



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Lithuania

For full text european analysis, please refer to:

Cornet A., Karakikla-Mitsakou Z., Andersen J. et al. - Experiences and unmet needs of persons living with systemic lupus erythematosus in Europe: Lupus Europe's 2024 Swiss knife survey, Autoimmunity Reviews, Volume 24, Issue 8, 2025, 103838, ISSN 1568-9972,
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DEMOGRAPHICS:

	<u>Lithuania</u>	<u>EUROPE</u>	<u>Age</u>	<u>Lithuania</u>	<u>EUROPE</u>
Total number of responses	110	4525	Up to 25	3.6%	5.5%
			26 to 35	23.6%	15.8%
Gender	<u>Lithuania</u>	<u>EUROPE</u>	36 to 45	25.5%	26.9%
Man	1.9%	4.1%	46 to 55	19.1%	28.0%
Woman	98.1%	95.5%	56 to 65	22.7%	16.0%
Other / prefer not to answer	0.0%	0.4%	above 65	4.5%	6.2%
Total	100.0%	100.0%	NA	0.9%	1.5%
			Grand Total	100.0%	100.0%
Diagnosis	<u>Lithuania</u>	<u>EUROPE</u>	Diagnosis	<u>Lithuania</u>	<u>EUROPE</u>
SLE	90.0%	92.5%	Lupus Nephritis	22.0%	19.5%
Child onset SLE	10.0%	7.5%	APS	14.7%	19.2%
Grand Total	100.0%	100.0%	LN+APS	6.4%	6.2%
			None of the 2	56.9%	55.2%
			Grand Total	100.0%	100.0%

BURDEN

<u>Lupus under control past3mo</u>	<u>Lithuania</u>	<u>EUROPE</u>	<u>Satisfied with current state</u>	<u>Lithuania</u>	<u>EUROPE</u>
Yes	77.3%	66.5%	Yes	60.6%	47.6%
No	22.7%	33.5%	No	31.3%	47.4%
n=	110	4360	Prefer not to answer	8.1%	5.0%
			n=	99	3957
Flares over 5 years	<u>Lithuania</u>	<u>EUROPE</u>	Burden	<u>Lithuania</u>	<u>EUROPE</u>
A. Never	8.6%	7.9%	Overall burden of lupus on life	6.62	6.94
B. Once	7.6%	12.7%	activity of disease itself	6.54	6.63
C. Twice	10.5%	11.0%	physical conseq.of disease	7.00	7.41
D. 3 or 4 times	18.1%	13.3%	side effects of treatment	6.24	6.02
E. Annually	13.3%	9.7%	fatigue	7.72	7.95
F. Several times a year	28.6%	34.8%	Pain	6.52	6.79
G. Don't know	13.3%	10.6%	Psychological impact	6.90	6.99
n=	105	4124	Social impact	6.20	6.48
			Work / education impact	6.67	7.08
			Financial impact	6.70	6.46

0= no burden at all / 10 = extreme burden

<u>Lupus life Experience:</u>		<u>Lithuania</u>	<u>EUROPE</u>
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL		4.0%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL		8.9%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL		9.9%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL		8.9%	5.5%
E. Lupus story of flares and remission, flares not too frequent,Even when not flaring, side effects of lupus/medication, anxiety or fatigue are major burden on QoL		21.8%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life		5.0%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL		18.8%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life		8.9%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life		4.0%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL		9.9%	7.0%
K. Prefer not to answer		0.0%	1.9%
n=	101	4,057	

