Review

A charter to improve care for systemic lupus erythematosus

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ABSTRACT

Objective. *To develop evidenced recommendations to allow the global systemic lupus erythematosus (SLE) advocacy community to effectively advocate for change and improve care for patients with SLE.*

Methods. *A Global Working Group consisting of representatives from patient advocacy groups, professional organisations, and the SLE healthcare community defined key areas of unmet need in patients with SLE. Targeted principles for each area of unmet need guided a literature review to investigate the current global situation, pre-existing advocacy efforts, and best practices from other therapy areas. The results from this literature review allowed the Working Group to develop recommendations to improve care for patients with SLE.*

Results. *Barriers faced by patients with SLE can stem from poor recognition of symptoms, which leads to delays in accurate diagnosis, cycling between different healthcare professionals, and inconsistencies in receiving optimal care. Patient access to approved treatments for SLE also remains limited.*

This Patient Charter, co-developed with a group of internationally recognised clinicians and patient advocates, sets out the minimum standard of care people living with SLE should expect and receive under 4 principles with distinct recommendations for change.

Conclusion. *The intention is to improve health outcomes by uniting and empowering patients, caregivers, patient groups, and healthcare professionals to advocate for reforms to healthcare practices for people living with SLE.*

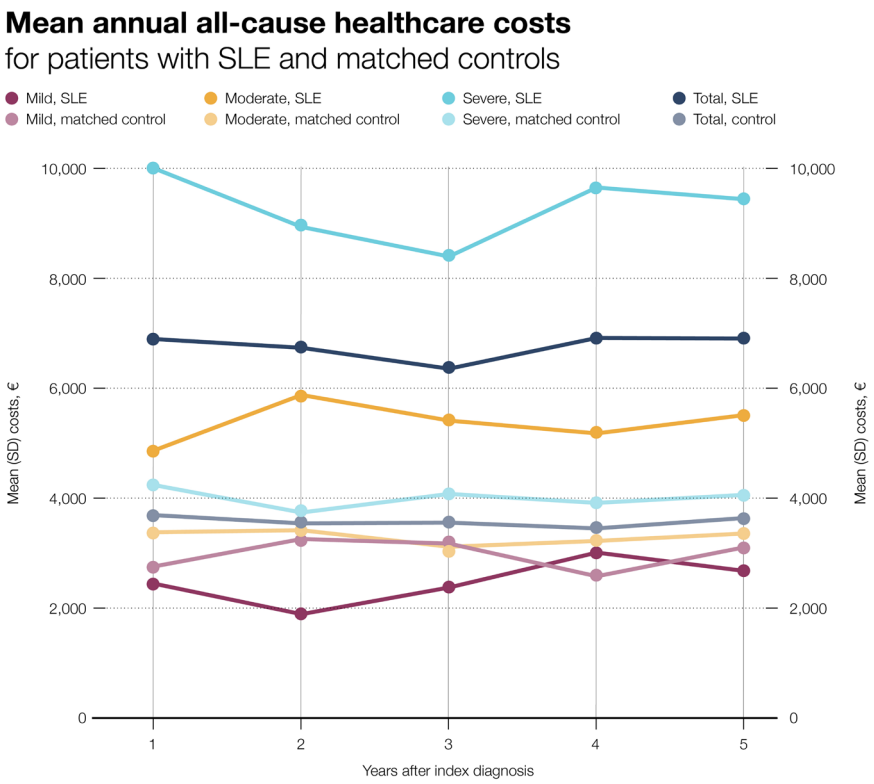
Introduction

Systemic lupus erythematosus (SLE) is a complex, chronic, and often debilitating immune-driven disease, in which the immune system attacks healthy tissue in the body (1). SLE is heterogeneous and can be characterised by a wide range of debilitating, diverse, and recurring symptoms including skin rashes, joint pain, fatigue, swelling, fevers, and serious organ damage (2). Patients with SLE also report detrimental effects in all aspects of health-related quality of life, including the ability to work, and the considerable mental health burden (3).

Approximately 5 million people worldwide have some form of lupus (4). SLE affects up to 300,000 people in the US (5), between 200,000–250,000 people in Europe (6), and approximately 200,000 people in Brazil (7, 8). Nine in ten people with SLE are women (9), and it is typically diagnosed in people between the ages of 15 and 44 years old (6). There are also ethnic disparities, with populations including individuals of African, Asian, and Aboriginal ancestry having a higher incidence and prevalence of SLE compared with white populations across the world (10). Socioeconomic status can also influence SLE's incidence, prevalence, and severity (11).

