POS1333

From Onset to Insights: Longitudinal Assessment of Disease Activity, Flares, and Damage Accrual in Patients With SLE Across 5 Registries in the Lupus Federated Data Network (LupusNet)

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Key Takeaways

- While registry-level SLE disease activity was relatively stable over the follow-up period in LupusNet, up to 25% of patients across registries experienced disease flares that were captured during follow-up visits
- Further investigation into patterns of disease activity, accrual of organ damage, and treatment trajectories is essential to identify potential areas for improving long-term health and minimising organ damage in patients with SLE
- Future research within LupusNet is expected to help identify subgroups of patients who exhibit the highest levels of disease activity, aiding in the development of targeted interventions and addressing critical therapeutic advances
- This study emphasises variability in management and outcomes across different geographic regions, highlighting the importance of understanding localised approaches to treatment and care strategies in SLE management

Background

- Systemic lupus erythematosus (SLE) is an autoimmune rheumatic disease characterised by a heterogeneous clinical presentation and periods of flare and remission, with variability in management across different parts of the world[1-3]
  - The goal of managing SLE is to achieve and maintain low disease activity or remission to prevent flares, minimise long-term damage, and reduce the accrual of organ damage[4-6]
  - Disease activity levels, flare rates, and the accrual of organ damage can vary widely among patients with SLE, including by time from diagnosis[2]
- The Lupus federated data Network (LupusNet) is the largest existing federated network for SLE and the first that aims to combine and harmonise data from 5 existing SLE registries, which enables greater data consistency and improves the understanding of the global clinical presentation and outcomes of SLE

Objective

To analyse disease activity levels, flare rates, and accrual of organ damage by time from SLE diagnosis in real-world patients from LupusNet

Methods

- Data from 5 SLE registries across 4 geographic regions, including Asia-Pacific, North America, Europe, and Central and South America, were mapped in LupusNet: Asia Pacific Lupus Collaboration (APLC), National Databank for Rheumatic Diseases (FORWARD), Spanish Society of Rheumatology Lupus Registry (RELESSER), Grupo Latino Americano de Estudio de Lupus (GLADEL 2.0), and Rheumatology Department of the Hospital Guillermo Almenara Irigoyen (Almenara)
- Disease activity and flares were assessed using the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) for APLC, RELESSER, GLADEL 2.0, and Almenara (collected at registration and follow-up visits) and the Systemic Lupus Activity Questionnaire (SLAQ) for FORWARD (collected 6 months after registration and at subsequent follow-up visits)
- Accumulated organ damage was measured using the American College of Rheumatology (ACR)/Systemic Lupus International Collaborating Clinics Damage Index (SDI) for APLC, RELESSER, GLADEL 2.0, and Almenara (collected at registration and follow-up visits)
- Use of glucocorticoids, antimalarials, immunosuppressants, immunomodulators, and B-cell–depletion therapies at the time of registration was described
- Registry datasets were harmonised using the Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) v5.4
  - The OMOP CDM included a standard representation of health care experiences and common vocabularies for coding clinical concepts to enable consistent application of analyses across multiple data sources
  - The types of data that were eligible for standardisation and harmonisation in LupusNet varied depending on the registry design, which included differences in the timing of data collection, disease measurement or severity scales, and reporting of treatment dosage and duration; this was taken into consideration when analysing results

Results

A total of 10,267 patients within LupusNet were included: 3908 in Asia-Pacific, 3066 in North America, 1806 in Europe, and 1487 in Central and South America. Demographic and clinical characteristics at registration are presented in Table 1

- Across the 5 registries, the median duration from SLE diagnosis to registry entry varied from 5 to 12 years
- At registration, the mean SLEDAI score ranged from 3.0 to 7.2; 1% to 6% of patients had received B-cell–depletion therapies, and 1% to 4% had been treated with immunomodulators (i.e., penicillamine, sulfasalazine, tacrolimus)

