Rheumatology, 2026, **65(2)**, keaf649
https://doi.org/10.1093/rheumatology/keaf649
Advance access publication 12 December 2025
Original Article

British Society for Rheumatology
RHEUMATOLOGY
OXFORD

Clinical science

International development and validation of a multilingual bank of items for the self-assessment of essential knowledge by lupus patients: the SLE Knowledge Assessment Score (SLAKE)

Antonin Satrin[1], Matteo Piga[2], Mariele Gatto[3], Yurilis Fuentes-Silva[4], José A. Gomez Puerta[5], Ivan Padjen[6], Guillermo Pons-Estel[7], Manuel F. Ugarte-Gil[8,9], Carlos Enrique Toro-Gutiérrez[10], Alexandra Legge[11], Ali Duarte-Garcia[12], François Chasset[13], Ioannis Parodis[14,15], Katia Baumgaertner[1], Laurent Chiche[16], Odirlei A. Monticielo[17], Omondi Oyoo[18], Raquel Faria[19,20,21], Shinji Izuka[22], Sofia Silva-Ribeiro[23], Galymzhan Togizbayev[24], Daniela Opris-Belinski[25], Lina El Kibbi[26], Amita Aggarwal[27], Mithu Maheswaranathan[28], Tai-Ju Lee[29], Sheilla Achieng[30], Anastasiia Shumilova[31], Ricard Cervera[32], Gamal Chehab[33], Faisal Parlindungan[34], Sander van Leuven[35], Karoline Lerang[36], Jeanette Andersen[37], Francesca Marchiori[37], Zoe Karakikla-Mitsakou[37], Christelle Sordet[1], Laurent Arnaud[1,*], for the international SLAKE development group[†]

[1]Department of Rheumatology, National Reference Center for Autoimmune Diseases (RESO), Strasbourg Academic Hospitals, Strasbourg, France
[2]Department of Medical Science and Public Health, Rheumatology Unity, University Clinic AOU Cagliari, University of Cagliari, Cagliari, Italy
[3]Department of Clinical and Biological Sciences, Academic Rheumatology Centre, University of Turin, Mauriziano Hospital, Turin, Italy
[4]Departamento de Medicina, Universidad de Oriente, Ciudad Bolívar, Venezuela
[5]Rheumatology Department, Hospital Clínic, University of Barcelona and IDIBAPS, Barcelona, Spain
[6]Division of Clinical Immunology and Rheumatology, Department of Internal Medicine, School of Medicine, Croatian Referral Centre for SLE and Related Diseases, University Hospital Centre Zagreb, University of Zagreb, Zagreb, Croatia
[7]Centro Regional de Enfermedades Autoinmunes y Reumáticas (GO-CREAR), Grupo Oroño, Rosario, Argentina
[8]Grupo Peruano de Estudio de Enfermedades Autoinmunes Sistémicas, Universidad Científica del Sur, Lima, Peru
[9]Rheumatology Department, Hospital Guillermo Almenara Irigoyen, EsSalud, Lima, Peru
[10]Reference Center of Osteoporosis and Rheumatology, Pontificia Javeriana University, Cali, Colombia
[11]Division of Rheumatology, Department of Medicine, Dalhousie University, Halifax, NS, Canada
[12]Division of Rheumatology, Mayo Clinic, Rochester, MN, USA
[13]Faculté de Médecine, Service de Dermatologie et Allergologie, Hôpital Tenon, INSERM U1135 CIMI, Sorbonne Université, Paris, France
[14]Division of Rheumatology, Department of Medicine, Solna, Center for Molecular Medicine (CMM), Karolinska University Hospital, Karolinska Institutet, Stockholm, Sweden
[15]Department of Rheumatology, Faculty of Medicine and Health, Örebro University, Örebro, Sweden
[16]Service de Médecine Interne, Hôpital Européen, Marseille, France
[17]Division of Rheumatology, Department of Internal Medicine, Hospital de Clínicas de Porto Alegre, Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil
[18]Rheumatology Unit, Department of Medicine, Faculty of Health Sciences, University of Nairobi, Nairobi, Kenya
[19]Unidade de Imunologia Clínica, Unidade Local de Saúde Santo António, Porto, Portugal
[20]UMIB—Unit for Multidisciplinary Research in Biomedicine, ICBAS—School of Medicine and Biomedical Sciences, University of Porto, Porto, Portugal
[21]ITR—Laboratory for Integrative and Translational Research in Population Health, Porto, Portugal
[22]Department of Allergy and Rheumatology, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan
[23]Center for Research and Social Intervention (CIS-Iscte), Iscte-University Institute of Lisbon, Lisbon, Portugal
[24]Department of Rheumatology, Almaty, Kazakhstan
[25]Spitalul Clinic Sfânta Maria, Universitatea de Medicină și Farmacie Carol Davila Bucharest, Romania
[26]Division of Rheumatology, Department of Internal Medicine, SMC Healthcare, Arab Adult Arthritis Awareness Group (AAAA Group), Riyadh, Saudi Arabia