In contrast to other autoimmune diseases, such as rheumatoid arthritis and psoriasis, there are few approved medicines for SLE. Many current treatments for SLE, including glucocorticoids, provide rapid symptom relief but are associated with significant toxicity and long-term adverse effects (12, 13).

The healthcare costs for patients with SLE are substantial; they remain high after diagnosis and rise with increasing disease severity (Fig. 1) (14). In Europe, the mean annual direct medical cost is higher in severe compared with non-severe patients (€4,748 *vs.* €2,650) (15). In the US and Japan, this cost difference is even greater (severe SLE: $52,951/¥2,136,780; mild SLE: $21,052/¥436,836) (16, 17).



Mean (SD) costs, € breakdown

	Years after index diagnosis				
	1	2	3	4	5
Mild SLE	**2,446** (3,991) n=148	**1,890** (2,665) n=146	**2,375** (4,514) n=141	**3,010** (8,884) n=136	**2,677** (5,118) n=129
Mild matched control	**2,757** (3,694) n=592	**3,257** (4,397) n=584	**3,174** (4,033) n=564	**2,579** (2,468) n=544	**3,106** (3,247) n=516
Moderate SLE	**4,867*** (8,322) n=484	**5,877*** (10,747) n=470	**5,411*** (10,130) n=452	**5,178*** (8,492) n=430	**5,512*** (9,812) n=415
Moderate matched control	**3,380** (3,554) n=1,931	**3,417** (3,872) n=1,875	**3,116** (2,877) n=1,807	**3,222** (2,468) n=1,719	**3,357** (3,304) n=1,659
Severe SLE	**10,001*** (19,253) n=528	**8,934*** (16,562) n=505	**8,396*** (15,770) n=484	**9,651*** (19,232) n=467	**9,437*** (15,260) n=443
Severe matched control	**4,239** (4,416) n=2,104	**3,739** (3,391) n=2,012	**4,077** (4,481) n=1,931	**3,914** (3,988) n=1,863	**4,060** (4,278) n=1,767
Total SLE	**6,895*** (14,424) n=1,160	**6,735*** (13,351) n=1,121	**6,355*** (12,713) n=1,077	**6,914*** (14,624) n=1,033	**6,903*** (12,420) n=987
Total control	**3,692** (3,994) n=4,627	**3,541** (3,740) n=4,471	**3,555** (3,830) n=4,302	**3,450** (3,609) n=4,126	**3,639** (3,770) n=3,942

* P<0.0001 for patients with SLE vs. matched controls

Fig. 1. Mean annual all-cause healthcare costs for patients with SLE and matched controls. Data from: A Schwarting et al.: The burden of systemic lupus erythematosus in Germany: Incidence, prevalence, and healthcare resource utilization. *Rheumatol Ther* 2021. https://doi.org/10.1007/s40744-021-00277-0
SD: standard deviation; SLE: systemic lupus erythematosus.

The Charter aims to unite and empower patients, caregivers, patient groups, and healthcare professionals (HCPs) to advocate for change and drive improvements to the care and treatment received by people living with SLE. This Patient Charter focuses on SLE. However, the authors hope that its recommendations could be applied to other forms of lupus if validated with relevant patient organisations and HCPs.

Methods

Working Group

Historically the low awareness, complexity and heterogeneity of SLE has negatively impacted patient care and outcomes. To address these challenges, in 2022, AstraZeneca convened two representatives from international and European patient advocacy groups, six rheumatologists and a rheumatology nurse to form a Global Working Group. The objective was to discuss and identify solutions to the global unmet needs of people living with SLE. As part of the initial meeting in March 2022, it was agreed that the global community lacked one clear and referenceable source for advocates to drive improvements in care. A Patient Charter was identified as a tool to unite and empower patients, patient groups, and HCPs to advocate for change and drive improvements to the care and treatment received by people living with SLE.

Literature review and patient advocacy exchange

A literature review was conducted to: 1. identify the current areas of unmet need in SLE globally, 2. establish a base understanding of pre-existing advocacy efforts and identify how a Patient Charter could add value, 3. explore examples of best practice from advocates in other disease areas who have effectively championed change through the effective implementation of a Patient Charter. This included a particular emphasis on data collected in patient surveys including, but not limited to, the Living with Lupus Survey conducted by Lupus Europe (6) and the ALPHA programme led by the Lupus Foundation of America (18). It also drew on a range of global resources that high-

lighted the marked economic impact of SLE through both direct and indirect healthcare costs, further illustrating the impact of sub-optimal care.