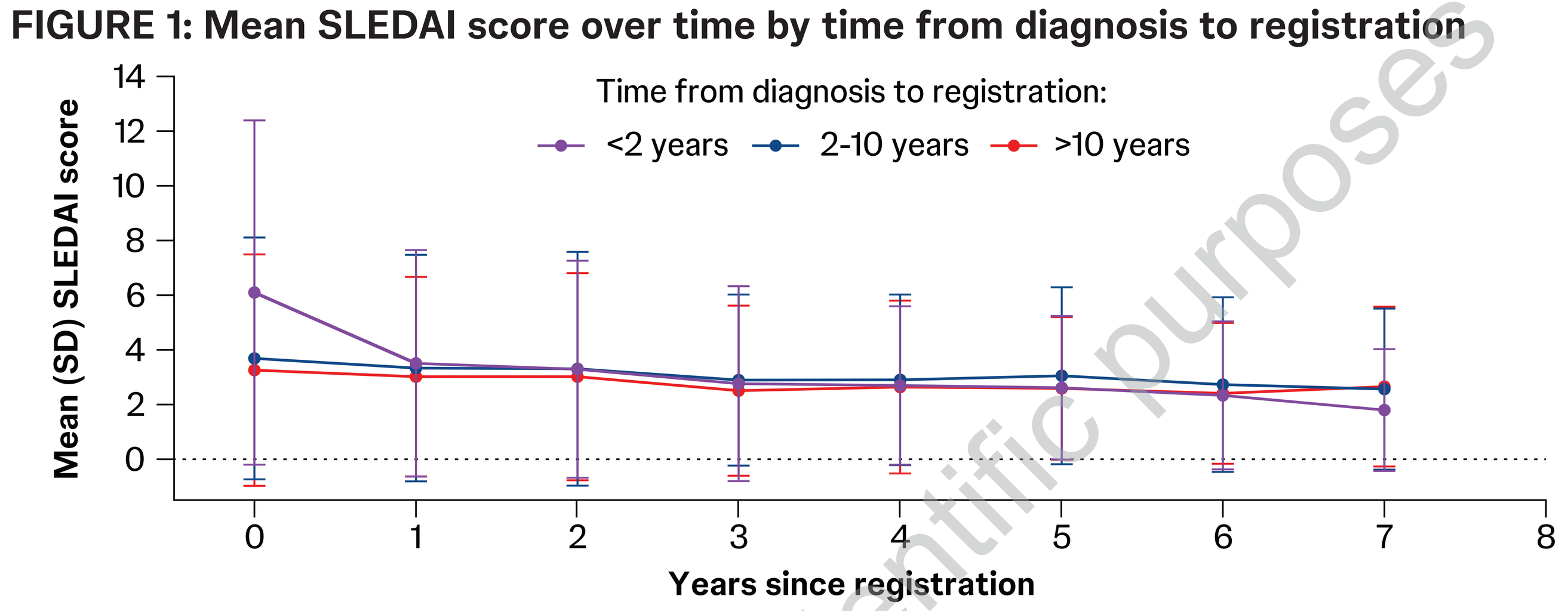
TABLE 1: Baseline demographic and clinical characteristics of patients in LupusNet