---

Received: 29 August 2025. **Accepted:** 31 October 2025

[27]Department of Clinical Immunology and Rheumatology, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, India
[28]Division of Rheumatology and Immunology, Duke University School of Medicine, Durham, NC, USA
[29]Division of Rheumatology, Immunology, and Allergy, Department of Medicine, National Taiwan University Hospital Hsinchu Branch, Hsinchu, Taiwan
[30]Division of Musculoskeletal and Dermatology Sciences, Centre for Musculoskeletal Research, The University of Manchester, Manchester, UK
[31]Laboratory of Thromboinflammation, V.A. Nasonova Research Institute of Rheumatology, Moscow, Russian Federation
[32]Department of Autoimmune Diseases, Hospital Clínic, University of Barcelona and IDIBAPS, Barcelona, Catalonia, Spain
[33]Department of Rheumatology, University Hospital Düsseldorf, Heinrich-Heine-University, Düsseldorf, Germany
[34]Rheumatology Division, Department of Internal Medicine, Faculty of Medicine, Universitas Indonesia, Rumah Sakit Universitas Indonesia, Depok, Indonesia
[35]Department of Rheumatology, Radboud University Medical Center, Nijmegen, the Netherlands
[36]Department of Rheumatology, Rikshospitalet/Oslo University Hospital, Oslo, Norway
[37]Lupus Europe, Belgium

*Correspondence to: Laurent Arnaud, Department of Rheumatology, National Reference Center for Rare Autoimmune Diseases (RESO), Hôpitaux Universitaires de Strasbourg, Hôpital de Hautepierre, 1 Avenue Molière BP 83049, 67098 Strasbourg Cedex, France. E-mail: laurent.arnaud@chru-strasbourg.fr

†See acknowledgements section for a list of the International SLAKE development group.

Abstract

Objectives: Patient education is increasingly acknowledged as an important aspect of the management of SLE. The aim of the study was to develop the SLE Knowledge Assessment Score (SLAKE), a digital multilingual self-assessment tool designed to quantify essential SLE knowledge.

Methods: International healthcare professionals (HCPs) and patient representatives engaged in a multi-step process to: identify essential SLE knowledge domains, select key domains via rating, and generate an item bank of 394 questions across 11 domains, which was then adapted into 19 languages. For validation, participants completed 44 questions (including 33 randomly selected), with scores calculated for total knowledge and the 11 specific domains. Statistical analyses examined associations between scores and demographic, clinical, and educational variables.

Results: SLAKE was used by 1182 SLE participants (1120 [94.8%] women, median age: 45 years [IQR: 35–54 years]), with a median SLE duration of 10 years (IQR: 4–20 years). The median SLAKE score was 37 (IQR: 34–40) of a maximum of 44 points, while the median score across the 11 SLAKE domains ranged between 3 and 4 over a maximum of 4 points. There was a significant positive association between SLAKE score and SLE duration ($P = 0.006$), previous participation to a patient education course or a patient training for lupus ($P < 0.0001$) and the education level ($P < 0.0001$) but not with age ($P = 0.48$) or gender ($P = 0.39$).

Conclusion: SLAKE is a valid, multilingual, digital self-assessment tool that effectively measures essential SLE knowledge. Its randomized question bank and domain-specific scoring enable targeted education, ultimately supporting better disease management.

Keywords: SLE, educational status, education, health literacy, patient education, digital health, digital technologies, patient-centred care, patients, patient medication knowledge.

Rheumatology key messages

- Tools to quantify essential lupus knowledge and tailor patient education are lacking in SLE.
- SLAKE is a multilingual, digital self-assessment tool for measuring essential knowledge in lupus.
- SLAKE enhances personalized patient education, supports targeted interventions, and informs clinical decision-making.

Introduction

The recent updates of the European Alliance of Rheumatology Associations (EULAR) recommendations for SLE [1, 2] have highlighted the importance of patient education as a foundational principle in the care of individuals living with the disease. Assessing patient knowledge is an integral component of the educational diagnosis process, and can be effectively conducted using validated questionnaires [3, 4].

In January 2024, the European Reference Networks (ERNs) for rare connective tissue and musculoskeletal diseases (ReCONNET) embarked on the development and validation of a multilingual item bank designed to facilitate the self-assessment of essential knowledge among SLE patients, referred to as the SLE Essential Knowledge Assessment Score (SLAKE). ERNs represent a collaborative framework of healthcare professionals (HCPs) across Europe dedicated to addressing rare and complex diseases that necessitate specialized knowledge for care [3]. Among diverse activities, the ERN ReCONNET actively promotes initiatives aimed at enhancing the understanding and management of rare autoimmune diseases such as SLE [5], with a particular emphasis on patient education.

The primary objective of SLAKE was to quantify the overall level of essential knowledge possessed by SLE patients, both at the individual level and across meaningful knowledge domains. SLAKE is grounded in the concept of functional health literacy, aiming to equip patients with essential, actionable knowledge for informed decision-making and disease self-management, which aligns with frameworks such as the WHO's definition of health literacy and the Knowledge-to-Action model [6], emphasizing the centrality of understanding critical disease information to support shared therapeutic planning and adherence. This multilingual assessment tool was designed to identify specific domains where essential knowledge may be lacking. The insights gained help inform targeted patient education efforts. The goal is to align the assessment results with accredited, on-demand online educational content tailored to the unique knowledge needs of each patient.

Methods

The SLAKE study utilized a multi-step approach and included a relevant range of representative individuals, such as HCPs and patient or patient representatives (see below).

Study participants

The SLAKE study involved an international panel of diverse HCPs, including physicians from various SLE-related specialties, nurses, and other health-related professionals. An international panel of patient experts and patient representatives was recruited through the following patient associations: Lupus Europe and Agrupación Lupus Chile. All participants gave informed consent. The study was approved by the Ethics Committee of Strasbourg University (# CE-2023-95).

