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Demographic and clinical characteristics of patients with systemic lupus erythematosus across five registries: the LupusNet federated data network

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ABSTRACT

Objective This study describes baseline demographics, clinical characteristics and treatments of patients diagnosed with systemic lupus erythematosus (SLE) at the time of registration in the registries of the Lupus Federated Data Network (LupusNet).

Methods Data were collected from five SLE registries in four global regions: APLC (Asia Pacific), FORWARD (North America), RELESSER (Europe), GLADEL 2.0 and Almenara (Latin America). LupusNet uses a federated data network approach and a privacy-by-design method, where only aggregated results are shared. Demographics, disease activity (based on Physician Global Assessment (PGA) and Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K) scores), accumulated damage (Systemic Lupus International Collaborating Clinics Damage Index) and treatment use data were mapped and harmonised using the Observational Medical Outcomes Partnership Common Data Model V.5.4.

Results A total of 10 370 patients were included in the analysis; of those, 3908 patients were in Asia Pacific, 3066 in North America, 1806 in Europe and 1590 in Latin America. The majority of patients were female (91%); the median (IQR) duration from SLE diagnosis to registry entry ranged from 5 (1–12) to 12 (6–19) years. Heterogeneity in disease activity was observed across registries based on mean (SD) SLEDAI-2K total (3.0 (4.1)–7.0 (7.4)) and PGA (0.4 (0.5)–1.2 (1.0)) scores. Across registries, SLE features most common were related to serologic activity (low complement and increased DNA binding (19%–47%)); other common clinical features included proteinuria and arthritis (4%–37%). Cataracts (4%–9%) were the most common characteristic related to accumulated damage. Glucocorticoids, antimalarials and immunosuppressants

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The epidemiology and clinical presentation of systemic lupus erythematosus (SLE) differ across patient subsets and geographies, with variations according to age, sex, race and ethnicity.

⇒ Current local or regional SLE registries use different approaches in recruiting patients and collecting patient data, limiting the understanding of SLE presentation, disease outcomes and treatment patterns globally.

WHAT THIS STUDY ADDS

⇒ This study describes baseline demographics, clinical characteristics and treatment patterns of patients with SLE at the time of registration in the Lupus Federated Data Network (LupusNet), which harmonises real-world data from multiple, diverse, existing SLE registries.

⇒ This study demonstrates significant heterogeneity in clinical characteristics and treatment patterns in patients with SLE across the registries of LupusNet.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ By recognising regional differences, LupusNet can contribute to improving outcomes for patients with SLE across the globe.

were the most commonly used treatments, with variations in their proportions observed across registries.

Conclusions These findings demonstrate significant heterogeneity in clinical characteristics and treatment patterns across the registries in LupusNet. By recognising regional differences, findings from LupusNet may help guide treatment approaches in SLE and optimise patient outcomes.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic, heterogeneous, rheumatic disease that presents with a relapsing–remitting course and is associated with significant disease burden and increased risk for morbidity and mortality.[1–3] SLE is characterised by extensive systemic involvement, manifesting across multiple organ systems.[4 5] Kidney damage, cardiovascular disease and infections are the leading causes of death in patients with SLE.[2 4] Accurate assessment of disease activity helps in guiding treatment decisions, monitoring response to therapy and predicting flares. Evaluating organ damage is also essential for understanding the long-term burden of the disease, preventing further damage and improving outcomes.

The epidemiology and clinical presentation of SLE differ across patient subsets and geographies, with variations according to age, sex, race and ethnicity.[4 6–9] The incidence and prevalence of SLE are significantly higher in females compared with males across all age groups and ethnic backgrounds, with females constituting approximately 90% of the affected population.[4 6] Additionally, females are typically diagnosed with SLE at a younger age than males.[6] European countries show a lower incidence of SLE compared with Asia, Australasia and the Americas.[6] The incidence, prevalence and/or severity of SLE is higher in black and Hispanic populations vs other ethnic groups.[6 10 11] Mortality rates are significantly higher among black patients compared with their White counterparts, with Black females experiencing the highest mortality among all racial and gender groups.[7] Hispanic patients tend to experience a more rapid accumulation of damage compared with other ethnic groups.[12] The global health disparities and heterogeneity in disease manifestations can impact the diagnosis, management and overall progression of the disease.

Currently, there is no cure for SLE; the treatment goal is sustained remission or (if unattainable) low disease activity to prevent irreversible organ damage, reduce the risk of death and improve or maintain quality of life.[2 4 13] Increasingly, a treat-to-target strategy is recommended to facilitate achieving an early and durable remission, or at least low disease activity.[14] Historically, treatments have included anti-inflammatory and immunomodulatory agents (eg, nonsteroidal anti-inflammatory drugs (NSAIDs), glucocorticoids, antimalarials and immunosuppressants).[4 13] Recently, targeted therapies for SLE have become available, and the European Alliance of Associations for Rheumatology guidelines have been updated to support their use.[14] Despite the new guidelines, glucocorticoids, immunosuppressants and antimalarials remain the most commonly prescribed treatments for SLE across the globe.[15–17] However, variations in treatment patterns can be observed within and across regions, likely due to healthcare disparities.[7]

Real-world registry data are often used to inform access, price and reimbursement decisions. Since registries are established at local or regional levels, they enrol a limited number of patients, use different inclusion criteria and serve various purposes, such as studying efficacy, monitoring safety and assessing disease progression.[18] These differences tend to limit the understanding of global SLE presentation, disease outcomes (particularly in subsets of patients) and treatment patterns.

