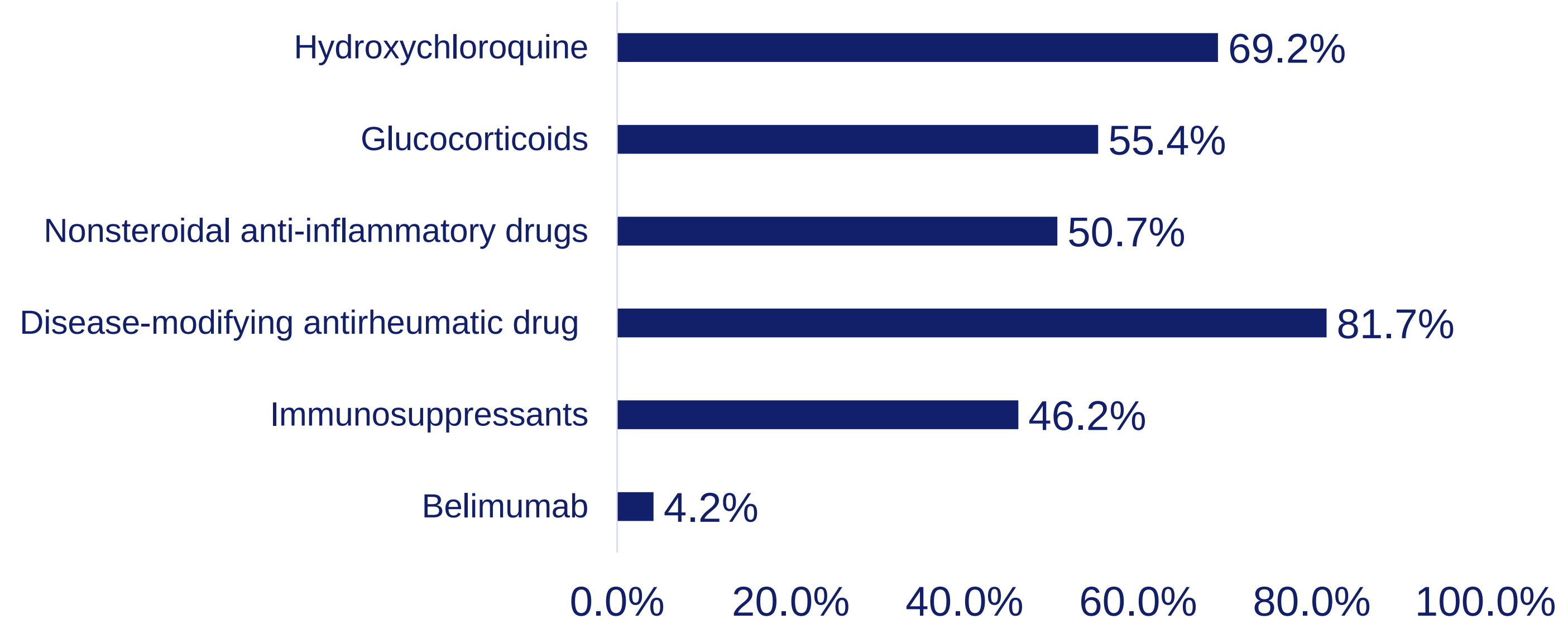
> Mean duration of disease at baseline was 14.4 (SD 11) years

> **Figure 1. Prevalence of Top Five Comorbidities across the Study Period (1999-2023)***



*Participants could have reported multiple comorbidities over the study period. It was required to only report once to be counted in a comorbidity group.