Multi-step approach

In Step 1, members of the HCP and patient panels were invited to independently identify the most critical domains of essential knowledge related to SLE through an active crowdsourcing approach [7]. This method encouraged these communities to self-report significant knowledge areas relevant to SLE. The concepts generated in Step 1 were reviewed to eliminate duplicates, and the remaining domains were categorized based on thematic similarities. In Step 2, the HCP panel evaluated the list of domains, rating each one on a scale from 0 to 10 to determine its significance for inclusion in SLAKE. Knowledge domains that received median scores >7 were deemed essential and were selected for the next steps. In Step 3, the HCP panel generated specific items based on the domains identified in Step 2. These items took the form of True/False questions intended to assess patients' essential knowledge of SLE. The steering committee then consolidated these items based on their thematic relevance, removed duplicates, and ensured consistency in style and wording. Additionally, the HCP panel was encouraged to create further items as necessary, with the goal of compiling at least 30 items per SLAKE domain. In Step 4, the HCP panel rated the relevance of each item for inclusion in the final SLAKE item bank using a 10-point scale (1 = not relevant at all; 10 = highly relevant). Due to the large number of items, each participant evaluated a randomly assigned subset representing approximately one-eighth of the total item pool (60 items). Items with a median score >7 were retained for the next phase. This selection step was particularly important to create a resource that is both linguistically and culturally appropriate to the community. In Step 5, the bank of items was cross-culturally adapted from English into multiple languages, including Arabic, Catalan, Croatian, Dutch, French, German, Hindi, Indonesian, Italian, Norwegian (Bokmål), Portuguese, Brazilian Portuguese, Romanian, Russian, Spanish, Swedish, Traditional Chinese (Taiwan) and Swahili. This adaptation was conducted using the ERN ReCONNET CROSSADAPT methodology [8], resulting in the final multilingual SLAKE item bank.

Essential knowledge testing

An adaptive digital platform was developed to facilitate self-assessment. Participants were recruited by disseminating the access link on social media, as well as directly by patient associations. Upon consenting to participate, individuals provided demographic, clinical, and educational background information. Participants were then presented with a set of 44 questions sourced from the SLAKE item bank, where they were asked to determine the answer of each statement as either true or false. The set of 44 questions included four questions from each of the 11 SLAKE domains. For each participant, 33 questions were randomly selected from the item bank (three questions per domain), and 11 were invariant questions selected by the steering committee (one per domain, administered to all participants to enhance item calibration). After submitting their answers, participants received a total score reflecting their number of correct answers (with a maximum score of 44 points), as well as individual scores for each domain (with a maximum score of 4 points). To further engage participants, SLAKE provided personalized motivational feedback based on their total score, tailored to each language. Participants were also invited to evaluate the platform by rating its usefulness, indicating whether they would recommend the assessment to other patients, and assessing the clarity of the questions in their own language.

Statistical analysis

Continuous data are reported as median values and 25th–75th percentile interquartile range (IQR), and categorical data as numbers and percentages. Comparison of categorical data between groups of interest was performed using the chi-squared test, while continuous data were compared using the Mann–Whitney *U* test. A standard least squares linear regression model was used to analyse associations between two continuous variables. The significance of statistical results remains unchanged after Bonferroni correction for multiple testing. All statistical analyses were performed using the software JMP v13.0 (Cary, NC, USA).

Results

In the first step, the international panel of HCPs and lupus experts ($n = 35$) and the group of patient experts ($n = 14$) were asked to spontaneously suggest the most important domains of essential knowledge in SLE. After regrouping similar proposals and removing duplicates, a total of 14 potential domains of essential SLE knowledge emerged (see Table 1).

In Step 2, the international panel of HCPs (32 participants) and a broader panel of SLE patients and patient representatives ($n = 50$) were asked to vote for the importance of each domain to be included in SLAKE, leading to the inclusion of 11 of the 14 initial potential domains (Table 2). The following three domains: 'diagnosis strategy', 'navigation of healthcare system' and 'research and clinical trials' were not deemed as essential as the other domains, particularly by HCPs.

In Step 3, the international HCP panel was asked to submit proposals for essential questions (items) related to each of these domains. Following two rounds of item generation, duplicate removal, deletion, rewording, and additional item generation, a raw bank of 465 questions was generated (Supplementary Fig. S1), with each of the 11 final SLAKE domains containing between 36 and 49 questions (Supplementary Table S1).

In Step 4, the international HCP panel, as well as participants from the lupus patient associations 'Lupus Europe' and 'Agrupacion Lupus Chile', assessed the raw item bank generated during Step 3 for essentialness of knowledge question, using a 0 (not essential) to 10 (very essential) scale to rate each. Subsequently, 394 (84.7%) were retained as essential. One question (item #1D1Q1: 'Lupus can vary in severity from person to person') was common to all participants and