The Lupus Federated Data Network (LupusNet) is an international and interdisciplinary initiative that was launched to establish a comprehensive, global SLE network with augmented patient numbers by harmonising data from local and regional SLE registries. LupusNet currently aggregates data from five major, longitudinal, observational registries of patients with SLE located in the Asia-Pacific region, North America, Europe and Latin America. These registries include the Asia Pacific Lupus Collaboration (APLC), The National Databank for Rheumatic Diseases (FORWARD), the Lupus Register of the Spanish Society of Rheumatology (RELESSER), the Grupo Latino Americano De Estudio de Lupus (GLADEL 2.0) and the Almenara Lupus Cohort (Almenara). The goal of this study is to describe the demographics, clinical characteristics and treatments of patients with SLE at the time of registry enrolment across the five registries of LupusNet.

METHODS

Federated study design and LupusNet

Data were collected from patients with SLE enrolled in one of the five lupus registries participating in LupusNet (APLC, FORWARD, RELESSER, GLADEL 2.0 and Almenara) at the time of enrolment in the registry. These five registries aim to capture both physician-reported and patient-reported data from patients with SLE (online supplemental table S1). All registries include patients with a physician-confirmed diagnosis of SLE, enrol patients with both prevalent and incident SLE and all, except for FORWARD, require patients to fulfil American College of Rheumatology classification criteria. They are autonomous and operate independently of one another. Thus, characteristics of the registry populations, including inclusion criteria, vary. The exit criteria (by which patient participation in the registry could be discontinued) for all participating registries were death, lost to follow-up or withdrawal of consent.

Collected data included baseline demographics, clinical characteristics, treatments, disease activity based on the Physician Global Assessment (PGA) and the Systemic Lupus Erythematosus Disease Activity Index 2000 (SLEDAI-2K) scores and accumulated damage based on

the Systemic Lupus International Collaborating Clinics Damage Index (SDI) during a 30-day window before and after enrolment into the registry; details of collected demographics and clinical characteristics, reported by patients and physicians, are provided in online supplemental tables S2 and S3. PGA, SLEDAI-2K and SDI data were not available for FORWARD and are presented only for APLC, RELESSER, GLADEL 2.0 and Almenara. Registry-specific variables included family history, socioeconomic factors and procedural data. Data collection frequency also varied by registry (online supplemental figure S1).

Study analysis

Registry datasets were harmonised using the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) V.5.4, whereby custom scripts were run on OMOP-converted databases at each registry, which returned censored aggregate data for analysis.[19] The OMOP CDM is a standard representation of healthcare experiences and common vocabularies for coding clinical concepts designed to enable consistent application of analyses across multiple data sources. All analyses were descriptive in nature and, thus, no formal sample size or power was calculated; no missing data imputation was employed. Continuous data were summarised using mean with SD or median with IQR. Categorical variables were summarised using counts and percentages. Variables related to disease severity, activity and accumulated damage were standardised across registries (variable standardisation details are provided in online supplemental methods).

Patient and public involvement

Patients or the public were not involved in the design, conduct, data analysis, reporting or dissemination of this study.

RESULTS

Patient demographic and clinical characteristics at registration

A total of 10 370 patients with SLE were included and mapped in LupusNet: 3908 across Asia-Pacific (APLC), 3066 in North America (FORWARD), 1806 in Europe (RELESSER) and 1590 across Latin America (GLADEL 2.0 and Almenara; online supplemental figure S2). The data collection timeframes ranged from 2013 to 2020 for APLC, 1997 to 2023 for FORWARD, 2015 to 2022 for RELESSER, 2019 to 2024 for GLADEL 2.0 and 2012 to 2024 for Almenara.

The majority of patients were female (91%), with a median age at diagnosis ranging from 27 years in GLADEL 2.0 to 35 years in FORWARD (table 1). Disease duration at the time of registration also varied widely by registry, with a median (IQR) disease duration of 8 (3–15), 9 (4–16), 12 (6–19), 5 (1–12) and 5 (2–10) years in the APLC, FORWARD, RELESSER, GLADEL 2.0 and Almenara cohorts, respectively. The proportion of newly diagnosed patients (within 1 year of SLE diagnosis) was 14% in APLC, 12% in FORWARD, 10% in RELESSER, 26% in GLADEL 2.0 and 21% in Almenara. Similarly, the median follow-up duration varied widely, ranging from 2 years in the APLC and FORWARD cohorts to 6 years in the Almenara cohort. Race and ethnicity varied substantially across cohorts, reflecting the geographic differences in the included registries.

Disease activity

SLE disease activity, as measured by the SLEDAI-2K total score at registration, was variable across the four registries (figure 1A). The mean±SD SLEDAI-2K score across the four registries was 4.4±5.1. Mean±SD values were highest for GLADEL 2.0 (7.0±7.4), followed by APLC (4.4±4.9), Almenara (3.5±3.9) and RELESSER (3.0±4.1).