A Patient Advocacy Exchange was also convened to understand the unmet needs of SLE patients. This group was made up of patient-led organisations from Lupus UK, UK; Nationale Vereniging LE Patienten (NVLE), Netherlands; Lupus Canada, Canada; Lupus Ontario, Canada; Association Française du Lupus et autres maladies auto-immunes (AFL+), France; ReumaNet, Belgium; Gruppo LES Italiano, Italy; Federación Española de Lupus (FELUPUS), Spain; Riksförening for SLE; Lupus Foundation of America, and international groups: World Lupus Federation, Lupus Europe, and Global Allergy & Airways Patient Platform (GAAPP). Attendees at the Advocacy Exchange highlighted the value of a shared vision of the future of lupus care, and shared examples of how current unmet needs impacted patients in their countries. It was key for the patient organisations that the Patient Charter provided patient-centric solutions to address the ongoing challenges in lupus care, providing them with a tool to advocate for change. They also agreed that a Patient Charter would complement policy-shaping efforts and unlock systemic barriers to higher standards of care.

The Working Group discussed findings of the literature review, the Patient Advocacy Exchange and regional guidelines on the management of SLE to establish consensus on five priority areas of unmet need. These were: awareness and understanding of symptoms of SLE, delays in diagnosis, limited access to specialist care, burden of disease, and limited treatment options and long-term steroid use.

Formulation of Patient Charter principles and recommendations

The Working Group held virtual meetings in which the five areas of unmet need were mapped to establish consensus on 4 principles of care. Owing to the convergence of content in areas of unmet need, 4 principles of care were agreed to be sufficient in addressing all areas identified. The principles of care set out the minimum standards of care people living with SLE should expect and receive, as well as specific recommendations for change that could be applied globally.

Discussion

Principle 1. I deserve recognition and understanding of my early symptoms of SLE to drive timely, accurate diagnosis and assessment, so that I can receive the best care available as soon as possible

Awareness of SLE is low amongst both the general public and HCPs (19-22). Patients also report challenges in the wider understanding of the direct and indirect impact of SLE amongst their peers and employers (23). There are ongoing awareness campaigns at a national level, for example Lupus Foundation of America's (LFA) 'Be Fierce, Take Control' campaign aims to raise awareness of the signs and symptoms of SLE among African American/Black and Hispanic/Latina women in the US (24).

Mean time to diagnosis is typically between three and seven years (18, 25), and patient surveys have demonstrated that patients are often misdiagnosed before receiving a SLE diagnosis (26). Primary care physicians are often the first point of contact for patients, yet most do not have sufficient exposure to or experience with SLE (27, 28). Clear communication between HCPs and patients with SLE is critical to mitigate clinical assumptions based on presenting symptoms (29, 30).

Moreover, within SLE care, patient-clinician discordance is a significant issue. Patients and physicians tend to assess SLE differently (31), with physicians more focused on long-term treatment goals and patients more concerned with the everyday impact of symptoms (32-35). This discordance may impact patients' treatment adherence and therapeutic decisions (36).

HCP-patient discussion guides should seek to focus on optimising the early dialogue between HCPs and patients around symptom communication and their physical as well as psychological needs. Referral pathways have been implemented for other disease areas as a helpful way to standardise the diagnosis and assessment of a disease and have been associated with a shorter time to diagnosis and treatment (37).

Disease measurement and management of SLE is complex and lacks standardisation both within and across countries (38, 39). There is also no global standard SLE diagnostic criteria (1, 40), making it more challenging for patients, HCPs, and providers to know what is expected in terms of diagnosis, assessment, and longer-term management. Diagnostic principles exist in regional and national best practice guidelines, such as those from the European Alliance of Associations for Rheumatology (EULAR) (41), British Society for Rheumatology (BSR) (42), Asia-Pacific League of Associations for Rheumatology (APLAR) (43), Latin American Group for the Study of Lupus (GLADEL) (44)/Pan-American League of Associations of Rheumatology (PANLAR) (44), American College of Rheumatologists (ACR) (45), and Systemic Lupus International Collaboration Clinics (SLICC) (46). However, there is an urgent need for greater consistency across guidelines with reference to the evidence they include and criteria they recommend as best practice. As set out in this Patient Charter, this may include diagnostic or referral criteria and alignment on treatment goals in SLE to include assessment of the adverse impacts of treatments which affect a patient's quality of life.