Characteristic	APLC (n=3908)	FORWARD (n=3066)	RELESSER (n=1806)	GLADEL 2.0 (n=980)	Almenara (n=507)
Female, n (%)	3597 (92)	2799 (91)	1625 (90)	876 (89)	468 (92)
Median (Q1-Q3) age at diagnosis, years	29 (21-39)	35 (26-46)	34 (25-43)	27 (21-35)	33 (25-42)
Median (Q1-Q3) age at registry entry, years	39 (30-50)	47 (37-57)	47 (38-57)	35 (27-44)	40 (32-51)
Median (Q1-Q3) duration from SLE diagnosis to registry entry, years	8 (3-15)	9 (4-16)	12 (6-19)	5 (1-12)	5 (2-10)
Median (Q1-Q3) follow-up duration, years	2 (1-5)	2 (0-7)	5 (1-6)	1 (1-1)	6 (2-10)
Mean (SD) SLEDAI score	4.4 (8.9)	NA	3.0 (4.1)	7.2 (7.6)	3.2 (3.8)
Mean (SD) SLAQ score	NA	16.9 (12.1)	NA	NA	NA
Treatment use, n (%)					
Glucocorticoids	3093 (79)	836 (27)	864 (48)	948 (97)	434 (86)
Antimalarials	2857 (73)	1051 (34)	903 (50)	860 (88)	443 (87)
Immunosuppressants	2170 (56)	542 (18)	469 (26)	629 (64)	235 (46)
Immunomodulators	151 (4)	17 (1)	–	25 (3)	19 (4)
B-cell–depletion therapies	40 (1)	20 (1)	92 (5)	55 (6)	<10 (<2)

Almenara=Rheumatology Department of the Hospital Guillermo Almenara Irigoyen, **APLC**=Asia Pacific Lupus Collaboration, **FORWARD**=National Databank for Rheumatic Diseases, **GLADEL 2.0**=Grupo Latino Americano de Estudio de Lupus, **LupusNet**=Lupus federated data Network, **Q**=quartile, **NA**=not available, **RELESSER**=Spanish Society of Rheumatology Lupus Registry, **SD**=standard deviation, **SLAQ**=Systemic Lupus Activity Questionnaire, **SLE**=systemic lupus erythematosus, **SLEDAI**=Systemic Lupus Erythematosus Disease Activity Index.

In patients who had a time from diagnosis to registration of <2 years, SLEDAI scores were numerically higher at the time of registration and decreased by the end of the first year. In the years after registration, SLEDAI scores were similar across groups and generally decreased over time (Figure 1)