Patient Doctor Communication						
Most missing	Lithuania	EUROPE				
Time	34.7%	31.6%	Doctor takes into account my opinion			
Empathy	13.7%	14.0%	when managing my treatment	6.65	7.44	
Communication within team	13.7%	22.3%	I am a key contributor to Sh. Dec. Mak.			
Acknwoledge the symptoms I mention	30.5%	22.9%	about my treatment mgnt	5.97	6.96	
Personalised info	13.7%	10.6%	I have an active role in controlling my			
lay language	13.7%	6.4%	disease	7.49	7.47	
An invite to ask	5.3%	5.7%	I have a trustful relationship with my			
Answers	16.8%	8.3%	doctor	7.10	7.56	
Consider non measurable	30.5%	25.0%	I say "the truth, all the truth and only the			
What symptoms mean for my life	14.7%	16.7%	truth" to my HCP with regards to my	8.73	8.82	
Clear info on Meds	29.5%	21.2%	I can share all my problems with my			
Certainty I can talk anything	6.3%	4.3%	doctor	7.45	7.71	
Holistic approach	22.1%	17.9%	My doctor takes into account my			
Info on Clinical Trials	15.8%	15.5%	psychological well-being	6.40	6.94	
Nothing	14.7%	23.7%				
Other	2.1%	3.5%				
n=	95	3,841	n=	113	3773	
			0 = fully disagree : 10 = fully agree			
Satisfaction with HealthCare team	6.83	7.33				
	0 = fully unsatisfied / 10 = fully satisfied					
Unmet needs						
Unmet Needs	Lithuania	EUROPE				
A. effic Clinic measured	15.1%	13.9%	Satisfaction with treatment:	Lithuania	EUROPE	
B. Effic NON Measured sympt	22.1%	25.3%	A. Satisfied, AND I believe this is			
C. reduc Steroids	10.5%	18.8%	the best that can be achieved for	31.0%	37.1%	
D. Lower side Eff	25.6%	23.7%	B. Satisfied, BUT I believe better			
E. less fatigue	37.2%	53.2%	control could be achieved for my	34.5%	30.4%	
F. LT kidney prot.	16.3%	19.1%	C. Not satisfied, BUT I believe			
G. Easier to take	10.5%	5.4%	this is the best that can be	19.5%	18.4%	
H. Access to existing	12.8%	7.7%	D. Not satisfied AND I believe			
I. Access non Pharma treatm.	33.7%	32.0%	better control could be achieved	14.9%	14.2%	
J. edu & access to support	17.4%	9.5%				
K. Financial burd	22.1%	19.8%	n=	87	3503	
L. Other	1.2%	3.5%				
n=	86	3,502				
Symptoms or Features experienced / Most bothersome						
Lithuania				Lithuania		
Patient reported Symptoms or features	Regularly	most prevent	most worry	most worry		least taken
	experience	live to the full	today	long term		into account
A.None	2.2%	0.0%	1.1%	0.0%	A.None	5.8%
B.Rash	39.8%	15.9%	12.6%	13.8%	B.Rash	15.1%
C.Sun	46.2%	17.0%	8.0%	10.3%	C.Sun	18.6%
D. Ulcers	25.8%	4.5%	2.3%	2.3%	D. Ulcers	5.8%
E.DryEyes	44.1%	17.0%	11.5%	13.8%	E.DryEyes	18.6%
F.dryskin	57.0%	8.0%	6.9%	4.6%	F.dryskin	17.4%
G.Hairloss	61.3%	18.2%	19.5%	19.5%	G.Hairloss	29.1%
H. Joints	66.7%	38.6%	29.9%	34.5%	H. Joints	9.3%
I.Jaccoud	10.8%	1.1%	2.3%	2.3%	I.Jaccoud	3.5%
J.Musclpain/weak	55.9%	33.0%	27.6%	18.4%	J.Musclpain/weak	7.0%
K. Headache	47.3%	18.2%	14.9%	18.4%	K. Headache	8.1%
L.Fatigue	77.4%	46.6%	43.7%	40.2%	L.Fatigue	44.2%
M. Flu-like	20.4%	5.7%	6.9%	2.3%	M. Flu-like	5.8%
N. Shrot Breath	21.5%	3.4%	8.0%	6.9%	N. Shrot Breath	1.2%
O. depres/anxiety	43.0%	17.0%	18.4%	19.5%	O. depres/anxiety	18.6%
P. Heamatologic	16.1%	1.1%	2.3%	5.7%	P. Heamatologic	2.3%
Q. Raynaud	19.4%	1.1%	3.4%	3.4%	Q. Raynaud	4.7%
R. Kidney	20.4%	9.1%	11.5%	16.1%	R. Kidney	2.3%
S. Chestpain	19.4%	2.3%	2.3%	1.1%	S. Chestpain	2.3%
T. Hiugh, Blood Pres	22.6%	2.3%	4.6%	5.7%	T. Hiugh, Blood Pres	2.3%
U. Cardiovasc	15.1%	6.8%	9.2%	6.9%	U. Cardiovasc	5.8%
V. Osteoporosis	25.8%	8.0%	8.0%	9.2%	V. Osteoporosis	9.3%
W. Brainfog	26.9%	4.5%	6.9%	5.7%	W. Brainfog	8.1%
n=	93	88	87	87	n=	86