Heterogeneity in the rates of SLEDAI-2K features at registration was also observed across registries, especially in increased DNA binding (19%–47%), proteinuria (4%–37%), arthritis (7%–21%) and leucopenia (4%–12%; figure 1B and online supplemental table S4). The SLE features most common across registries were related to serologic activity (low complement and increased DNA binding), followed by proteinuria, arthritis and rash. Low complement was most common in GLADEL 2.0 (48%), followed by APLC (42%), RELESSER (31%) and Almenara (30%), whereas increased DNA binding was most common in APLC (47%), followed by GLADEL 2.0 (37%), RELESSER (23%) and Almenara (19%). SLE features related to disease activity, including lupus nephritis (LN)-associated features (ie, proteinuria, haematuria, pyuria and urinary casts), were markedly higher for GLADEL 2.0 compared with other registries, likely due to GLADEL 2.0's specific recruitment of patients with LN (online supplemental table S1).

Consistent with SLEDAI-2K reports, PGA scores were variable across the four registries, with an overall mean±SD PGA score at registration of 0.9±0.8. The mean±SD PGA score at registration for APLC, RELESSER, GLADEL 2.0 and Almenara was 0.8±0.8, 0.9±0.8, 1.2±1.0 and 0.4±0.5, respectively. Based on the PGA score rating, the majority of patients were classified as having mild or no disease activity at registration in the APLC (80%), RELESSER (72%) and Almenara (85%) cohorts, whereas 43% of patients in GLADEL 2.0 were classified as having moderate or severe disease, likely due to GLADEL 2.0's focus on enrolling patients with LN (figure 2).

Accumulated damage

The mean±SD SDI score at registration across the four registries was 0.7±1.2, with individual scores of 0.6±1.1, 0.7±1.3, 0.7±1.2 and 1.0±1.3 for APLC, RELESSER, GLADEL 2.0 and Almenara, respectively (figure 3 and online supplemental table S5). The most commonly observed SDI characteristic across four registries (≥4% of patients) was cataracts, which was highest in RELESSER (9%), followed by APLC (6%), GLADEL 2.0 (5%) and Almenara (4%). Other SDI characteristics experienced

Table 1 Baseline demographic and clinical characteristics of patients in LupusNet*†

Characteristic	APLC, N=3908	FORWARD, N=3066	RELESSER, N=1806	GLADEL 2.0, N=1083	Almenara, N=507
Sex (female), n (%)	3597 (92)	2799 (91)	1625 (90)	970 (90)	468 (92)
Age at diagnosis, years, median (IQR)	29 (21–39)	35 (26–46)	34 (25–43)	27 (21–36)	33 (25–42)
Age at registry entry, years, median (IQR)	39 (30–50)	47 (37–57)	47 (38–57)	35 (27–44)	40 (32–51)
Duration from SLE diagnosis to registry entry, years, median (IQR)	8 (3–15)	9 (4–16)	12 (6–19)	5 (1–12)	5 (2–10)
Follow-up duration, years, median (IQR)	2 (1–5)	2 (0–7)	5 (1–6)	4 (2–4)	6 (2–10)
Body mass index, kg/m^2, median (IQR)‡§	NR	26.8 (22.0–33.8)	24.2 (21.5–27.7)	25.2 (22.4–28.7)	NR
Race, n (%)					
African	<10 (<0.3)	–	–	–	–
American Indian or Alaska Native	–	32 (1)	–	–	–
Asian	3442 (88)	–	–	–	<10 (<2)
Asian Indian	<10 (<0.3)	–	–	–	–
Black or African American	–	345 (11)	–	90 (8)	<10 (<2)
Middle Eastern or North African	<10 (<0.3)	–	–	–	–
Mixed ancestry¶	–	–	–	716 (66)	496 (98)
Other Pacific Islander	<10 (<0.3)	–	–	–	–
Sri Lankan	<10 (<0.3)	–	–	–	–
West Indian	<10 (<0.3)	–	–	–	
White	–	1527 (50)	–	277 (26)	<10 (<2)
Other or unknown	447 (11)	1162 (38)	–	–	–
Not available	–	–	1806 (100)	–	–
Ethnicity, n (%)					
Hispanic or Latino	<10 (<0.3)	144 (5)	–	–	–
Mixed ancestry¶	<10 (<0.3)	–	–	701 (65)	496 (98)
Not Hispanic or Latino	–	1871 (61)	–	–	–
Other or unknown	3898 (99)	1051 (34)	–	382 (35)	11 (2)
Not available	–	–	1806 (100)	–	–

*The absence of values for some categories is due to variations in data collection by the registries, and the sum of values in some categories may not total to 100%.
†If <10 patients, the actual number is masked.
‡Body mass index was not collected in APLC or Almenara.
§Missing values: RELESSER, n=357 (20%).
¶In Almenara and GLADEL 2.0, mixed ancestry was recorded as Mestizo, referring to individuals of both European and indigenous non-European descent.
Almenara, Almenara Lupus Cohort; APLC, Asia Pacific Lupus Collaboration; FORWARD, National Databank for Rheumatic Diseases; GLADEL 2.0, Grupo Latino Americano de Estudio de Lupus; IQR, interquartile range; LupusNet, Lupus Federated Data Network; NR, not reported; RELESSER, Lupus Register of the Spanish Society of Rheumatology; SLE, systemic lupus erythematosus.

by ≥3% of patients across registries were an estimated glomerular filtration rate of <50% (highest in Almenara (5%)) and diabetes (highest in Almenara (4%)).