FIGURE 1: Mean SLEDAI score over time by time from diagnosis to registration

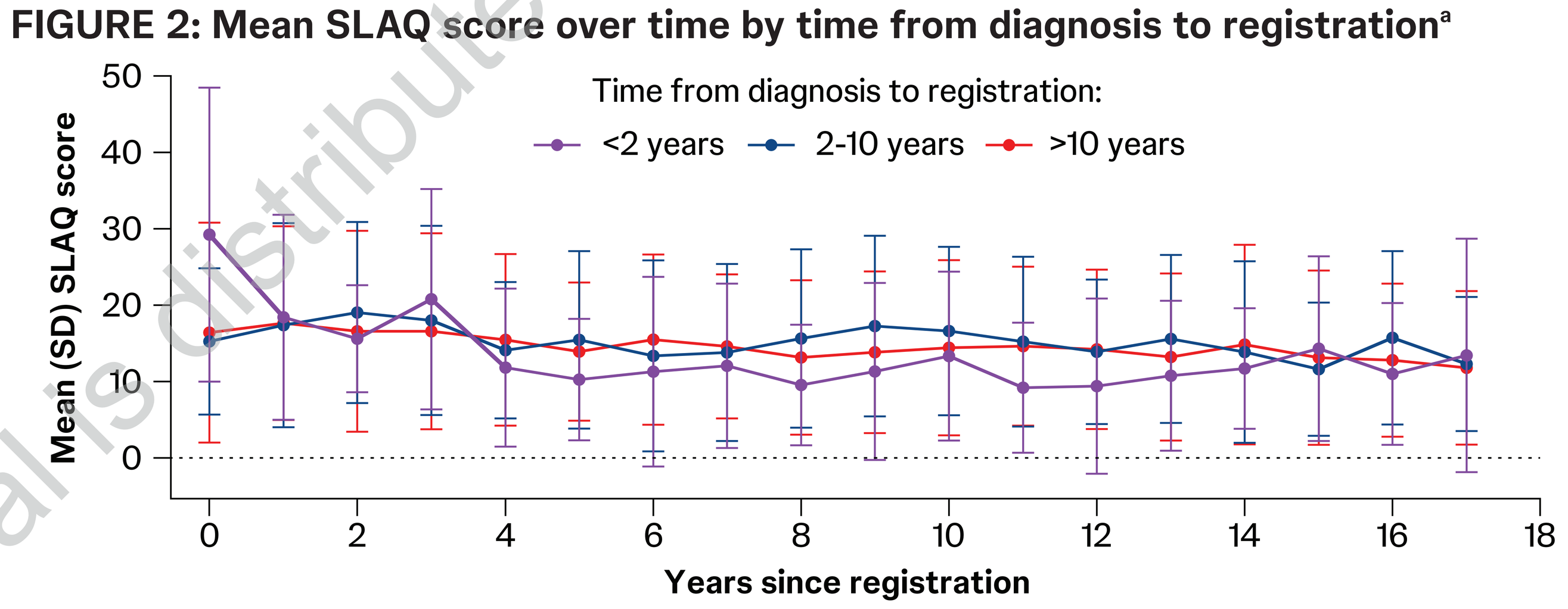


SD=standard deviation, **SLEDAI**=Systemic Lupus Erythematosus Disease Activity Index.

Patients who had a shorter time from diagnosis to registration (<2 years) also had higher SLAQ scores at the time of registration, which decreased after registration and did not vary significantly in the following years (Figure 2)

- Overall, SLAQ scores after registration were comparable across groups by time from diagnosis to registry entry

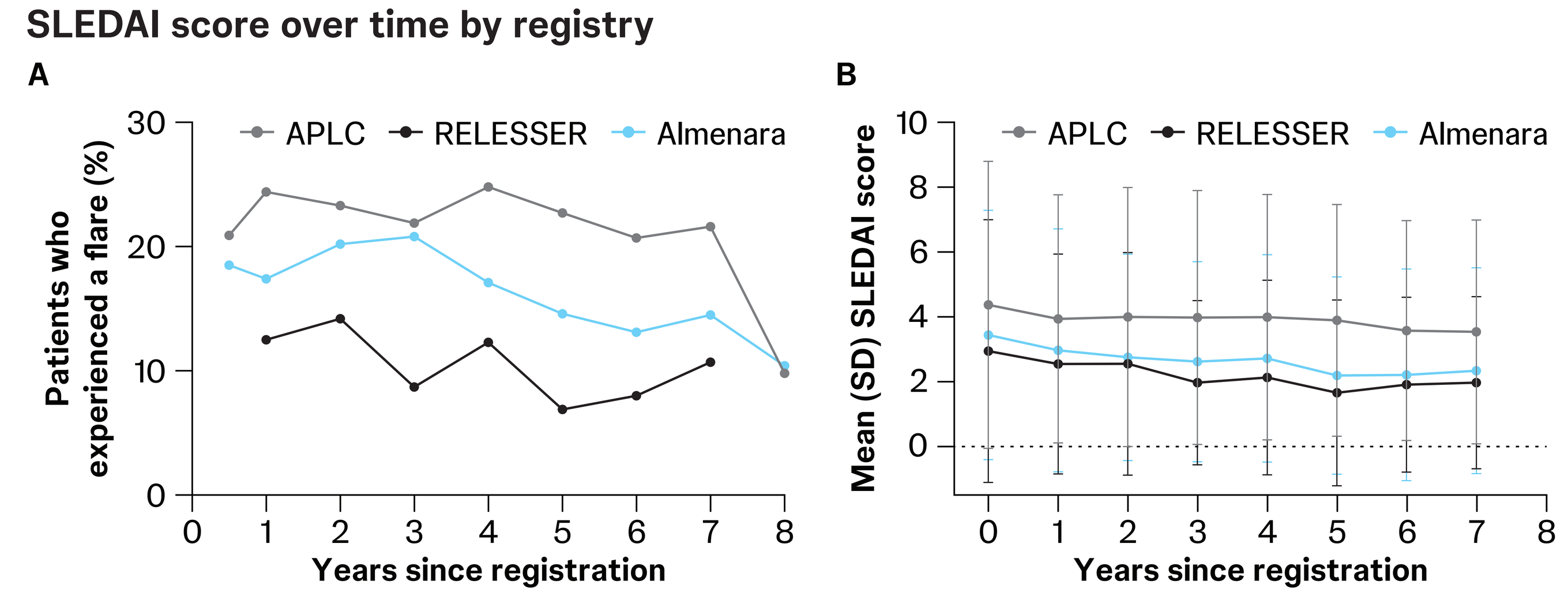
FIGURE 2: Mean SLAQ score over time by time from diagnosis to registration[a]