Table 1. Initial list of 14 potential essential domains of knowledge in SLE

Suggested domain	Detailed domain description
Disease understanding	Assessing patients' knowledge about the basic facts and characteristics of SLE, such as the definition of the disease, its chronic nature, and its impact on different body systems, including the difference between disease activity and damage.
Symptoms recognition	Evaluating patients' knowledge of common symptoms associated with SLE, such as joint pain, fatigue, skin rashes, and other organ involvement, and their understanding of when to seek medical attention.
Diagnosis strategy	Understanding the diagnostic process for SLE, including the role of physical exams, medical history, and laboratory tests, including immunological tests.
Pregnancy and family planning	Assessing patients' understanding of the impact of SLE on pregnancy and the importance of preconception counselling, contraceptive options, and close monitoring during pregnancy, along with insights into the impact of SLE on sexual life and beliefs concerning hereditary disease transmission.
Treatment options and medication management	Testing patients' knowledge about different treatment modalities for SLE, including medications, lifestyle modifications, and self-care strategies, with consideration of the 'treat to target' approach and awareness of potential treatment side effects.
Therapeutic adherence	Assessing the patient's understanding of the importance of adhering to prescribed treatment regimens, including medication schedules, potential side effects, and the consequences of non-adherence.
Non-pharmacological management	Testing patients' knowledge about the role of non-pharmacological management and self-care practices, such as maintaining a balanced diet, physical activity, stress and fatigue management, and sun protection, in managing SLE and improving overall well-being.
Disease monitoring	Awareness of the importance of regular monitoring of disease activity and organ function. Knowledge of long-term care needs, including regular follow-up visits, disease management strategies during periods of remission, and understanding the basics of biological assessments.
Flare management	Assessing patients' knowledge of how to identify and manage disease flares, including recognizing worsening symptoms, seeking appropriate medical care during flares, and adjusting medications as instructed by healthcare providers.
Complications and co-morbidities	Evaluating patients' knowledge of potential complications and co-morbidities associated with SLE, such as kidney involvement, cardiovascular risks, osteoporosis, and increased susceptibility to infections.
Support and resources	Assessing patients' awareness of available support networks, patient advocacy organizations, and reliable sources of information for staying updated about SLE research, treatments, and self-management strategies.
Communication with healthcare providers	Evaluating patients' knowledge about the importance of open and effective communication with their healthcare team, including sharing symptoms, making shared decisions, reporting medication side effects, and scheduling regular follow-up appointments.
Navigation of healthcare system	Understanding and effectively moving through various healthcare services and providers to receive appropriate, timely, and coordinated care
Research and clinical trials	Familiarity with ongoing research, clinical trials, and the potential benefits and risks associated with participation.

Table 2. Selection of the 11 essential domains of knowledge for inclusion in SLAKE

List of potential domains for inclusion in SLAKE	Median score (IQR)			Selected for inclusion in SLAKE
	All participants (*n* = 82)	HCPs (*n* = 32)	Patients (*n* = 50)	
Disease understanding	10 (3–10)	9 (3–10)	10 (4–10)	
Symptoms recognition	10 (3–10)	10 (5–10)	10 (3–10)	
Diagnosis strategy	7 (0–10)	6.5 (2–9)	8 (0–10)	Not included
Pregnancy and family planning	9 (0–10)	9 (5–10)	9.5 (0–10)	
Treatment options and medication management	9 (2–10)	9 (3–10)	10 (2–10)	
Therapeutic adherence	10 (3–10)	9.5 (5–10)	10 (3–10)	
Non-pharmacological management	9 (0–10)	9 (2–10)	9 (0–10)	
Disease monitoring	9 (4–10)	8 (5–10)	9 (4–10)	
Flare management	9 (0–10)	9 (4–10)	10 (0–10)	
Complications and co-morbidities	8 (0–10)	8 (5–10)	8.5 (0–10)	
Support and resources	8 (2–10)	6.5 (2–10)	9 (3–10)	
Communication with healthcare providers	8.5 (1–10)	8 (2–10)	9 (1–10)	
Navigation of healthcare system	7 (2–10)	6 (2–10)	8.5 (2–10)	Not included
Research and clinical trials	7 (0–10)	5 (0–10)	7.5 (1–10)	Not included

SLAKE, SLE Knowledge Assessment Score; IQR, interquartile range; HCPs, healthcare professionals.

received a median score of 10 (IQR: 8–10), with no significant difference between HCPs and patients ($P = 0.83$). Also, serving as internal quality control, and unknown to participants, one question was shown twice to each rater, with a median absolute difference between the 2 ratings of 0 (IQR: 0–1), suggesting very high intra-rater reliability.

In Step 5, the bank of items was cross-culturally adapted (or translated) from English into 19 languages using the ERN ReCONNET CROSSADAPT methodology [8]. Briefly, the CROSSADAPT process is initiated by the identification of 'key terms' that are crucial for maintaining the original meaning of questions. Each language group, led by a senior member and two collaborators, independently assesses the existence and equivalence of these key terms in their native languages. Reconciliation meetings are held to establish agreed-upon terms for consistent usage across translations when difficulties arise with key terms. Subsequently, each language group translates the full list of questions, followed by a reconciliation meeting involving one CTD patient in each group. The purpose of this meeting is to address potential discrepancies among translations, ensuring a comprehensive assessment from a linguistic, cultural and patient perspective. Collective feedback and consensus-based decision-making guide the resolution process. This methodology ensures linguistic accuracy, cultural relevance, and contextual appropriateness for the cross-cultural adaptation of instruments for research and care in the context of rare CTDs [8]. The online platform (available at https://tinyurl.com/msrdep9y) was developed and thoroughly tested by a large panel of HCPs and patients for both its technical readability and appropriateness across the multiple language versions.

