

## Abstracts

## Pre-meeting

Friday 1st September 2023

## Reducing illness burden, modifying disease and improving treatment outcomes: a patient-physician collaboration

## 01 SLE BURDEN OF DISEASE: THE PATIENT'S PERSPECTIVE

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10.1136/lupus-2023-la.1

Systemic lupus erythematosus (SLE) imposes a great burden on the lives of patients. Patients' and physicians' concerns about the disease diverge considerably. Physicians focus on controlling disease activity to prevent damage accrual, while patients focus on symptoms that impact on health-related quality of life (HRQoL). The existing clinician reported outcomes (ClinRO), such as disease activity indices, remission, low disease activity (LLDAS), response (SRI and BICLA) do not include the patient perspective.

Several investigations show that patients judged in remission by the treating physician, still report the presence of relevant clinical symptoms.<sup>1 2</sup>

- Patients and physicians assess the disease differently (discordance up to 58% of cases)
- Patients tend to score disease activity higher than physicians
- Patients consider subjective manifestations as more relevant than physicians
- Physicians consider laboratory abnormalities as more relevant

It seems there is a discordance between patients and physicians when it comes to prioritising outcomes.

The best way to identify the patients' priorities is through Patient Reported Outcomes (PROs). PROs allow us to capture aspects of the disease which have an impact on patients and constitute their burden of the disease. Ideally, the dialogue between doctor and patient should address the most bothersome symptoms for the individual patient. What is most bothersome for one might not be the same as for someone else and it most likely won't be the same priority as the doctor has. At the same time, some of the most bothersome symptoms are difficult (if not impossible) to manage with traditional SLE treatments. In these cases, the communication becomes even more important, and a communication gap can be detrimental to the HRQoL and overall care.<sup>3</sup>

## REFERENCES

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2. Cornet A, et al. Living with systemic lupus erythematosus in 2020: a European patient survey. *Lupus Sci Med*. 2021 Apr;**8**(1):e000469. doi: 10.1136/lupus-2020-000469. PMID: 33849920; PMCID: PMC8051432.
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## Learning Objectives

- Describe the burden of the disease from the patient's perspective

- Explain the importance of patient-physician communication
- Distinguish between patient and physician priorities

## 02 CHALLENGES IN THE DEVELOPMENT OF A UNIVERSAL SLE PATIENT CHARTER

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Despite advances in understanding and managing systemic lupus erythematosus (SLE), patients continue to face significant challenges in receiving optimal care and support. The concept of a universal SLE patient charter, outlining the rights, needs and expectations of SLE patients, has emerged as a potential solution to address these challenges. However, the development and implementation of such a charter present several significant hurdles.

Firstly, there is a need for consensus among healthcare professionals, patient advocacy groups, researchers, and policy-makers, regarding the content and scope of the charter. Standardizing care and efforts to ensure that the charter reflects evidence practices are crucial components in the development and implementation of a universal SLE patient charter. This requires robust communication and collaboration to guarantee that the charter encompasses the diverse needs and perspectives of the global SLE community.

Secondly, the inherent heterogeneity of SLE poses a challenge in creating a charter that can accommodate the unique experiences and requirements of individual patients. SLE manifests differently in each patient, making it crucial to strike a balance between specificity and inclusivity within the charter.<sup>1</sup>

Thirdly, the charter must address the barriers to access and equity in SLE care. Issues such as disparities in healthcare access, limited availability of specialized healthcare professionals, and high treatment costs need to be considered and addressed within the charter.<sup>2–6</sup>

In addition, the charter should emphasize the importance of patient education and empowerment to facilitate informed decision-making and self-management. Furthermore, the implementation and enforcement of the charter pose practical challenges. Adequate resources and infrastructure, along with legal and regulatory frameworks, are required to support the implementation of charter principles across different healthcare systems and jurisdictions. Additionally, the charter should encourage the integration of research and data collection efforts to advance our understanding of SLE. Despite these challenges, a universal SLE patient charter holds great potential in improving the quality of care and outcomes for SLE patients globally. It can serve as a guiding document to promote patient-centered care, raise awareness, and advocate for the rights of SLE patients.

## REFERENCES

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