[a]SLAQ scores were collected in the FORWARD registry only.
FORWARD=National Databank for Rheumatic Diseases, **SD**=standard deviation, **SLAQ**=Systemic Lupus Activity Questionnaire.

Across visits and registries, an average of 16% (range: 8%-25%) of patients experienced a flare (a change in SLEDAI score ≥3 between visits) that was captured at a follow-up visit, with slightly higher SLEDAI scores observed at earlier visits (Figure 3)

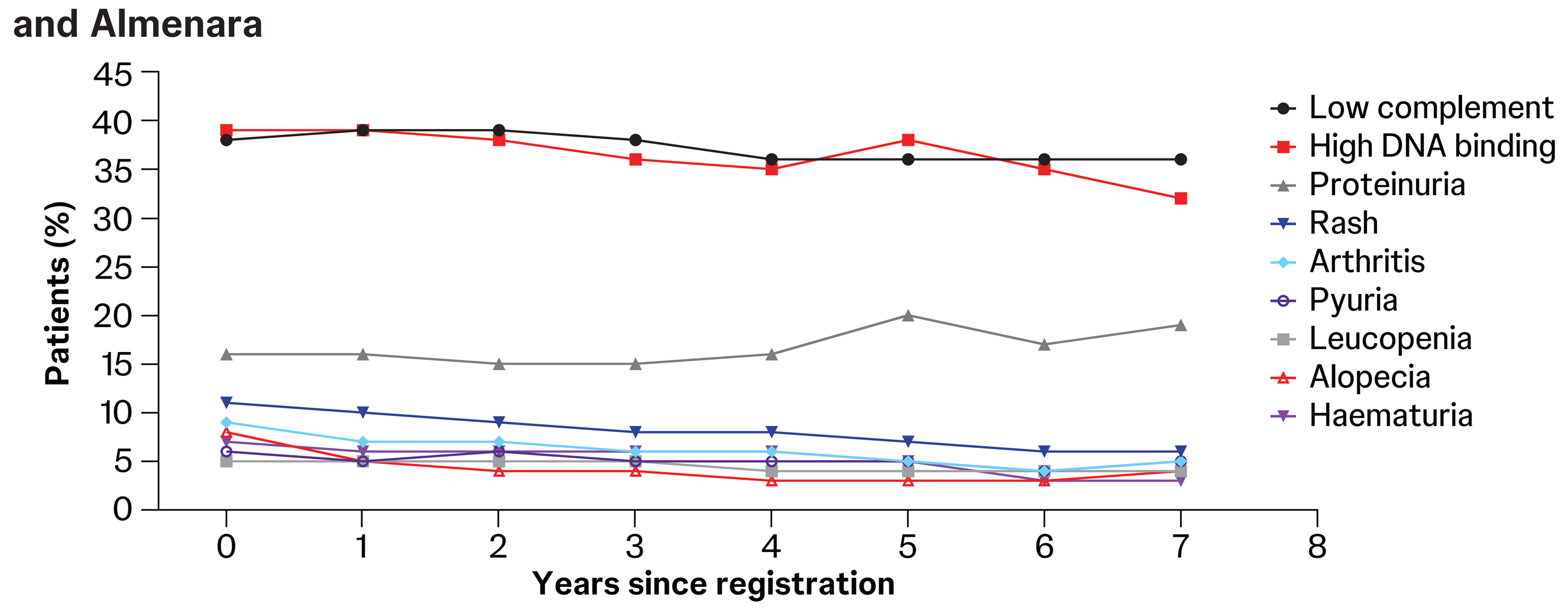
FIGURE 3: (A) Proportion of patients who experienced a flare and (B) mean SLEDAI score over time by registry