In Step 6, SLAKE was tested by 1182 participants with a self-reported diagnosis of SLE confirmed by a medical doctor. This test population comprised 1120 (94.8%) women and 60 men (2 preferred not to tell), with a median age of 45 years (IQR: 35–54 years) and a median SLE duration of 10 years (IQR: 4–20 years) since diagnosis. The SLAKE participants were mostly residing (Supplementary Table S2) in Italy ($n = 152$; 12.9%), Venezuela ($n = 106$; 9.0%), Spain ($n = 101$; 8.5%) and Croatia ($n = 85$, 7.2%). Strikingly, only 175 (14.8%) had participated in a patient education course or patient training for lupus. The educational level of participants (ISCED 2011 classification [9], see Supplementary Table S3) was: preschool and primary education ($n = 22$; 1.9%), secondary and post-secondary non-tertiary education ($n = 444$, 37.6%), and tertiary education ($n = 716$, 60.6%).

The median SLAKE score of the 1182 participants with SLE was 37 (IQR: 34–40, range: 7–44) over a maximum of 44 points (Fig. 1). The detailed scores for the 11 essential SLE knowledge domains are provided in Table 3.

There was no significant association (Table 4) between the age of participants ($P = 0.48$) or gender ($P = 0.39$) and total SLAKE score. However, there was a positive association between total SLAKE score and SLE duration ($P = 0.006$), previous participation in a patient education course or patient training for lupus ($P < 0.0001$), as well as with education level ($P < 0.0001$).

Regarding participant satisfaction with SLAKE, the median scores (0–10 scale) were 9 (IQR: 7–10) for each of the three following questions: 'Did you find SLAKE useful?' 'Would you recommend SLAKE to someone else?' and 'Are the questions [spelling and grammar] easy to understand in your language?'

Table 3. Median scores of the 1182 participants for the 11 essential SLE knowledge domains

Domain	Median (IQR)	Min–Max
Disease understanding	4 (3–4)	0–4
Symptoms recognition	4 (3–4)	0–4
Pregnancy and family planning	3 (2–4)	0–4
Treatment options and medication management	3 (3–4)	0–4
Therapeutic adherence	3 (3–4)	0–4
Non-pharmacological management	3 (3–4)	0–4
Disease monitoring	3 (3–4)	0–4
Flare management	4 (3–4)	0–4
Complications and co-morbidities	4 (3–4)	0–4
Support and resources	4 (3–4)	0–4
Communication with healthcare providers	4 (3–4)	0–4
Total SLAKE score	37 (34–40)	7–44

IQR, interquartile range; SLAKE, SLE Knowledge Assessment Score.

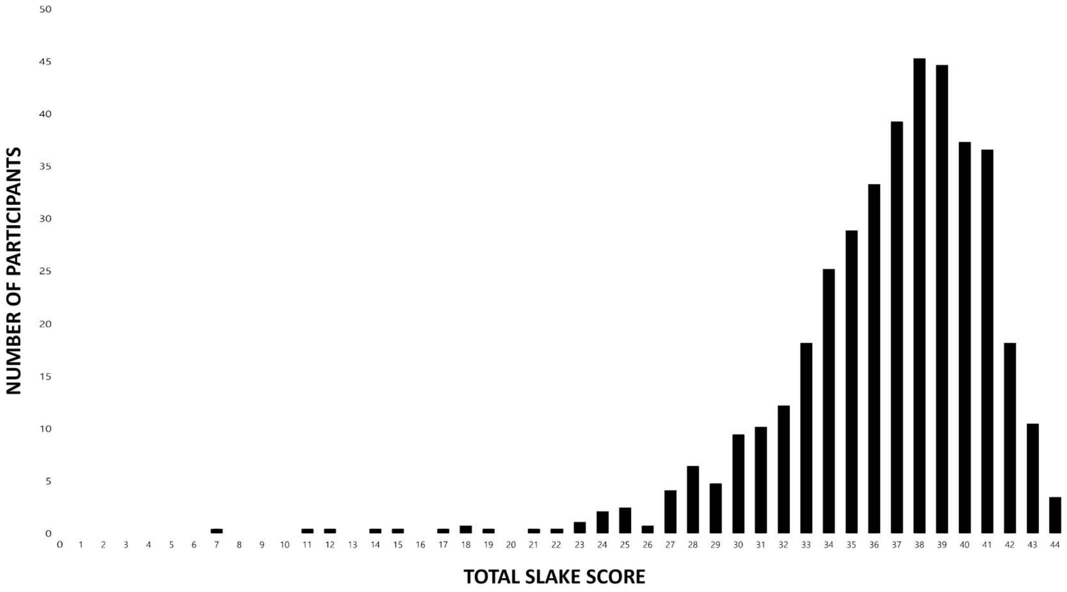

Figure 1. Distribution of total SLAKE of the 1182 participants with SLE

Table 4. Associations between participants' main characteristics and total SLAKE score

Patient characteristics	Total SLAKE score, median (IQR)	*P*-value
Gender		
Women ($n = 1120$)	37 (34–40)	0.39
Men ($n = 60$)	37 (34–40)	
NA ($n = 2$)	34 (34–34)	
Patient education programme		
Yes ($n = 175$)	39 (36–41)	<0.0001
No ($n = 1007$)	37 (34–39)	
Educational level		
Preschool and primary ($n = 22$)	33 (31–37)	<0.0001
Secondary and post-secondary ($n = 444$)	36 (33–39)	
Tertiary education ($n = 716$)	38 (35–40)	

SLAKE, SLE Knowledge Assessment Score; IQR, interquartile range; NR, not relevant (association between the 2 continuous variables assessed using standard least squares).