> **Figure 2. Proportion of Patients by Treatment across the Study Period***

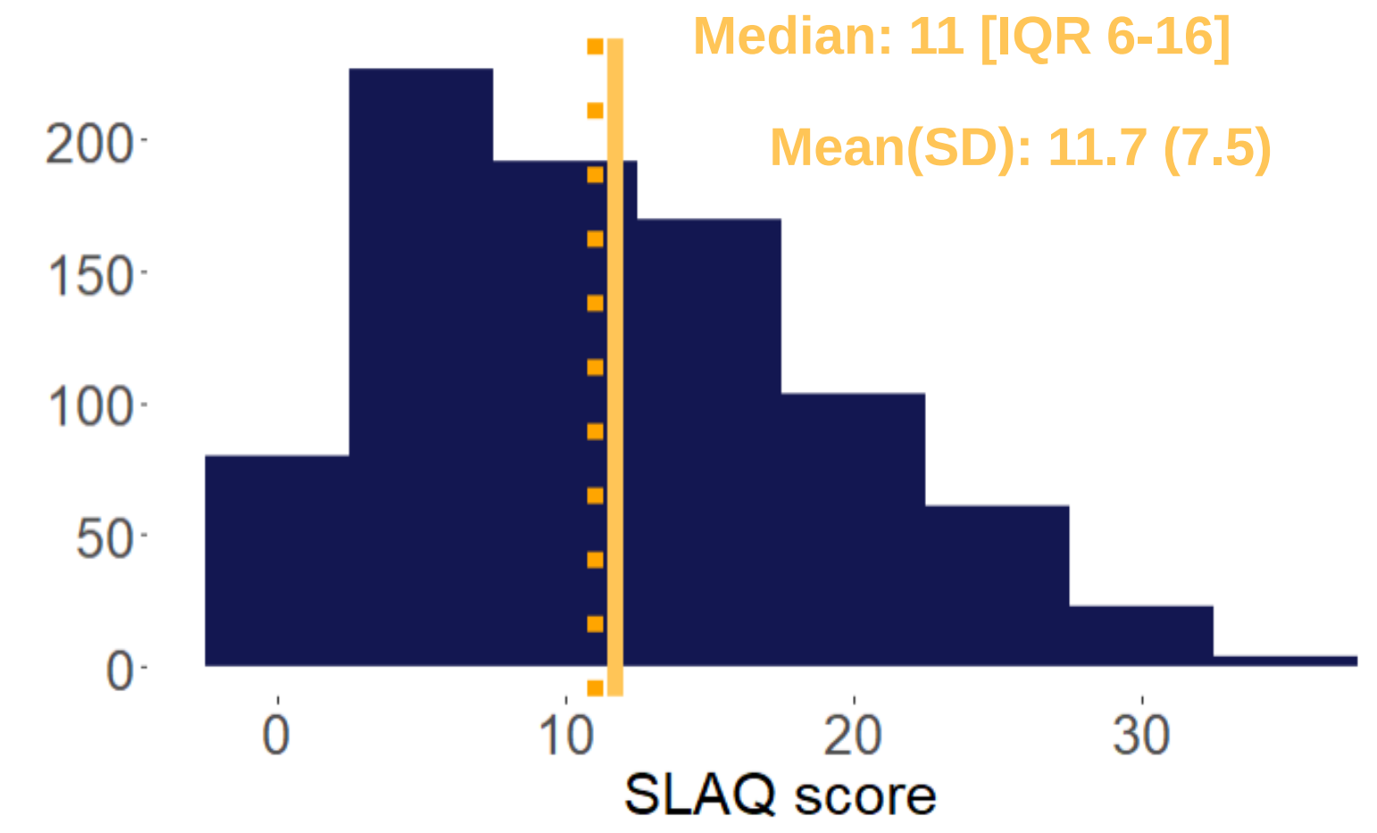


*Participants could have received multiple treatments over the study period. It was required to only report the use of a treatment once to be counted in a treatment group.