Symptoms or Features experienced / Most bothersome

<u>Patient reported Symptoms or features</u>	<u>EUROPE</u>				<u>EUROPE</u>	
	<u>Regularly experience</u>	<u>most prevent live to the full</u>	<u>most worry today</u>	<u>most worry long term</u>	<u>least taken into account</u>	
A.None	1.4%	2.9%	3.1%	1.5%	A.None	16.0%
B.Rash	42.6%	9.2%	8.3%	6.6%	B.Rash	10.5%
C.Sun	60.4%	25.9%	13.0%	11.0%	C.Sun	13.4%
D. Ulcers	36.1%	4.4%	2.7%	1.6%	D. Ulcers	8.6%
E.DryEyes	56.1%	10.4%	7.6%	6.1%	E.DryEyes	14.0%
F.dryskin	50.4%	3.8%	2.9%	1.9%	F.dryskin	11.3%
G.Hairloss	48.7%	10.6%	12.4%	9.9%	G.Hairloss	22.1%
H. Joints	72.8%	44.8%	33.0%	32.3%	H. Joints	8.7%
I.Jaccoud	9.4%	3.1%	3.4%	4.7%	I.Jaccoud	3.6%
J.Musclpain/weak	62.6%	33.5%	26.2%	24.9%	J.Musclpain/weak	11.7%
K. Headache	49.4%	17.0%	12.8%	10.3%	K. Headache	8.5%
L.Fatigue	84.9%	59.0%	44.7%	36.7%	L.Fatigue	34.8%
M. Flu-like	29.4%	4.5%	3.3%	2.3%	M. Flu-like	4.0%
N. Shrot Breath	29.2%	5.6%	7.5%	6.6%	N. Shrot Breath	4.7%
O. depres/anxiety	43.8%	13.4%	16.0%	14.8%	O. depres/anxiety	17.8%
P. Heamatologic	23.6%	3.0%	5.5%	8.4%	P. Heamatologic	2.2%
Q. Raynaud	35.0%	5.1%	3.4%	3.1%	Q. Raynaud	5.5%
R. Kidney	17.0%	5.3%	12.0%	22.8%	R. Kidney	2.3%
S. Chestpain	22.7%	2.8%	5.4%	4.8%	S. Chestpain	2.7%
T. Hiugh, Blood Pres	20.6%	2.4%	4.7%	5.9%	T. Hiugh, Blood Pres	2.6%
U. Cardiovasc	7.7%	2.8%	7.3%	19.3%	U. Cardiovasc	2.4%
V. Osteoporosis	17.2%	2.9%	4.8%	9.1%	V. Osteoporosis	3.7%
W. Brainfog	41.7%	10.0%	14.1%	14.5%	W. Brainfog	17.5%
	n=	3,848	3,584	3,564	n=	3,397

Swiss Knife Survey - Country level data

DATA FOR: Lithuania

For full text european analysis, please refer to:

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