Discussion

Following a multi-step development process involving an international panel of HCPs, including SLE experts, as well as patients and patient representatives, we developed a multilingual online digital bank comprising 394 validated questions. It aims at empowering individuals by assessing their core understanding of SLE. SLAKE was validated with the participation of 1182 individuals with SLE from diverse geographical and educational backgrounds. It provides a global knowledge score alongside subscores for each of the 11 key domains of SLE knowledge. A major strength of SLAKE lies in its dynamic structure: for each assessment, 33 out of the 44 questions are randomly drawn from the validated item bank. This approach mitigates memorization bias, a frequent limitation in static, paper-based tests [10]. Furthermore, SLAKE subscores help patients pinpoint knowledge gaps. This allows for further engagement with targeted, curated, and validated content tailored to improve knowledge in those particular domains [11]. SLAKE can serve as a baseline assessment prior to structured education programs, be integrated into outpatient clinic setting, or embedded into digital platforms as part of telemedicine program. Ultimately, this approach lays the foundation for a personalized patient education program, designed to meet the individual's specific educational needs and support better disease management.

A key finding of the study is that the median SLAKE score was high in this large patient sample. This likely reflects both the high educational level of participants (60.6% had tertiary education) as well as the median disease duration of 10 years. During the validation phase, a statistically significant relationship was observed between SLAKE scores and the duration of SLE disease ($P = 0.006$). This indicates that patients with a longer history of SLE tend to have higher SLAKE scores, potentially reflecting increased disease experience, ongoing education, or greater engagement with disease management over time [12]. In the future, it will be interesting to assess SLAKE performance on an inception cohort and to study its sensitivity to change, as it remains currently unknown whether SLAKE can detect meaningful improvement after patient education, especially in highly educated and experienced populations. Of note, a strongly significant association was found between higher education levels and SLAKE scores ($P < 0.0001$). This suggests that patients with more advanced formal education may have better access to, comprehension of, or motivation to acquire essential information about their condition, thereby leading to improved knowledge [12, 13]. Furthermore, patients who had previously participated in patient education courses or training sessions specific to lupus exhibited markedly higher SLAKE scores ($P < 0.0001$). This underscores, indirectly, the efficacy of structured educational interventions in enhancing patient knowledge and potentially improving attitudes and self-management practices related to SLE [14]. In particular, SLAKE may also assist clinicians in identifying knowledge gaps that hinder adherence or self-management, enabling more individualized educational interventions. Additionally, future trials assessing SLAKE scores before and after participation in patient education programs will be a priority in the development plan of SLAKE to further validate its responsiveness and utility in measuring the impact of educational interventions. Conversely, neither age nor gender demonstrated a significant association with the total SLAKE score. This suggests that, within the validation sample, essential knowledge related to SLE is relatively consistent across different age groups and between genders.

Notably, SLAKE has primarily been disseminated online through social media platforms, patient association websites and mailing lists. This approach may have introduced a selection favouring participants with higher digital literacy [15, 16] as well as individuals with more interest and motivation to learn about their disease. However, this is unlikely to compromise its utility when used in routine clinical settings. Nevertheless, digital deserts—areas with poor internet access—may limit SLAKE's reach among underserved populations.

Importantly, the availability of the tool in 19 languages, including widely spoken languages such as English, Spanish, Arabic, Chinese, and Russian, as well as others like Hindi, Indonesian, Catalan, and Swahili, expands its global applicability. Of note, SLAKE was developed within the framework of the ERN ReCONNET, which is supported by the European Union, reflecting the predominance of European languages. Analysis of the distribution of total SLAKE scores (see Fig. 1) suggests that the high median score reflects participants' genuine knowledge level rather than a ceiling effect and its sensitivity across a broad spectrum of participants' abilities, regardless of cultural differences and the availability of lupus treatments in the participating countries. SLAKE appears feasible for clinical use, with patients completing the questionnaire within a reasonable time and achieving a high median score, indicating both usability and comprehension. Also, it may be informative to examine SLAKE scores at the subnational level, such as by city or region. The healthcare facility where a patient receives care may significantly influence disease-related knowledge. Patients followed in major academic centres or national referral institutions, often located in capital cities, may have greater access to structured education and disease-specific information compared with those managed in regional or local clinics.

Given the evolving nature of SLE management, medical knowledge, and patient expectations, the SLAKE platform is designed to be dynamic. Regular updates of the item bank and associated educational content are planned to ensure continued clinical relevance, maintain alignment with current guidelines, and address emerging knowledge gaps over time. Its digital format also offers unique opportunities for large-scale dissemination, real-time updates, and integration into various care and education pathways, including remote and resource-limited settings. As part of the broader e-health landscape, SLAKE exemplifies how digital solutions can support more preventive, patient-centred care. By facilitating early identification of knowledge gaps and promoting targeted education, such tools may help shift healthcare towards a more proactive model—potentially reducing long-term costs and limiting the environmental footprint of care delivery.

