

6 PROPOSED INSIGHTS FROM PATIENT'S EXPERIENCE TO FEED YOUR 2024 LUPUS PRACTICES

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Objective Provide lupus doctors with concrete insights from patient's experiences that can feed their day to day practices and improve outcomes.

Methods Lupus Europe's Patient Advisory Network, Youth group and Board provided qualitative input on patient experiences on a range of topics. Their input was thematically analysed and conclusions drawn.

Results Diagnosis - A lupus diagnosis for many patients provided answers and an initial sense of relief. However, for a significant number it triggered fear and anxiety. **Signposting at diagnosis to support groups** would be welcomed and may allay some fears. Doctors sometimes tell patients that their lupus is 'mini' or small when the lupus is 'low severity' medically, perhaps trying to reassure. However, feedback is that this is patronising and minimises the effect lupus has. Only a handful of people felt it would make them feel better. For many, the unpredictable aspect of lupus made such a statement "irrelevant".

Information - Patients would like substantially more information from their doctor, at diagnosis. Some found initial information in support groups or patient organisations, others used books or the internet, which sometimes flagged outdated and worrying information. The use of the internet is a large part of many lupus patients journey, at diagnosis to learn about Lupus, find support groups or seek research and journals, but also when they identify new symptoms or get new medication. Using google for lupus is rarely a good idea! **What would be most helpful is that the doctor directs them to reliable sources of information online and in print, if required (like the lupus100.org site).** To note, Chat GPT is not (yet?) a resource that is used by patients for Lupus information.

Adherence - On adherence, patients said side effects were the biggest issue, followed by mechanical issues, such as size and taste. A pill box was seen as helpful to improve adherence to pharmacological treatments (also to check if you have already taken your medication, a common issue with lupus fog). When asked how doctors could improve adherence, the overwhelming consensus was **explaining exactly why each treatment is needed and the risks of not adhering.**

Hot topics - Pregnancy can be challenging with lupus but often possible. Patients want doctors to tell young women and men that it is possible with proper care. The need to **discuss pregnancy with males** came up repeatedly. On the topic of sex the results were more mixed with 50/50 on wanting, or not, doctors to proactively raise the subject. Also of interest, **alcohol, smoking and drug use** are topics that patients will not spontaneously raise, but would like to discuss with their doctor.

Communication - Around half of respondents have a lupus doctor who operates in a multi-disciplinary team but a common theme was poor communication between different specialists. A theme that came out very strongly was that **patients want to feel listened to** and that lab results are only part of the picture. They want doctors to consider how Lupus is affecting their function, quality of life and their mental health. Which specific elements doctors extract from this is up to

them, but **ensuring the patient feels heard** brings positive impacts and credibility.

Holistic approach - Diagnosis can be a relief but can also cause anxiety, as can a life with Lupus, so a **discussion around mental health** would be welcomed by many. Patients feel that doctors tend to place emphasis on clinical and lab findings when these are not always the most important things to patients. They seek a **holistic approach where quality of life and function are considered** and want doctors to listen to what matters most to them. Empathy and a non-judgemental approach are highly valued.

Conclusion In day to day practice, small things can make a big difference. Signposting patients to support groups or proper information; Expressing that you have heard them; Bringing up for possible discussion the hot topics of Pregnancy (also with men), alcohol, smoking and drugs; and Addressing the issue of mental health in a more holistic approach are proposed insights for improved Patient-Doctor collaboration.

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WHAT IS STILL UNCLEAR IN LUPUS PREGNANCIES?

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Objective Despite the many years efforts of physicians and scientist to improve the outcome of pregnancies in patients with systemic lupus erythematosus (SLE), a recent publication¹ underlines the occurrence of many complications for the mother and the child. Aim of this abstract is to summarize the better strategies to ensure a good maternal and neonatal outcome.

Methods The physicians' task should be considered in 3 different scenarios: before, during and after pregnancy. The correct approach and the challenges of these 3 periods will be analyzed.