Recommendations to improve care

- Expand the delivery of SLE public awareness campaigns to empower those experiencing symptoms consistent with SLE to seek care earlier and ensure their condition is recognised and understood by others.
- Greater focus on SLE and patient profiles within clinical education (including for primary care professionals) to increase clinical understanding of the heterogenous signs and symptoms of SLE.
- Development of a standardised list of diagnostic criteria and clinical investigation tools for all healthcare professions to improve SLE diagnosis consistently across regions.

- Development and implementations of referral pathways ensuring a consistent approach to timely SLE diagnosis and assessment. Screener tools and primary care alerts should also be considered to support earlier identification of patients who could benefit from a comprehensive SLE assessment.

Principle 2. I deserve access to information about my SLE, so I can play an active role in the management of my condition, minimise flares, and reduce the impact of SLE on my life

Recent guidelines recognise the importance of patient involvement in the management of their care (41, 43), as it can lead to greater patient empowerment, adherence to treatment, and improved outcomes.

A 2018 survey of patients with SLE in the US revealed 48% of respondents were unable to predict when a flare would occur and 35% delayed seeking care after experiencing a flare for three days or more (47). Moreover, the World Lupus Federation's (WLF) 2022 survey found that less than 6% of patients discuss the possibility that SLE could seriously impact or cause irreversible organ damage with their clinician, more than a year after diagnosis (48). Improving patients' knowledge of SLE is an important factor in enabling them to identify flares, and to know how and when to engage with HCPs to minimise long term organ damage (49).

Materials and tools can help patients better prepare for conversations with their clinician and ensure they can seek the right information. In the Netherlands, The National Association for People with Lupus, APS, Scleroderma and MCTD (NVLE), developed a consultation card (Consult kaart) to help patients prepare for conversations with their clinicians (50). Providing digital tools to help patients manage and monitor their condition going forward can also contribute to positive health outcomes. Lupus Foundation of America's online self-management program, Strategies to Embrace Living with Lupus Fearlessly (SELF), found that 57% of participants mastered one or more new skills after 90 days (51).

Patients also need support to address the impacts that living with SLE can have on their mental health. A Lupus Europe (LE) survey found that 17% of respondents living with SLE identified depression and/or anxiety as one of their most bothersome symptoms (6). Of those respondents, only 26% reported they had access to psychological support and 30% to adequate social support (6).

A recent study in the Netherlands on the preferences of women with SLE regarding pre-pregnancy counselling revealed that patients prefer tailored information and expressed preferences regarding the timing of the information (52). Information about the impact of SLE on a patient's life should be tailored to each patient's lifestyle, concerns, or preferences, and at the appropriate time (48).

Various cultural factors have been shown to impact health-seeking behaviour and therefore engagement with the health system. In addition, low educational attainment and low health literacy can interfere with the ability of patients to understand health information (53). 'Let's Talk About Lupus' (Hablemos de Lupus/Falando de Lúpus) is an educational initiative for Latin American patients, compiling information that is accessible and relevant for this group of individuals (54). Given that SLE disproportionately affects those with low socioeconomic status, improved access to information at the correct literacy level to be easily consumed by all patients is vital (55).

Caregivers also play an important role in supporting patients with SLE to manage their condition. This includes day-to-day care *e.g.* keeping track of medication administration, less frequent medical appointments or clinic visits, and providing psycho-emotional support (56).

Recommendations to improve care

- Patients should have timely access to tailored information, and tools to help them understand their disease and prepare for conversations with clinicians.
- The use of patient self-management tools should be explored. Digital health tools should be used to provide consistent patient information and self-management tools to support patients to manage their care and treatment, and assess the impact of symptoms on their day-to-day life.
- All proposed strategies and interventions should undergo an equality impact assessment and be evaluated for their accessibility to different socioeconomic groups. Interventions should be co-created and/or tested with a broad cross-section of patients with SLE to ensure take-up by all patients.

Principle 3. I deserve access to a coordinated multidisciplinary care team who fully understand my condition and my experience, regardless of who am I or where I live

Patients with SLE have highlighted a lack of coordinated care in the management of their SLE (39). This includes duplicate diagnostic testing, contradicting information about SLE diagnosis or treatment, and time wasted on avoidable consultations (39).

A challenge for patients is timely access to care across the entire pathway (39). Access can be impacted by geography, socioeconomic status and health literacy levels of patients (1, 57). The availability of HCPs with specialist knowledge of, or expertise in, SLE also varies significantly (58). In LE's 2020 survey, just under half of all respondents reported having access to a multidisciplinary team, 35% to a 'specialised nurse that knows SLE', 30% to physiotherapy, rehabilitation or occupational therapy, and 29% to adequate social support (6).