Almenara=Rheumatology Department of the Hospital Guillermo Almenara Irigoyen, **APLC**=Asia Pacific Lupus Collaboration, **RELESSER**=Spanish Society of Rheumatology Lupus Registry, **SD**=standard deviation, **SLEDAI**=Systemic Lupus Erythematosus Disease Activity Index.

The most common SLEDAI features observed during follow-up visits were consistent with those observed at registration (e.g., low complement, increased anti-dsDNA antibody, nephritis [i.e., proteinuria, pyuria, and haematuria], arthritis, rash, alopecia, and leucopenia; Figure 4)

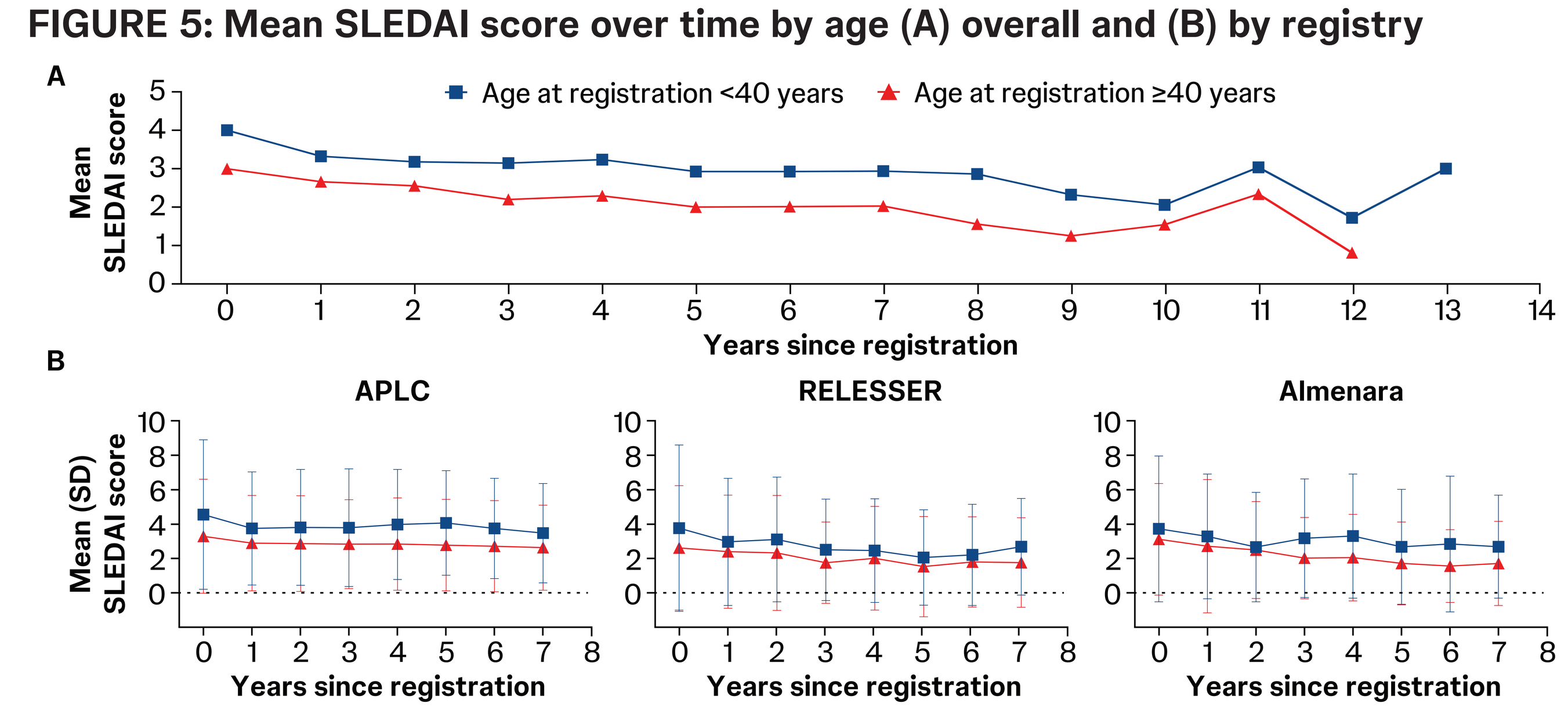
FIGURE 4: Most frequently observed[a] SLEDAI features over time in APLC, RELESSER, and Almenara