> **Table 2. All-cause ER Visits and Hospitalizations across the Study Period**

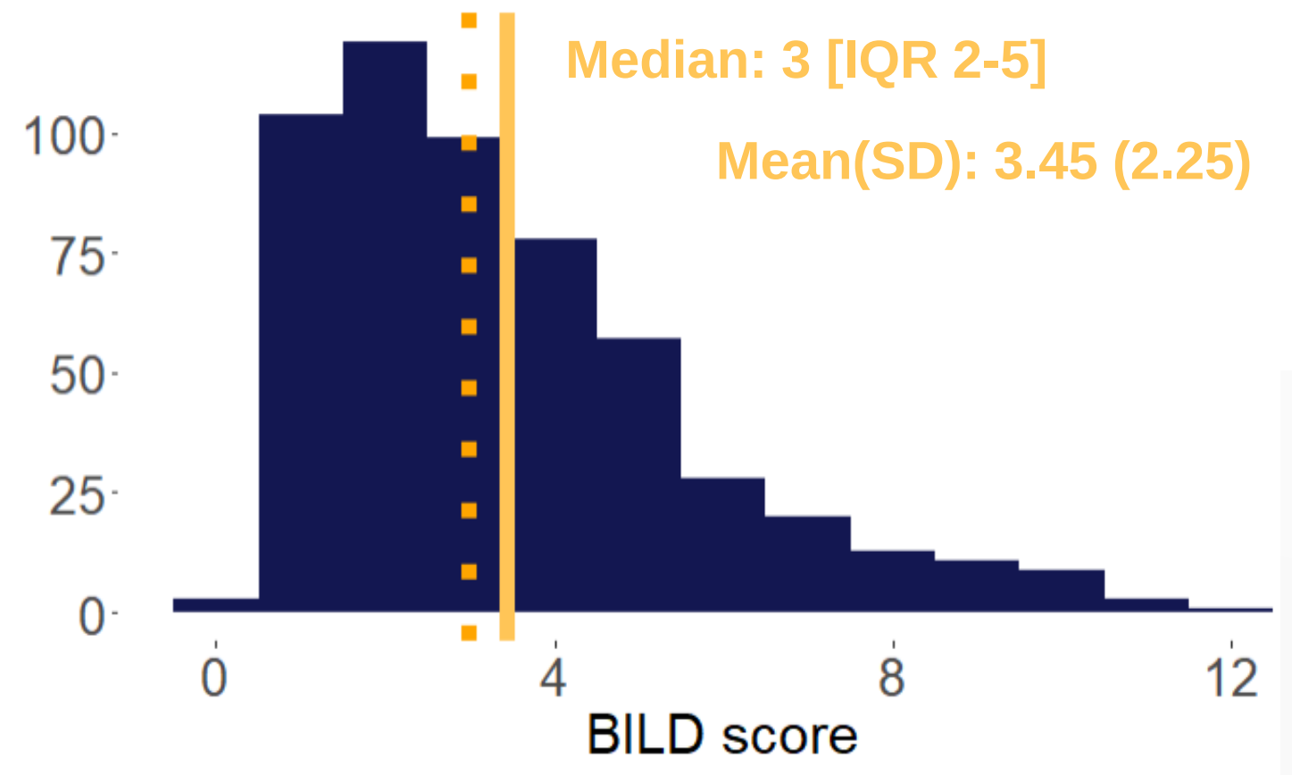
Variable, mean (SD) or %	Overall (n = 1,902)
Patients with at least one ER visit (%)	1,120 (59%)
Patients with at least one hospitalization (%)	921 (48%)
Number of hospitalizations (SD)	3.59 (4.27)
Average length of stay in days (SD)	4.48 (2.72)

> **Figure 3. Systemic Lupus Activity Questionnaire (SLAQ) Score[1] (n = 861)**



[1]SLAQ score is a composite score that ranges from 0 to 47, with higher scores indicating higher SLE disease activity. SLAQ was administered in FLR since January 2007

> **Figure 4. Brief Index of Lupus Damage (BILD) Score[2] (n = 545)**



[2]BILD score ranges from 0 to 24, with higher scores indicating worse cumulative lupus-related damage. BILD was administered in FLR since July 2014

REFERENCES

1. Frederick Wolfe, Kaleb Michaud, The National Data Bank for rheumatic diseases: a multi-registry rheumatic disease data bank, Rheumatology, Volume 50, Issue 1, January 2011, Pages 16–24, https://doi.org/10.1093/rheumatology/keq155

CONCLUSION

> With data collected over 25 years, the FLR is a rich source of information that allows generation of insights on the health and experiences of people with SLE over an extended period.

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