Existing best practice guidelines recommend input from a multidisciplinary team to determine a patient's care and treatment plan (41-43, 45). However, not all guidelines specify which professionals should sit on a multidisciplinary team (41-43, 45). Rheumatologists are the most likely clinical profession to have expertise in SLE, but depending on the symptoms and damage to different organs, patients may also need access to dermatologists, cardiologists, haematologists, nephrologists, neurologists, gastroenterologists, ophthalmolo-

gists, physiotherapists, social workers, and other HCPs (41, 43, 44). Multidisciplinary teams may also include behavioural health experts or social workers who can help address the impact of social determinants of health (59). It is important that large care teams are coordinated, and all healthcare providers involved should receive updates on the diagnosis, treatment, and management plans for these patients. Patients with SLE should also be central in the development of these plans. Clinical virtual networks, such as the European Reference Network ReCONNET programme, aim to coordinate patient care across Europe and give patients with rare diseases access to specialised care, which might not be otherwise accessible within their locality (60).

There is a growing acknowledgement of the importance of telehealth in helping to treat patients who may be unable to travel to attend appointments (61). A recent study in Hong Kong found that utilising telemedicine for SLE during the COVID-19 pandemic resulted in better patient satisfaction and similar short-term disease control when compared with standard, in-person care (62). However, all virtual or telehealth care should be complemented with in-person care, especially for more severe SLE (62). EULAR has developed a set of principles for remote care for rheumatic and musculoskeletal diseases, as have the Brazilian Society of Rheumatology (63), which should be considered as part of any service redesign for SLE services (64).

Recommendations to improve care

- Every patient with SLE should have access to a multidisciplinary care team specific to their needs.
- Information should be publicly available for both patients and clinicians that outlines the range of specialists a multidisciplinary care team should encompass.
- All patients living with SLE should have a dedicated personalised care plan, developed in partnership with a multidisciplinary healthcare team, to help with the self-management of their condition. These plans should be updated and reviewed regularly and consider all aspects of health-related quality of life .
- Appropriate shared care infrastructure should be put in place to enable the coordinated sharing of information and care across different care boundaries and geographies.
- Telehealth solutions should be implemented as part of comprehensive SLE care to support patients to receive care regardless of where they live. All virtual or telehealth care must be complemented with in-person care, especially for more severe SLE.

Principle 4. I deserve access to appropriate and comprehensive pharmacological and non-pharmacological care, which reduces the burden of my SLE and allows me to have a high quality of life for as long as possible

Finding the right pharmacological and non-pharmacological care that helps people minimise the burden of their SLE remains one of the most important challenges facing high-quality care.

Patients take a median of five treatments to manage their SLE (6). Pharmacological treatments can include anti-malarial drugs, immunosuppressants, non-steroidal anti-inflammatory drugs, steroids, and biologic therapies, depending on the severity of disease (65-67). WLF's 2022 patient survey revealed that 23% of respondents did not think their doctor had sufficiently communicated what treatment options are available (Fig. 2) (68). Research has also shown that patient uncertainty is an active barrier underscoring low participation numbers in clinical trials and therefore impacting access to innovative treatments (69).

Many of the current treatments for SLE are associated with significant toxicity and long-term organ damage, in particular glucocorticoids (12, 13). Up to 80% of patients with SLE are exposed to glucocorticoids within five years of treatment (70). WLF's 2022 patient survey also found that 25% of patients feel their doctor had not sufficiently communicated the potential negative effects of steroid treatments on their organs, which can include diabetes, hypertension, cataracts, osteoporosis, and avascular necrosis amongst others (Fig. 2) (48, 71). The 2023 EULAR recommendations on the management of lupus recommend that long-term use of steroids as maintenance treatment should be minimised to equal or less than 5 mg per day, reduced from 7.5 mg per day in their previous recommendations. The recommendations also state that where possible, glucocorticoid treatment be withdrawn completely and used only as a bridging therapy (72). To achieve lower steroid use, while achieving the remission target and reducing treatment impact to the patient, earlier use of immunosuppressant and biologic treatment is recommended. It is also recommended that the use of immunosuppressants is not necessary before biologics (73).

Non-pharmacological care also has an important role to play in supporting people to manage the burden of SLE (73). To help manage the symptoms of fatigue, patients can benefit from programmed exercise and counselling (74). Other examples include smoking cessation, avoiding overexposure to sunlight and neuromodulation with aerobic exercise (75).