It is worth noting that as of today, all questions are given the same weight in the total SLAKE score; however, in the future, the goal is to calibrate the item bank using item response theory (IRT). IRT is a statistical framework that models the relationship between an individual's latent trait (e.g. knowledge) and their probability of correctly answering an item [17]. A key concept in IRT is the difficulty parameter, which indicates the degree of difficulty of an item. By calibrating items with IRT, we can more accurately measure the underlying knowledge trait and better tailor assessments to individual ability levels. This would also help reduce a potential ceiling effect by providing participants with targeted questions tailored to their individual ability levels.

Finally, beyond its immediate educational utility, SLAKE also provides a robust framework that could be leveraged for future research initiatives, including studies exploring the impact of patient knowledge on adherence, quality of life, and healthcare utilization. SLAKE focuses on assessing patients' knowledge about lupus, but not their practical skills or competence, and may nevertheless support future personalized educational interventions. Further investigations are needed to evaluate whether the use of SLAKE-based education, or other structured patient education programs, can lead to measurable improvements in these clinically meaningful outcomes. One approach to longitudinally monitoring each patient could involve the use of a digital platform (e.g. an app) that enables the visualization of changes over time and their association with diverse clinical outcomes. This, in turn, could inform a data-driven weighting of items that are more strongly linked to favourable outcomes.

In conclusion, the development and validation of SLAKE represent a significant advancement in the assessment of SLE-related essential knowledge among diverse patient populations. Developed through a rigorous multi-step and multi-stakeholder process, this innovative digital tool offers a reliable, dynamic, and personalized measure of essential SLE knowledge globally as well as across 11 domains. Its innovative question bank, featuring random item selection to prevent memorization bias, enhances measurement accuracy and applicability in both clinical and research settings. Moreover, its availability in 19 languages broadens its global reach, facilitating cross-cultural comparisons and implementation in diverse healthcare systems. While demographic factors such as age and gender did not appear to influence SLAKE scores significantly, clinical experience with the disease and educational attainment were key determinants associated with increased disease-specific knowledge among patients with SLE. These findings highlight the importance of targeted educational strategies and ongoing patient engagement to enhance disease management and patient empowerment. SLAKE may also serve as a foundation for integrating structured patient education into routine clinical care, enabling HCPs to tailor interventions based on individual knowledge gaps identified through the tool. In the future, calibrating the question bank using Item Response Theory will further refine SLAKE's precision to identify participants with increased educational needs. Ultimately, the total SLAKE score as well as the 11 domain subscores will allow further engagement with targeted, curated, and validated content tailored to improve knowledge in those particular domains.

Supplementary material

Supplementary material is available at *Rheumatology* online.

Data availability

All data supporting the findings of this study are available within the paper.

Author contributions

L.A. designed the study, with contributions from A.S. All authors contributed to data collection. L.A. drafted the manuscript. All authors reviewed and revised the manuscript for critical intellectual content. All authors approved the final version of the manuscript.

Funding

The ERNs are funded by the European Union. This publication was supported by the ERN ReCONNET Grant Agreement 101157143.

Disclosure statement: M.P. received lecture and consultancy fees from AstraZeneca, GSK, Otsuka, and Roche. M.G. received lecture and consultancy fees from AstraZeneca, GSK, Otsuka, and Roche. L.C. declares research grants paid to his institution from AstraZeneca and GSK, personal consulting fees from Novartis and AstraZeneca, and personal speaking fees from BMS, GSK and Novartis. M.F.U.-G. has grant support from Janssen. He has been a speaker for AstraZeneca and Novartis, and he has been part of advisory boards for Adium, AstraZeneca, Ferrer and GSK. R.C. received lecture and consultancy fees from AstraZeneca, GSK, Otsuka, Roche, Werfen, Rubió, BMS, and Zenas. R.F. received lecture and consultancy fees from AstraZeneca and GSK. G.P.-E. has received research grants, consulting fees, honoraria for speaking engagements, and support to attend scientific meetings from AstraZeneca, Boehringer Ingelheim, GSK, Janssen, Novartis, Remegen, Roche, Viatris, and Werfen. M.M. received consulting fees from AstraZeneca and UCB. S.v.L. holds the role of Associate Editor for *Rheumatology* and has not peer reviewed or made any editorial decisions for this article. L.A. has performed consultancy for Alexion, Amgen, AstraZeneca, AbbVie, Alpine, Biogen, BMS, Boehringer-Ingelheim, Chugaï, GSK, Grifols, Janssen-Cilag, Kezar, LFB, Lilly, Medac, Novartis, Oséus, Pfizer, Roche, and UCB. The remaining authors report no disclosures related to this manuscript.

Acknowledgements

This work was promoted in the framework of ERN ReCONNET. ERN ReCONNET is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. ReCONNET-CROSSADAPT was approved by the steering committee of the European Reference

Network ReCONNET. The authors would like to thank the patient associations Lupus Europe and Agrupacion Lupus Chile for their involvement in the development and dissemination of SLAKE, as well as all the persons living with lupus who have contributed to its development.