Treatment at registration

Across the registries, the most commonly used SLE treatments at registration were glucocorticoids, antimalarials and immunosuppressants (figure 4 and online supplemental table S6). Use of these treatments varied across registries and was highest in GLADEL 2.0 (97%, 89% and 67%, respectively) and lowest in FORWARD (27%, 34% and 18%, respectively; figure 4A). Notably, FORWARD reported relatively low use of hydroxychloroquine and glucocorticoids, even when treatment patterns were assessed over a similar data collection period (2008–2020) as other registries (online supplemental figure S3).

The use of biologics (including off-label use of anti–tumour necrosis factor, anti-CD80/CD86, anti-interleukin 6 and B-cell therapies) was limited across all registries. Treatments related to comorbidities and organ involvement were available in RELESSER and GLADEL 2.0. Vitamin D supplementation was reported only in GLADEL 2.0 (44%). Other treatments commonly

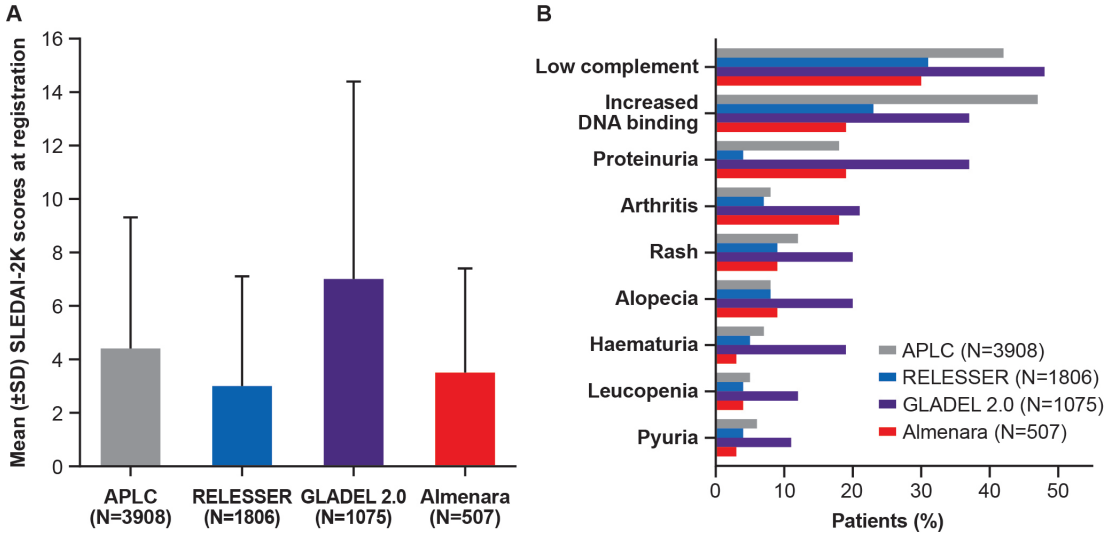

Figure 1 Disease activity based on SLEDAI-2K scores at registration: (A) calculated SLEDAI-2K total scores*† and (B) most frequently observed SLEDAI-2K features (in >10% of patients in any registry).*‡ *The FORWARD registry does not collect these data. †Percentages include only patients who had a calculated SLEDAI-2K total score recorded at registration: >99% (3904/3908) of patients from APLC, 92% (1662/1806) from RELESSER, >99% from GLADEL 2.0 (1075/1083) and 100% (507/507) from Almenara. ‡Percentages represent patients who completed SLEDAI-2K assessments: >99% (3874/3908) of patients from APLC, 94% (1692/1806) from RELESSER, >99% from GLADEL 2.0 (1075/1083) and 100% (507/507) from Almenara. Almenara, Almenara Lupus Cohort; APLC, Asia Pacific Lupus Collaboration; FORWARD, National Databank for Rheumatic Diseases; GLADEL 2.0, Grupo Latino Americano de Estudio de Lupus; RELESSER, Lupus Register of the Spanish Society of Rheumatology; SD, standard deviation; SLEDAI-2K, Systemic Lupus Erythematosus Disease Activity Index 2000.

used at registration were antihypertensives (RELESSER: 27%; GLADEL 2.0: 31%) and statins (RELESSER: 19%; GLADEL 2.0: 15%; figure 4B).

Treatment use based on SLEDAI-2K disease activity was available for APLC, RELESSER and Almenara. The rate of antimalarial use was consistent regardless of the severity of disease activity (figure 4C). Similarly, the use of glucocorticoids and immunosuppressants in Almenara did not vary with the severity of disease activity. In contrast, glucocorticoids and immunosuppressants were more frequently used in patients with higher disease activity in APLC and RELESSER. Although the number of patients using other immunomodulators and B-cell therapy was limited across registries, these treatments were more frequently used in severe cases.

DISCUSSION

LupusNet is a global SLE network currently containing data from more than 10 000 patients from registries

Figure 2 Severity distribution of disease activity based on PGA rating at registration. The FORWARD registry does not collect these data. Percentages represent only patients with a PGA score recorded at registration, which were >99% (3883/3908) of patients from APLC, 56% (1019/1806) from RELESSER, 91% (982/1083) from GLADEL 2.0 and 33% (166/507) from Almenara. Almenara, Almenara Lupus Cohort; APLC, Asia Pacific Lupus Collaboration; FORWARD, National Databank for Rheumatic Diseases; GLADEL 2.0, Grupo Latino Americano de Estudio de Lupus; PGA, Physician Global Assessment; RELESSER, Lupus Register of the Spanish Society of Rheumatology.