As we look to the future, new standards of care in SLE are urgently needed to achieve greater disease control and improve patient outcomes. This includes better monitoring and adapting pharmacological and non-pharmacological care, considering all effective treatments as necessary in response to an individual patient's disease manifestation and quality of life, and pushing for earlier adoption of innovative treatment strategies for patients with SLE as appropriate. Finally, improved patient-clinician communication to agree on treatment and care goals is vital.

One approach to elevated standards of care for patients with SLE is treat to target (77). Treat to target is a strategy that defines a treatment target, such as remission, and applies tight control to reach this target (77). The Definitions of Remission in SLE (DORIS) provides a framework for defining remission in SLE (78). Similarly, the Asia Pacific Lupus Collaboration (APLC) has validated a working definition of Lupus Low Disease Activity State (LLDAS) (79). Both DORIS and LLDAS have shown that benefits of re-

Field	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
My doctor has sufficiently communicated the effects of lupus on my organs.	9% 482	13% 756	19% 1088	30% 1699	29% 1606	5631
My doctor has sufficiently communicated the effects of steroid treatment on my organs.	10% 563	15% 827	17% 908	30% 1609	27% 1458	5365
My doctor and I have discussed long-term treatment goals for lupus.	10% 541	16% 875	18% 1018	32% 1794	24% 1363	5591
My doctor and I have created a disease management plan for lupus that considers my lifestyle and quality of life.	13% 744	20% 1092	20% 1107	27% 1496	20% 1085	5524
My doctor has sufficiently communicated what treatment options are available to me for lupus.	9% 502	14% 800	17% 966	35% 1974	25% 1385	5627
If my lupus treatment makes me feel good enough, I don't see a need to consider other treatment options.	11% 605	19% 1073	23% 1277	29% 1602	18% 1020	5577

Fig. 2. Patient's indicated level of agreement or disagreement with statements regarding communication with their clinician. Source: World Lupus Federation Survey: Global Survey Reveals Extensive Impact of Lupus on Organs, 2022. https://lupus.az1.qualtrics.com/results/public/bHVwdXMtVVJfOXV4Y1d5bkUxWENiNUJrLTYyMjIyMjQ3YzE2NTlmMDAxMTUzODM4Mw==#/pages/Page_1d98651a-11c8-48f3-a7eb-4314e9e1d9e5 Accessed December 2023.

mission or low disease activity could include better health-related quality of life, lower damage accrual, fewer flares, and decreased risk of hospitalisation, as well as lower mortality. Similarly, achievement of renal remission within 12 months after induction therapy is recommended as a treatment target for active lupus nephritis, to prevent renal flares and damage accrual (80).

Ensuring that pharmacological and non-pharmacological treatments meet treat-to-target goals will be crucial for improved patient outcomes.

Recommendations to improve care

- SLE care must be holistic and patient-centred and make use of the best-available pharmacological and non-pharmacological care strategies to minimise burden of disease.
- Clinical trial participation should be encouraged and discussed with all patients with SLE during clinician consultations to discuss options.
- Glucocorticoid use should be minimised or monitored to the lowest possible dose (according to treatment recommendations, a standard of ≤5 mg per day, removed completely where possible or used only as bridging therapy) via a management plan to ensure organ damage and long-term impacts are avoided.
- Clinical guidelines for SLE should be regularly updated and implemented to ensure that clinicians are equipped with the latest, consistent information to inform treatment and care decisions, including the latest evidence on measuring clinical outcomes and improved quality of life.

Conclusion

SLE places a significant burden on the lives of millions of people worldwide, impacting patients' quality of life, mental health, and relationships. It has a substantial impact on healthcare systems, due to sub-optimal disease management, and on society, through the loss of productivity caused by the debilitating long-term symptoms and impact of SLE.

The principles and recommendations we have set out in this Patient Charter demonstrate the core elements of quality care that people living with SLE must expect to receive. We urge HCPs, providers, health systems, and policymakers around the world to swiftly implement SLE diagnosis and care guidelines that reflect these principles and ensure that the latest advancements and current approaches in SLE care reach the patients who need them.

Patient and public involvement

Representatives from the patient advocacy groups Lupus Europe, World Lupus Federation, and Lupus Foundation of America were members of the Working Group. The literature review that underpinned the Patient Charter's principles drew on evidence from patient surveys including the Living with Lupus Survey conducted by Lupus Europe (6) and the ALPHA programme led by the Lupus Foundation of America (18).

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