

Starting the conversation:

A global survey sheds light on potential barriers to reducing organ damage in people living with lupus

A global survey of 648 rheumatologists, nephrologists and internal medical specialists explored perspectives and practices around the treatment of systemic lupus erythematosus (SLE) and organ damage – which impacts up to 48% of patients, most within five years of diagnosis.¹ Healthcare professionals (HCPs) reported challenges in identifying risks and measuring disease activity along with a potential increase in patients with organ damage caused by interruptions in care experienced during the COVID-19 pandemic. The findings suggest a need for earlier conversations about organ damage prevention between HCPs and people living with lupus.

COVID-19 impact on organ damage

Expert HCPs reported that the COVID-19 pandemic and other factors negatively impacted patients in several ways that could have increased their risk of organ damage.

57%

of HCPs reported that some of their SLE patients did not schedule in-person visits due to fear of contracting COVID-19.

44%

of HCPs suspect that some of their patients developed organ damage during the pandemic due to several factors that may have prevented them from getting optimal care.

1 in 4

HCPs reported that their patients experienced more flares (23%) and more severe symptoms (23%) vs. pre-pandemic.

Fast fact:

Lupus flares increase the risk of organ damage.²

Identifying at-risk patients

HCPs who participated in the survey said that it is difficult to determine which patients are at the highest risk for organ damage and reported a need for improved tools and resources to evaluate this risk.

53%

of respondents think it's easy to identify which patients are at risk of organ damage.

44%

of HCPs find it difficult to monitor/measure organ impact from SLE.

81%

said that the identification of biomarkers that give a more accurate picture of organ damage would help them better manage their patients' disease.

Fast fact:

Organ damage in lupus occurs most frequently in the kidneys, skin, heart and nervous system and is a key determinant of poor long-term outcomes.^{3,4}

Communicating about organ damage

A need for better ways to predict and monitor organ damage risk may explain why some surveyed HCPs said that they wait to discuss the topic with their patients.

46%

HCPs surveyed only discuss the risk of organ damage once SLE patients present with symptoms.

65%

respondents typically wait more than a year after diagnosis before discussing the potential for organ damage with their patients.

30%

don't typically bring up the risk of organ damage unless their patient does.

Fast fact:

Organ damage can occur in up to 48% of patients, most within five years of diagnosis.¹



“Important conversations about organ damage are happening between people with lupus and their doctors, but more action is needed and should be happening at diagnosis if we are going to truly reduce the burden of organ damage on people with lupus and their families.”

– Mike Donnelly, Vice President of Communications, Lupus Foundation of America (Secretariat of the World Lupus Federation)

Perception of disease progression

According to the survey, many HCPs know that lupus can damage organs over time, underscoring the importance of frequent communication about the underlying disease and risk of organ damage.

2 in 5

tell their patients that even if they have no symptoms, organ damage can still be occurring.

24%

the number of patients HCPs believe will experience permanent, irreversible organ damage within five years of diagnosis.

37%

the percentage of patients HCPs estimate will experience permanent irreversible organ damage within 20 years of diagnosis.

Fast fact:

Approximately 40% of patients with SLE develop lupus nephritis, which causes inflammation in the kidneys and can lead to end-stage kidney disease.⁵

Current treatment approaches

HCP survey responses indicate that more information about available treatments might help them balance the need for rapid symptom relief with long-term treatment goals.

72%

of HCPs said that the current standard of care (SOC) regimen (anti-malarial medicines, steroids and immunosuppressants) can sufficiently reduce the risk of long-term organ damage for most lupus patients.

78%

said it would be helpful to see data showing the benefits of different therapies for patients at risk for organ damage.

79%

of HCPs surveyed said that a lack of disease-modifying therapies makes it difficult to treat lupus.

Fast fact:

Research shows that standard of care does not prevent organ damage in a significant number of patients and in fact, may contribute to it.⁶⁻⁹



“Even though lupus can present so differently from patient to patient, we know that the presence of underlying inflammation means that we must always consider the potential risk for organ damage. We need to educate our patients early in their diagnosis and then work together to mitigate that risk.”

– Dr Rajeev Raghavan, nephrologist, Clinical Professor of Medicine, University of Houston Tilman Fertitta Family College of Medicine and Adjunct Associate Professor, Baylor College of Medicine

Defining disease modification in lupus

Survey findings suggest a lack of consensus around the etiology of lupus and the understanding of lupus as a modifiable disease with a primary source on inflammation could potentially slow the widespread adoption of a treat-to-target (T2T) approach in lupus.

80%

of HCPs agreed that the disease is so heterogeneous that they believe that lupus is caused by several overlapping conditions.

76%

of HCPs surveyed agreed that organ damage is primarily caused by underlying active disease and steroids.

63%

of HCPs think that the heterogeneity of the disease and overlapping comorbidities make it impossible to treat the source of the disease.

92%

of HCPs wish there was a better way to treat SLE so they didn't have to worry about what will happen next to their patients.

Fast fact:

Defining currently available disease modifying therapies for lupus will help physicians implement a T2T approach, which is being used to improve outcomes in other inflammatory conditions.¹⁰

The cost of organ damage

Organ damage SLE causes significant financial and emotional burdens to millions of people worldwide and costs billions of dollars to manage each year.¹¹

59%

of respondents to a World Lupus Federation patient survey reported that organ damage led to challenges participating in social or recreational activities.¹²

€4748

direct medical costs of severe SLE patients in a study of five countries. Flares increased the annual total cost by about €1002.¹³

33%

of respondents to a World Lupus Federation survey found that organ damage led to financial insecurity or problems.¹²

About the global lupus research and methodology

The global HCP survey was conducted by Material on behalf of GSK between July and September 2022 among 648 HCPs across seven countries—Canada (n=41), China (n=100), France (n=102), Germany (n=102), Japan (n=100), Spain (n=100) and the United States (n=103).

The survey was designed to explore the attitudes and practices of HCPs in the treatment of their patients with SLE, including those with LN, with a focus on topics related to disease modification in lupus, as well as organ damage.

Surveyed HCPs had a primary specialty of rheumatology, nephrology, or internal medicine and were board certified in their specialty with a minimum number of SLE patients, including those with lupus nephritis:

- HCPs in the US had a minimum of 15 SLE patients
- HCPs in Canada, China, Germany, and Spain had a minimum of 10 SLE patients
- HCPs in Japan and France had a minimum of 5 SLE patients

The HCPs were not employed or under contract with pharmaceutical companies, healthcare manufacturers, or government regulatory agencies.

Results of any sample are subject to sampling variation. The magnitude of the variation is measurable and is affected by the number of interviews and the level of the percentages expressing the results. In this particular study, the chances are 95 in 100 that a survey result does not vary, plus or minus, by more than 9.7 percentage points from the result that would be obtained if interviews had been conducted with all persons in the universe represented by the sample. The margin of error for any subgroups will be slightly higher.

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