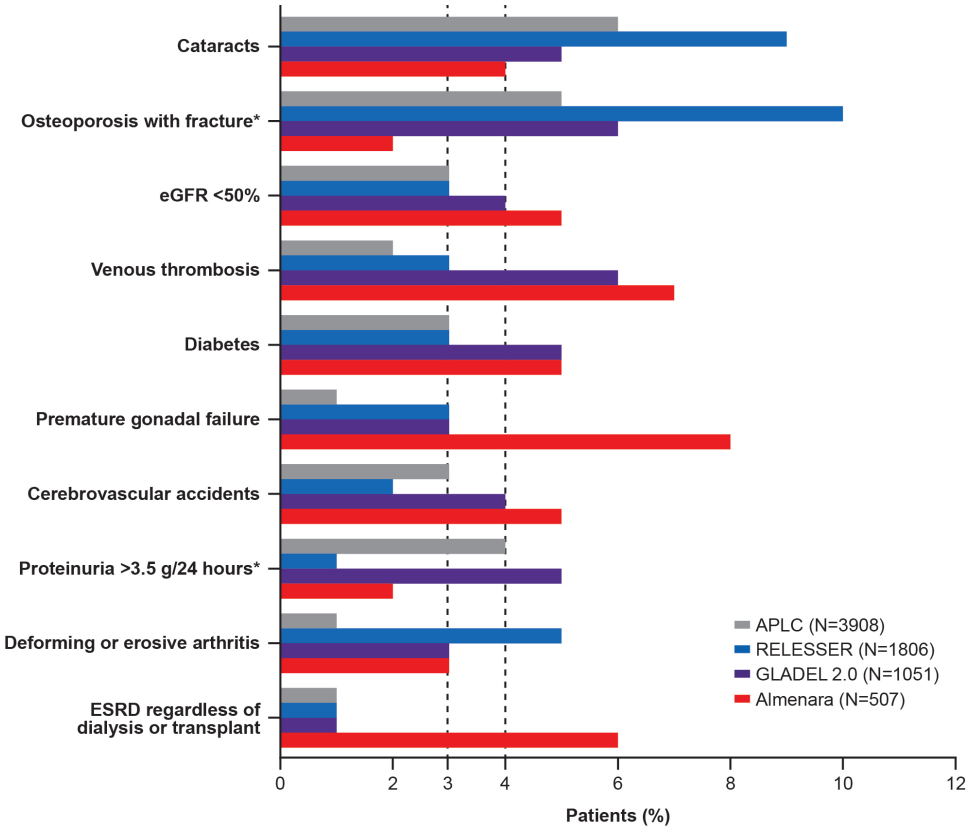

Figure 3 Most frequently observed SDI characteristics (in ≥5% of patients in any registry). The FORWARD registry does not collect these data. *Incidence is <2% for Almenara. Almenara, Almenara Lupus Cohort; APLC, Asia Pacific Lupus Collaboration; eGFR, estimated glomerular filtration rate; ESRD, end-stage renal disease; FORWARD, National Databank for Rheumatic Diseases; GLADEL 2.0, Grupo Latino Americano de Estudio de Lupus; RELESSER, Lupus Register of the Spanish Society of Rheumatology; SDI, Systemic Lupus International Collaborating Clinics Damage Index.

across four continents and 29 countries/territories. Using an innovative, federated data network approach, LupusNet allows investigations across its five component registries to better understand disease characteristics and treatment patterns in patients with varying genetic backgrounds, environmental exposures and socioeconomic statuses, which can influence disease presentation and severity.[20–27] Across registries, common shared characteristics included a predominance of female patients, a mean age at onset of 25–27 years, frequent serological activity as a hallmark clinical feature and cataracts as the most common form of accumulated damage. However, there is significant heterogeneity in clinical features and treatment patterns across the LupusNet registries, underscoring its value for understanding SLE at all stages of the disease.

The observed variability in disease activity among SLE registries can be attributed to several factors, including patient demographics and sociodemographics, treatment strategies and recruitment criteria. For example, GLADEL 2.0 recruited patients with and without renal involvement, including those with active LN and newly diagnosed LN, prior to initiation or completion of treatment.[28] This may explain the higher SLEDAI-2K and PGA scores observed in this cohort compared with APLC, RELESSER and Almenara. Global disparities in healthcare accessibility may also contribute to variability in disease activity and accumulated damage, as supported by the association of lower socioeconomic status with worse prognosis.[20] Patient demographics, such as ethnicity and genetic ancestry, also impact clinical outcomes.[20 21 23] For example, national biomarker studies in multiethnic cohorts have shown differences in gene expression and disease activity between patients with SLE of different ethnicities.[23] Higher mortality has also been observed in those with non-European ethnicity.[21] Further investigation is warranted to better understand the impact of these factors across registries.