[a]Observed in ≥5% of patients at registry entry.
Almenara=Rheumatology Department of the Hospital Guillermo Almenara Irigoyen, **APLC**=Asia Pacific Lupus Collaboration, **RELESSER**=Spanish Society of Rheumatology Lupus Registry, **SLEDAI**=Systemic Lupus Erythematosus Disease Activity Index.

Across registries, younger patients (<40 years of age) had slightly higher SLEDAI scores at follow-up visits than older patients (Figure 5)

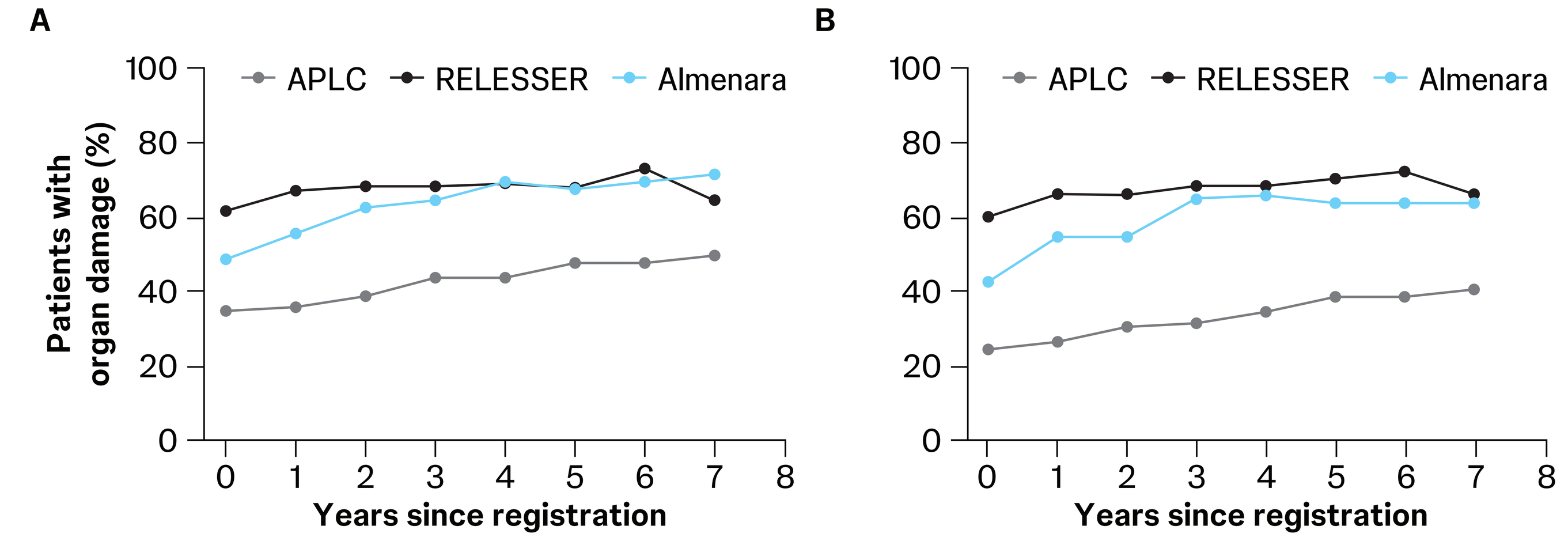
FIGURE 5: Mean SLEDAI score over time by age (A) overall and (B) by registry