Results Ideally, a patient should start the pregnancy when the diseases is in low disease activity or in stable remission under a treatment safe for the fetal health. This is not always the case because sometimes unwanted pregnancies occur or, in other circumstances, desired pregnancies do not come. In both cases the treating physician will be involved in the solution finding process so it could be of help to know in advance what could be done and prepare sound specific protocols. The pre-conceptional counselling also involves the case specific evaluation of potential risk factors for the future pregnancy. These include the evaluation of lupus phenotype, antibody profile and other biomarkers such as the complement system whose levels are important predictors of fetal outcome even if not linked to clinically important disease activity.²

The monitoring of lupus patients during gestation is performed by a multidisciplinary team where gynecologist together with rheumatologists/internists are the main players. It is sometimes difficult to have different specialists at the same time in the same place, so different organizational models of multidisciplinary team have been developed to ensure

quick consultation and decision sharing. An early diagnosis of lupus flares and pregnancy complications allow in many cases effective treatments.

Puerperium is a difficult time for all the women. But for mothers with systemic lupus it is also combined with doubts on lactation and pharmacological treatment, disease linked fatigue that has to be added to the overworking of the period, and risk of disease flares often occurring. At this time, the patients need to be closely followed by the treating specialists to prevent disease relapses and also to avoid the occurrence of depression, potentially dangerous also for the child growth.

Conclusions SLE is a relatively rare disease, and this do not facilitate physicians to face peculiar aspects of their patients' life such as reproduction. On the other had the high prevalence of young women in the affected population support the need of detailed protocols to follow them before, during, and after pregnancy. A pre-conceptional counselling with consequent appropriate disease management, a multidisciplinary pregnancy monitoring, and a careful care of puerperium can significantly reduce the problems often reported when data are driven from admirative registries¹ and not prospectively followed cohorts.²

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REFERENCES

1. Mehta B, Jannat-Khah D, Glaser KK, et al. Fetal and maternal morbidity in pregnant patients with Lupus: a 10-year US nationwide analysis. *RMD Open* 2023;9:e002752.
2. Crisafulli F, Andreoli L, Zucchi D, et al. Variations of C3 and C4 before and during pregnancy in systemic lupus erythematosus: association with disease flares and obstetric outcomes. *J Rheumatol.* 2023 Oct;50(10):1296–1301.

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EULAR/ACR SLE CLASSIFICATION CRITERIA: 5 YEARS LATER

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Objective To review lessons learned since the 2019 publication of the European League Against Rheumatism/American College

Abstract 112 Table 1 External validation of the EULAR/ACR criteria in various cohorts since the 2019 publication. For Chung et al 2022, the data with attribution are used, given that attribution should be applied in all cohorts

Publication	Region	Specific population	SLE patients			Non-SLE	
			n	%ANA+	Sensitivity	n	Specificity
Adamichou 2020	Greece	Early	690	94	89	401	97
Costa Carneiro 2020	U.K.		100	-	98	-	-
Ma 2020	U.S.	Pediatric	156	100	97	379	98
Pons-Estel 2020	Latin America		1217	96	90	-	-
Rubio 2020	U.S.		217	96	94	-	-
Suda 2020	Japan		100	97	97	-	-
Teng 2020	China		199	99	97	175	90
Abdwani 2021	Oman	Pediatric	113	100	89	51	90
Aljaberi 2021	U.S.	Pediatric	112	96	85	105	83
Batu 2021	Turkey	Pediatric	262	99	92	174	89
Duarte-Garcia 2021	U.S.		139	100	91	-	-
Guavita-Navarro 2021	Colombia		146	92	90	-	-
Levinsky 2021	Israel, U.S.	Pediatric	112	100	96	113	89
Magallares 2021	Spain		79	100	86	-	-
Petri 2021	SLICC cohort		293	98	91	423	89
Pitta 2021	Brazil	Pediatric	670	100	100	-	-
Smith 2021	U.K.	Pediatric	482	96	96	129	81
Ugarte-Gil 2021	Americas		640	-	93	-	-
Al-Mayouf 2022	Arab/Italy	Pediatric	55	100	98	49	88
Al-Mayouf 2022	Arab/Italy	Monogenic	49	96	90	-	-
Cheng 2022	China	Pediatric	221	99	98	214	94
Cheng 2022	China		221	100	99	214	90
Chung 2022	China	ANA+	562	-	96	971	95
Inoue 2022	Japan		105	-	92	495	98
Insfrán 2022	Brazil		209	100	100	-	-
Ohara 2022	Japan	Pediatric	53	100	100	53	85
Selvananda 2022	Malaysia		205	97	91	100	94
Tan 2022	Australia		394	97	95	123	88
Torun 2022	Turkey		393	98	94	308	91
Schmidtman 2023	Germany		606	95	87	1015	97
Total			8800			5492	