While attainment of remission or low disease activity can reduce the risk of damage and other adverse outcomes,[14 29 30] the prevention of chronic damage remains a challenge. In LupusNet, cataracts, diabetes, osteoporosis and proteinuria were common features frequently associated with damage, highlighting the need for a comprehensive understanding of the drivers of long-term outcomes. The high prevalence of cataracts observed may be due, in part, to the relatively high rates of glucocorticoid use at registration. Trends, such as higher frequencies of renal- and gonadal-related damage in the Almenara cohort, could reflect the impact of ancestry and sociodemographic characteristics or the availability of certain treatments (eg, use of cyclophosphamide is a risk factor for renal and ovarian toxicity).[20 31 32]

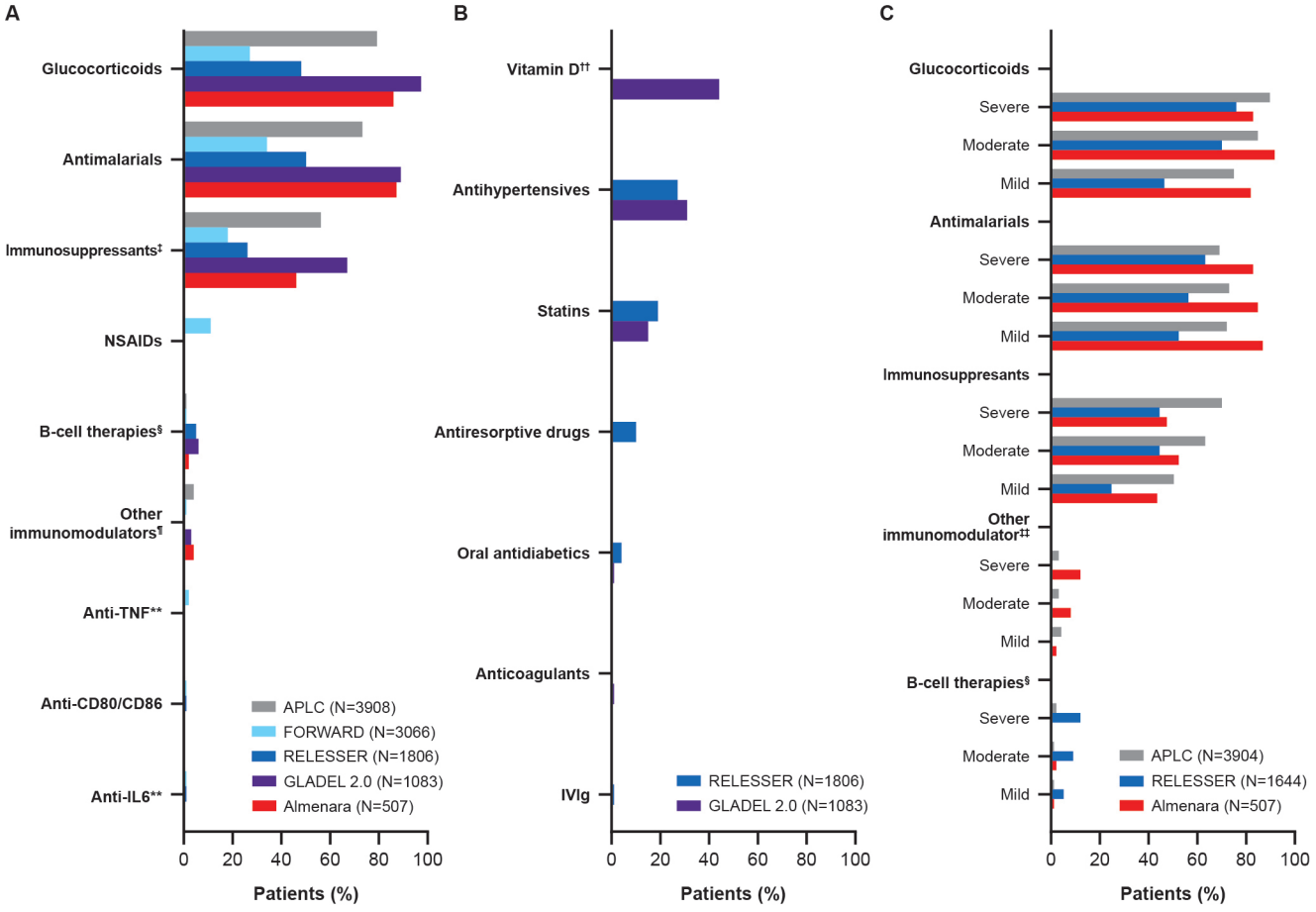

Figure 4 Distribution of treatment use at registration: (A) SLE treatments, (B) treatments related to comorbidities and organ involvement* and (C) SLE treatments by SLEDAI-2K disease activity.† *Treatment use related to comorbidities and organ involvement was reported only in RELESSER and GLADEL 2.0. †SLEDAI-2K disease activity was defined as mild (SLEDAI score 0–5), moderate (SLEDAI score 6–10) or severe (SLEDAI score >10). ‡Immunosuppressants include azathioprine, cyclophosphamide, cyclosporine, danazol, leflunomide, methotrexate, mycophenolate mofetil, mycophenolic acid and tofacitinib. §B-cell therapies include belimumab and rituximab. ¶Other immunomodulators include penicillamine, sulfasalazine and tacrolimus. Anifrolumab use was not recorded in LupusNet. **FORWARD includes patients with rheumatologic diseases beyond SLE. Treatments reflect patients' drug exposures at the time of registry entry, which, for some FORWARD patients, may be prior to their SLE diagnosis. ††Vitamin D supplementation was reported only in GLADEL 2.0. ‡‡Other immunomodulator refers to tacrolimus only. These data were not specifically collected by RELESSER. Almenara, Almenara Lupus Cohort; APLC, Asia Pacific Lupus Collaboration; FORWARD, National Databank for Rheumatic Diseases; GLADEL 2.0, Grupo Latino Americano de Estudio de Lupus; IL6, interleukin 6; IVIg, intravenous immunoglobulin; LupusNet, Lupus Federated Data Network; NSAID, nonsteroidal anti-inflammatory drug; RELESSER, Lupus Register of the Spanish Society of Rheumatology; SLE, systemic lupus erythematosus; SLEDAI, Systemic Lupus Erythematosus Disease Activity Index; SLEDAI-2K, Systemic Lupus Erythematosus Disease Activity Index 2000; TNF, tumour necrosis factor.