Almenara=Rheumatology Department of the Hospital Guillermo Almenara Irigoyen, **APLC**=Asia Pacific Lupus Collaboration, **RELESSER**=Lupus Register of the Spanish Society of Rheumatology Lupus Register, **SD**=standard deviation, **SLEDAI**=Systemic Lupus Erythematosus Disease Activity Index.

Across registries, the proportion of patients with organ damage (SDI >0) increased slightly over time in both the overall SLE population (Figure 6A) and the subgroup with a SLEDAI score of 0 and without lupus nephritis (Figure 6B)

FIGURE 6: Proportion of patients with organ damage over time by registry (A) overall and (B) in the subgroup with a SLEDAI score of 0 and without lupus nephritis



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PRESENTED AT: EULAR European Congress of Rheumatology; 11-14 June 2025; Barcelona, Spain. **REFERENCES: 1.** Stojan G, Petri M. *Curr Opin Rheumatol.* 2018;30(2):144-150. **2.** Ameer MA, et al. *Cureus.* 2022;14(10):e30330. **3.** Hoi A, et al. *Arthritis Res Ther.* 2021;23(1):191. **4.** Fanouriakis A, et al. *Ann Rheum Dis.* 2024;83(1):15-29. **5.** Pons-Estel BA, et al. *Ann Rheum Dis.* 2018;77(11):1549-1557. **6.** Gordon C, et al. *Rheumatology (Oxford).* 2018;57(1):e1-e45. **ACKNOWLEDGEMENTS:** This study was sponsored by Johnson & Johnson. Medical writing support was provided by Anna Douyon, PhD, of Lumanity Communications Inc., and funded by Johnson & Johnson. **DISCLOSURES: FZ**, **AO**, **AS**, **CB**, **MvS**, **SG**, **RS**, and **CSK** are employees of and may hold stock/stock options in Johnson & Johnson. **MFU-G** received consulting and/or speaker fees from AstraZeneca, Ferrer, GSK, Novartis, and Tecnofarma; and received research support from Johnson & Johnson. **GJP-E** received grants and consulting fees from and participated as a speaker, advisor, and/or on a steering committee for AstraZeneca, Boehringer Ingelheim, GSK, Johnson & Johnson, Novartis, Pfizer, RemeGen, Sanofi, and Werfen Diagnostics. **OAM** received speaker fees and/or honoraria from AbbVie, AstraZeneca, Celltrion, GSK, Janssen-Cilag, Novartis, and UCB. **RK-R** received research grants from Bristol Myers Squibb, GSK, and Novartis. **SN** received consulting and speaker fees from AstraZeneca, Biogen, Boehringer Ingelheim, Idorsia/Viatris, and Otsuka. **AF-N** received consulting and speaker fees from AstraZeneca, Eli Lilly, Galapagos, Gebro Pharma, GSK, and Novartis; and received research grants from argenx, AstraZeneca, Chemo, Galapagos, Janssen, Merck Serono, MSD, Novartis, Takeda, and UCB. **RVG-C**, **VP-Q**, **RQ**, **VS**, **CNP**, **FMR**, **JAE-V**, **CNA**, **KZ**, **MR**, **KM**, **PK**, **EM**, **WL**, **AH**, **MN**, **CSL**, **SFL**, **LH**, **IR-F**, **ZP**, **MG-I**, **JM-B**, **JCA**, **RMA**, and **FJNG** declared no conflicts of interest.