



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Poland

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,*

For more information, contact: [secretariat@lupus-europe.org](mailto:secretariat@lupus-europe.org)

#### DEMOGRAPHICS:

	Poland	EUROPE	Age	Poland	EUROPE
Total number of responses	133	4525	Up to 25	8.3%	5.5%
			26 to 35	23.3%	15.8%
<u>Gender</u>	<u>Poland</u>	<u>EUROPE</u>	36 to 45	36.1%	26.9%
Man	3.1%	4.1%	46 to 55	19.5%	28.0%
Woman	96.9%	95.5%	56 to 65	6.8%	16.0%
Other / prefer not to answer	0.0%	0.4%	above 65	2.3%	6.2%
Total	100.0%	100.0%	NA	3.8%	1.5%
			Grand Total	100.0%	100.0%
<u>Diagnosis</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Diagnosis</u>	<u>Poland</u>	<u>EUROPE</u>
SLE	91.7%	92.5%	Lupus Nephritis	21.0%	19.5%
Child onset SLE	8.3%	7.5%	APS	15.3%	19.2%
Grand Total	100.0%	100.0%	LN+APS	8.1%	6.2%
			None of the 2	55.6%	55.2%
			Grand Total	100.0%	100.0%

#### BURDEN

<u>Lupus under control past3mo</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Satisfied with current state</u>	<u>Poland</u>	<u>EUROPE</u>
Yes	61.8%	66.5%	Yes	39.1%	47.6%
No	38.2%	33.5%	No	54.5%	47.4%
n=	123	4360	Prefer not to answer	6.4%	5.0%
			n=	110	3957
<u>Flares over 5 years</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Burden</u>	<u>Poland</u>	<u>EUROPE</u>
A. Never	3.5%	7.9%	Overall burden of lupus on life	6.66	6.94
B. Once	14.8%	12.7%	activity of disease itself	6.65	6.63
C. Twice	13.0%	11.0%	physical conseq.of disease	7.29	7.41
D. 3 or 4 times	20.0%	13.3%	side effects of treatment	6.40	6.02
E. Annually	7.0%	9.7%	fatigue	8.11	7.95
F. Several times a year	26.1%	34.8%	Pain	6.32	6.79
G. Don't know	15.7%	10.6%	Psychological impact	7.00	6.99
n=	115	4124	Social impact	5.63	6.48
			Work / education impact	6.34	7.08
			Financial impact	6.58	6.46
			0= no burden at all / 10 = extreme burden		

<u>Lupus life Experience:</u>	<u>Poland</u>	<u>EUROPE</u>
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	7.1%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	13.3%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	13.3%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	4.4%	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	19.5%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life	7.1%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	21.2%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life	2.7%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life	3.5%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	5.3%	7.0%
K. Prefer not to answer	2.7%	1.9%
n=	113	4,057

### Patient Doctor Communication

Most missing	Poland	EUROPE			
Time	24.5%	31.6%	Doctor takes into account my opinion when managing my treatment	7.65	7.44
Empathy	7.8%	14.0%	I am a key contributor to Sh. Dec. Mak. about my treatment mngt	6.65	6.96
Communication within team	22.5%	22.3%	I have an active role in controlling my disease	7.24	7.47
Acknowledge the symptoms I mention	21.6%	22.9%	I have a trustful relationship with my doctor	7.52	7.56
Personalised info	9.8%	10.6%	I say "the truth, all the truth and only the truth" to my HCP with regards to my	8.96	8.82
lay language	5.9%	6.4%	I can share all my problems with my doctor	8.01	7.71
An invite to ask	6.9%	5.7%	My doctor takes into account my psychological well-being	7.25	6.94
Answers	5.9%	8.3%	n=	113	3773
Consider non measurable	20.6%	25.0%	0 = fully disagree : 10 = fully agree		
What symptoms mean for my life	20.6%	16.7%			
Clear info on Meds	23.5%	21.2%			
Certainty I can talk anything	7.8%	4.3%			
Holistic approach	17.6%	17.9%			
Info on Clinical Trials	16.7%	15.5%			
Nothing	28.4%	23.7%			
Other	0.0%	3.5%			
n=	102	3,841			
Satisfaction with HealthCare team	7.17	7.33			
0 = fully unsatisfied / 10 = fully satisfied					