Glucocorticoids, antimalarials and immunosuppressants were the most common SLE treatments observed in LupusNet at registration. Antimalarials were frequently used regardless of disease severity, while glucocorticoid and immunosuppressant use increased with more severe disease. This treatment pattern is generally consistent with clinical practice guidelines and recommendations for the management of SLE, where antimalarials are recommended as first-line therapy along with glucocorticoids.[14 17 33] Immunosuppressants can be used to expedite the tapering/discontinuation of glucocorticoids[14] and should be considered in organ-threatening and refractory disease.[14 33]

Treatment patterns varied across registries, potentially due to differences in geographic preferences, timing of registration vs availability of certain treatments, underlying disease profiles of the populations and socioeconomic factors influencing equal access to healthcare.[22] Specifically, in Almenara and GLADEL 2.0, higher antimalarial use may be due to research that promoted their benefits.[24 25] Glucocorticoid use was higher in GLADEL 2.0, Almenara and APLC, which may be due to differences in socioeconomics, consistent with other studies like the SLE Prospective Observational Cohort Study and African cohort studies that showed higher rates of glucocorticoid use in low- and

middle-income countries and lower rates in high-income countries.[26 27] In contrast, FORWARD showed relatively low use of hydroxychloroquine and glucocorticoids, which may relate to the community-based nature of the registry with some patients receiving care outside rheumatology settings, and incomplete baseline medication capture in older case report forms. Data on the use of advanced therapies, such as biologics and B-cell therapies, are limited, likely due in part to the timing of their availability, as they were not yet approved at the time of registration for some patients. Further research is being conducted to explore treatment patterns in LupusNet over time.

The findings should be interpreted in light of the inherent limitations associated with observational database research. Representation from Europe was limited to Spain, which reflects a more restricted ethnicity and ancestry composition compared with the broader continent, potentially limiting generalisability to diverse European populations. Additional limitations include differences in registry design, which impacted the types of data eligible for standardisation and harmonisation, such as differences in inclusion criteria, the timing of data collection, use of disease measurement or severity scales (including collection of patient-reported or healthcare provider-reported measures) and the reporting of treatment dosing regimens and duration. Some outcome measures cannot be calculated in this study as not all registries captured all the data points required. Distribution of disease activity based on the PGA rating is subjective, and conclusions regarding disease activity at registration should be interpreted cautiously. Finally, registry data are vulnerable to selection and information bias.

In conclusion, this study demonstrates that there is significant heterogeneity in clinical characteristics and treatment patterns across the registries in LupusNet. This variation in patient population and disease activity will enable better understanding of disease heterogeneity and treatment patterns, with the potential to expand by incorporating additional SLE registries. By recognising regional differences, LupusNet can contribute to improving outcomes for patients with SLE across the globe.

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REFERENCES

1 Stojan G, Petri M. Epidemiology of systemic lupus erythematosus: an update. *Curr Opin Rheumatol* 2018;30:144–50.
2 Ameer MA, Chaudhry H, Mushtaq J, *et al*. An overview of systemic lupus erythematosus (SLE) pathogenesis, classification, and management. *Cureus* 2022;14:e30330.
3 Hoi A, Koelmeyer R, Bonin J, *et al*. Disease course following high disease activity status revealed patterns in SLE. *Arthritis Res Ther* 2021;23:191.
4 Morand EF, Fernandez-Ruiz R, Blazer A, *et al*. Advances in the management of systemic lupus erythematosus. *BMJ* 2023;383:e073980.
5 Cojocaru M, Cojocaru IM, Silosi I, *et al*. Manifestations of systemic lupus erythematosus. *Maedica (Bucur)* 2011;6:330–6.
6 Rees F, Doherty M, Grainge MJ, *et al*. The worldwide incidence and prevalence of systemic lupus erythematosus: a systematic review of epidemiological studies. *Rheumatology (Oxford)* 2017;56:1945–61.
7 Hasan B, Fike A, Hasni S. Health disparities in systemic lupus erythematosus-a narrative review. *Clin Rheumatol* 2022;41:3299–311.
8 Bang SY, Shim SC. Early human migration determines the risk of being attacked by wolves: ethnic gene diversity on the development of systemic lupus erythematosus. *J Rheum Dis* 2024;31:200–11.
9 González LA, Ugarte-Gil MF, Pons-Estel GJ, *et al*. The rise and rise of lupus. *Lupus (Los Angel)* 2023;32:713–26.
10 Sun K, Eudy AM, Criscione-Schreiber LG, *et al*. Racial differences in patient-provider communication, patient self-efficacy, and their