International SLAKE development group collaborators: Tobias Alexander, Laura Andreoli, Olga Araújo, Abirianty Araminta, Chiara Bellochi, Lorenzo Beretta, Hugo Bergier, Inita Bulina, Irene Bultink, Joan Calzada-Hernández, Chiara Cardamone, Ting-Wei Chang, Rudrarpan Chatterjee, Claudia Cobilinschi, Fabrizio Conti, Claudio Cruciani, Johanda Damanik, Roberto Depascale, Christina Düsing, Gerard Espinosa, Franco Franceshini, Micaela Redi, Samira García-Hirsh, Andrese A. Gasparin, Philipp Gauckler, Sophie Geneton, Tiphaine Goulenok, Iva Gunnarsson, Hussein Halabi, Alberta Hoi, Iris van Ingen, Carolina Isnardi, Sandra Jägerback, Michelle Kahlenberg, Baïdy Kane, Lou Kawka, Nikita Khmelinskii, Ting-yuan Lan, Maarten Limper, Worawit Louthrenoo, Carla Macieira, Monisha Madhumita, Anselm Mak, Sigrid Reppe Moe, Ihsane Hhamouchi, Lucia Manfredi, Robert Marcec, António Marinho, Sandra Meisalu, Nathalie Morel, Marta Mosca, Johanna Mucke, Sandra Navarra, Kamila Nurbaeva, Marzena Olesinska, Giovanni Orsolini, Cristina Pamfil, Mykolas Petraitis, Susanne Pettersson, Margarita Ileckyte, Subitchan Ponnarasu, Delia Popa, Chitra R, Lekshmi Rahulan, Giuseppe Ramirez, Tatiana Reshetnyak, Christophe Richez, Sanaa S. Said, Rosaria Salerno, Juan Sarmiento-Monroy, Natalia S. Sartori, Ioana Saulescu, Savino Sciascia, Polina Sholkina, Christopher Sjöwall, Cedric Sztejkowski, Mona Thorud, Zahi Touma, Guilherme L. Tres, Massimo Triggiani, Simona Truglia, Michel Tsang-a-Sjoe, Mislav Caic, Nelly Ziade.

Disclaimer

The content of this publication represents the views of the authors only, and it is their sole responsibility; it cannot be considered to reflect the views of the European Commission and/or the Health and Digital Executive Agency (HaDEA) or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

References

1. 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.
2. Parodis I, Girard-Guyonvarc'h C, Arnaud L *et al.* EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Ann Rheum Dis 2024; 83:720–9.
3. Talarico R, Aguilera S, Alexander T *et al.* The added value of a European Reference Network on rare and complex connective tissue and musculoskeletal diseases: insights after the first 5 years of the ERN ReCONNET. Clin Exp Rheumatol 2022;40 Suppl 134:3–11.
4. Beauvais C, Pereira B, Pham T *et al.* Development and validation of a self-administered questionnaire measuring essential knowledge in patients with axial spondyloarthritis. J Rheumatol 2023; 50:56–65.
5. Arnaud L, Ruiz-Irastorza G, Aranow C *et al.*; European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases; Systemic Lupus Erythematosus International Collaborating Clinics group; European Lupus Society rare systemic lupus erythematosus taskforce member panel. ERN ReCONNET-SLICC-SLEuro expert consensus on the therapeutic management of rare systemic lupus erythematosus manifestations. Lancet Rheumatol 2025;7:e505–18.
6. World Health Organization. WHO guideline on self-care interventions for health and well-being, 2022 revision. 1st ed. Geneva: World Health Organization, 2022.
7. Khare R, Good BM, Leaman R, Su AI, Lu Z. Crowdsourcing in biomedicine: challenges and opportunities. Brief Bioinform 2016; 17:23–32.
8. Arnaud L, Sander O, Rednic S *et al.* European Reference Network (ERN) ReCONNET methodology for the cross-cultural adaptation of instruments for research and care in the context of rare connective tissue diseases (CROSSADAPT). Orphanet J Rare Dis 2025;20:230.
9. UNESCO. ISCED 2011 operational manual: guidelines for classifying national education programmes and related qualifications—UNESCO Bibliothèque Numérique n.d. https://unesdoc.unesco.org/ark:/48223/pf0000232343 (24 June 2025, date last accessed).
10. Luo H, Yang X. Efficiency of computerized adaptive testing with a cognitively designed item bank. Front Psychol 2024;15:1353419.
11. Shao Y, Hu H, Liang Y *et al.* Health literacy interventions among patients with chronic diseases: a meta-analysis of randomized controlled trials. Patient Educ Couns 2023;114:107829.
12. Jung SM, Park S-H, Lee J, Park Y-J, Shim SC. Understanding patient perspectives on health-related searches on the internet: insights from an online survey of Korean patients with systemic lupus erythematosus. Lupus 2025;34:39–46.
13. Maheswaranathan M, Eudy AM, Barr AC *et al.* Association of health literacy and numeracy with lupus knowledge and the creation of the lupus knowledge assessment test. J Rheumatol 2022; 49:585–91.
14. Ra JH, Leung J, Baker EA, Kim AHJ. Patient perspective on using digital resources to address unmet needs in systemic lupus erythematosus. Arthritis Care Res 2021;73:1568–76.
15. Topolovec-Vranic J, Natarajan K. The use of social media in recruitment for medical research studies: a scoping review. J Med Internet Res 2016;18:e286.
16. Maheswaranathan M, Eudy AM, Bailey SC, Rogers JL, Clowse ME. Low health numeracy is associated with higher disease activity in systemic lupus erythematosus. Lupus 2021;30:489–94.
17. Siemons L, Krishnan E. A short tutorial on item response theory in rheumatology. Clin Exp Rheumatol 2014;32:581–6.

Rheumatology, 2026, 65, 1–8
https://doi.org/10.1093/rheumatology/keaf649
Original Article