### Unmet needs

Unmet Needs	Poland	EUROPE	Satisfaction with treatment:	Poland	EUROPE
A. effic Clinic measured	15.2%	13.9%	A. Satisfied, AND I believe this is the best that can be achieved for	28.6%	37.1%
B. Effic NON Measured sympt	25.3%	25.3%	B. Satisfied, BUT I believe better control could be achieved for my	35.2%	30.4%
C. reduc Steroids	19.2%	18.8%	C. Not satisfied, BUT I believe this is the best that can be	18.7%	18.4%
D. Lower side Eff	26.3%	23.7%	D. Not satisfied AND I believe better control could be achieved	17.6%	14.2%
E. less fatigue	56.6%	53.2%	n=	91	3503
F. LT kidney prot.	17.2%	19.1%			
G. Easier to take	6.1%	5.4%			
H. Access to existing	18.2%	7.7%			
I. Access non Pharma treatm.	33.3%	32.0%			
J. edu & access to support	6.1%	9.5%			
K. Financial burd	24.2%	19.8%			
L. Other	1.0%	3.5%			
n=	99	3,502			

### Symptoms or Features experienced / Most bothersome

	Poland				Poland	
Patient reported Symptoms or features	Regularly experience	most prevent live to the full	most worry today	most worry long term	least taken into account	
A.None	0.0%	13.5%	3.9%	1.0%	A.None	16.2%
B.Rash	38.1%	5.2%	6.9%	4.9%	B.Rash	17.2%
C.Sun	55.2%	13.5%	2.9%	5.8%	C.Sun	15.2%
D. Ulcers	30.5%	2.1%	3.9%	1.9%	D. Ulcers	8.1%
E.DryEyes	63.8%	8.3%	5.9%	4.9%	E.DryEyes	19.2%
F.dryskin	67.6%	5.2%	2.9%	2.9%	F.dryskin	19.2%
G.Hairloss	63.8%	10.4%	14.7%	11.7%	G.Hairloss	26.3%
H. Joints	70.5%	33.3%	27.5%	30.1%	H. Joints	2.0%
I.Jaccoud	5.7%	1.0%	2.9%	4.9%	I.Jaccoud	3.0%
J.Musclpain/weak	64.8%	33.3%	27.5%	29.1%	J.Musclpain/weak	11.1%
K. Headache	59.0%	20.8%	16.7%	16.5%	K. Headache	4.0%
L.Fatigue	85.7%	53.1%	45.1%	35.0%	L.Fatigue	26.3%
M. Flu-like	25.7%	4.2%	2.9%	1.9%	M. Flu-like	5.1%
N. Shrot Breath	19.0%	3.1%	3.9%	5.8%	N. Shrot Breath	2.0%
O. depres/anxiety	50.5%	18.8%	23.5%	24.3%	O. depres/anxiety	14.1%
P. Heamatologic	33.3%	3.1%	2.9%	8.7%	P. Heamatologic	2.0%
Q. Raynaud	34.3%	6.3%	4.9%	4.9%	Q. Raynaud	8.1%
R. Kidney	21.9%	6.3%	11.8%	22.3%	R. Kidney	5.1%
S. Chestpain	27.6%	1.0%	8.8%	5.8%	S. Chestpain	3.0%
T. Hiugh, Blood Pres	21.0%	1.0%	6.9%	3.9%	T. Hiugh, Blood Pres	5.1%
U. Cardiovasc	7.6%	0.0%	3.9%	21.4%	U. Cardiovasc	3.0%
V. Osteoporosis	11.4%	1.0%	2.0%	5.8%	V. Osteoporosis	6.1%
W. Brainfog	45.7%	4.2%	19.6%	20.4%	W. Brainfog	16.2%
n=	105	96	102	103	n=	99

# Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	EUROPE				EUROPE	
	Regularly experience	most prevent live to the full	most worry today	most worry long term	least taken into account	
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	3,534	n=	3,397

Swiss Knife Survey - Country level data

DATA FOR: Poland

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