associations with systemic lupus erythematosus-related damage: a cross-sectional survey. *J Rheumatol* 2021;48:1022–8.
11 Lim SS, Bayakly AR, Helmick CG, *et al*. The incidence and prevalence of systemic lupus erythematosus, 2002-2004: the Georgia Lupus Registry. *Arthritis Rheumatol* 2014;66:357–68.
12 Hernández Cruz B, Alonso F, Calvo Alén J, *et al*. Differences in clinical manifestations and increased severity of systemic lupus erythematosus between two groups of Hispanics: European Caucasians versus Latin American Mestizos (data from the RELESSER registry). *Lupus (Los Angel)* 2020;29:27–36.
13 Basta F, Fasola F, Triantafyllias K, *et al*. Systemic lupus erythematosus (SLE) therapy: the old and the new. *Rheumatol Ther* 2020;7:433–46.
14 Fanouriakis A, Kostopoulou M, Andersen J, *et al*. EULAR recommendations for the management of systemic lupus erythematosus: 2023 update. *Ann Rheum Dis* 2024;83:15–29.
15 Mysler E, Monticielo OA, Al-Homood IA, *et al*. Opportunities and challenges of lupus care in Latin America, the Middle East, and Asia-Pacific: a call to action. *Mod Rheumatol* 2024;34:655–69.
16 Smolen JS, Landewé RBM, Bijlsma JWJ, *et al*. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2019 update. *Ann Rheum Dis* 2020;79:685–99.
17 Pons-Estel BA, Bonfa E, Soriano ER, *et al*. First Latin American clinical practice guidelines for the treatment of systemic lupus erythematosus: Latin American Group for the Study of Lupus (GLADEL, Grupo Latino Americano de Estudio del Lupus)-Pan-American League of Associations of Rheumatology (PANLAR). *Ann Rheum Dis* 2018;77:1549–57.
18 Lofland J, Wan E, Berry P, *et al*. Systemic lupus erythematosus registries: are the measures captured in the real world similar to those in clinical trials. *Arthritis Rheum* 2019;71:2868–9.
19 Observational Health Data Sciences and Informatics. Standardized data: the OMOP common data model. 2024. Available: https://www.ohdsi.org/data-standardization/
20 Sánchez E, Rasmussen A, Riba L, *et al*. Impact of genetic ancestry and sociodemographic status on the clinical expression of systemic lupus erythematosus in American Indian-European populations. *Arthritis Rheum* 2012;64:3687–94.
21 Kandane-Rathnayake R, Golder V, Louthrenoo W, *et al*. Lupus low disease activity state and remission and risk of mortality in patients with systemic lupus erythematosus: a prospective, multinational, longitudinal cohort study. *Lancet Rheumatol* 2022;4:e822–30.
22 Williams JN, Drenkard C, Lim SS. The impact of social determinants of health on the presentation, management and outcomes of systemic lupus erythematosus. *Rheumatology (Oxford)* 2023;62:i10–4.
23 Northcott M, Gearing LJ, Bonin J, *et al*. Immunosuppressant exposure confounds gene expression analysis in systemic lupus erythematosus. *Front Immunol* 2022;13:964263.
24 Pons-Estel GJ, Catoggio LJ, Cardiel MH, *et al*. Lupus in Latin-American patients: lessons from the GLADEL cohort. *Lupus (Los Angel)* 2015;24:536–45.
25 Pons-Estel GJ, Alarcón GS, Burgos PI, *et al*. Mestizos with systemic lupus erythematosus develop renal disease early while antimalarials retard its appearance: data from a Latin American cohort. *Lupus (Los Angel)* 2013;22:899–907.
26 Legge A, Reynolds JA, Ugarte-Gil MF, *et al*. Meeting report: The Systemic Lupus International Collaborating Clinics (SLICC) World Lupus Seminar on Africa. *Lupus Sci Med* 2025;12:e001452.
27 Aringer M, Arnaud L, Furie RA, *et al*. Real-world treatment patterns and clinical characteristics in patients with moderate-to-severe systemic lupus erythematosus: an analysis of the SLE Prospective Observational Cohort Study (SPOCS). *Lupus Sci Med* 2025;12:e001336.
28 Gómez-Puerta JA, Pons-Estel GJ, Quintana R, *et al*. A longitudinal multiethnic study of biomarkers in systemic lupus erythematosus: launching the GLADEL 2.0 Study Group. *Lupus (Los Angel)* 2021;30:630–40.
29 Ugarte-Gil MF, Wojdyla D, Pons-Estel GJ, *et al*. Predictors of remission and low disease activity state in systemic lupus erythematosus: data from a multiethnic, multinational Latin American cohort. *J Rheumatol* 2019;46:1299–308.
30 Ugarte-Gil MF, Alarcón GS. Low disease activity early in the course of systemic lupus erythematosus. *J Rheumatol* 2024;51:739–40.
31 Sharma SK, Jain S, Bahl P, *et al*. Ovarian dysfunction with moderate-dose intravenous cyclophosphamide (modified NIH regimen) and mycophenolate mofetil in young adults with severe lupus: a prospective cohort study. *Arthritis Res Ther* 2020;22:189.
32 Mok CC. Con: cyclophosphamide for the treatment of lupus nephritis. *Nephrol Dial Transplant* 2016;31:1053–7.
33 Gordon C, Amissah-Arthur M-B, Gayed M, *et al*. The British Society for Rheumatology guideline for the management of systemic lupus erythematosus in adults. *Rheumatology (Oxford)* 2018;57:e1–45.