



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Czech Rep

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

DEMOGRAPHICS:

	Czech Rep	EUROPE	Age	Czech Rep	EUROPE
Total number of responses	141	4525	Up to 25	6.4%	5.5%
			26 to 35	17.7%	15.8%
<u>Gender</u>	<u>Czech Rep</u>	<u>EUROPE</u>	36 to 45	30.5%	26.9%
Man	4.3%	4.1%	46 to 55	29.8%	28.0%
Woman	95.7%	95.5%	56 to 65	5.7%	16.0%
Other / prefer not to answer	0.0%	0.4%	above 65	7.1%	6.2%
Total	100.0%	100.0%	NA	2.8%	1.5%
			Grand Total	100.0%	100.0%
<u>Diagnosis</u>	<u>Czech Rep</u>	<u>EUROPE</u>	<u>Diagnosis</u>	<u>Czech Rep</u>	<u>EUROPE</u>
SLE	90.1%	92.5%	Lupus Nephritis	29.6%	19.5%
Child onset SLE	9.9%	7.5%	APS	10.4%	19.2%
Grand Total	100.0%	100.0%	LN+APS	6.7%	6.2%
			None of the 2	53.3%	55.2%
			Grand Total	100.0%	100.0%

BURDEN

<u>Lupus under control past3mo</u>	<u>Czech Rep</u>	<u>EUROPE</u>	<u>Satisfied with current state</u>	<u>Czech Rep</u>	<u>EUROPE</u>
Yes	74.8%	66.5%	Yes	50.8%	47.6%
No	25.2%	33.5%	No	42.9%	47.4%
n=	135	4360	Prefer not to answer	6.3%	5.0%
			n=	126	3957
<u>Flares over 5 years</u>	<u>Czech Rep</u>	<u>EUROPE</u>	<u>Burden</u>	<u>Czech Rep</u>	<u>EUROPE</u>
A. Never	8.6%	7.9%	Overall burden of lupus on life	6.60	6.94
B. Once	9.4%	12.7%	activity of disease itself	6.35	6.63
C. Twice	11.7%	11.0%	physical conseq.of disease	6.99	7.41
D. 3 or 4 times	6.3%	13.3%	side effects of treatment	6.32	6.02
E. Annually	18.0%	9.7%	fatigue	7.81	7.95
F. Several times a year	33.6%	34.8%	Pain	6.48	6.79
G. Don't know	12.5%	10.6%	Psychological impact	6.13	6.99
n=	128	4124	Social impact	5.86	6.48
			Work / education impact	6.64	7.08
			Financial impact	6.00	6.46
			0= no burden at all / 10 = extreme burden		

<u>Lupus life Experience:</u>	<u>Czech Rep</u>	<u>EUROPE</u>
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	9.5%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	6.3%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	10.3%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	4.8%	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	17.5%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life	7.9%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	19.0%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life	7.1%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life	4.8%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	11.1%	7.0%
K. Prefer not to answer	1.6%	1.9%
n=	126	4,057

Patient Doctor Communication

Most missing	Czech Rep	EUROPE		
Time	27.1%	31.6%	Doctor takes into account my opinion	
Empathy	6.8%	14.0%	when managing my treatment	7.42 7.44
Communication within team	9.3%	22.3%	I am a key contributor to Sh. Dec. Mak.	
Acknowledge the symptoms I mention	16.9%	22.9%	about my treatment mngt	6.74 6.96
Personalised info	5.9%	10.6%	I have an active role in controlling my	
lay language	4.2%	6.4%	disease	7.73 7.47
An invite to ask	0.8%	5.7%	I have a trustful relationship with my	
Answers	3.4%	8.3%	doctor	7.53 7.56
Consider non measurable	15.3%	25.0%	I say "the truth, all the truth and only the	
What symptoms mean for my life	15.3%	16.7%	truth" to my HCP with regards to my	8.62 8.82
Clear info on Meds	16.9%	21.2%	I can share all my problems with my	
Certainty I can talk anything	2.5%	4.3%	doctor	7.92 7.71
Holistic approach	21.2%	17.9%	My doctor takes into account my	
Info on Clinical Trials	7.6%	15.5%	psychological well-being	7.35 6.94
Nothing	33.9%	23.7%		
Other	0.0%	3.5%	n=	113 3773
n=	118	3,841	0 = fully disagree : 10 = fully agree	
Satisfaction with HealthCare team	7.69	7.33		
0 = fully unsatisfied / 10 = fully satisfied				

Unmet needs

Unmet Needs	Czech Rep	EUROPE	Satisfaction with treatment:	Czech Rep	EUROPE
A. effic Clinic measured	10.6%	13.9%	A. Satisfied, AND I believe this is		
B. Effic NON Measured sympt	11.5%	25.3%	the best that can be achieved for	41.5%	37.1%
C. reduc Steroids	32.7%	18.8%	B. Satisfied, BUT I believe better		
D. Lower side Eff	23.1%	23.7%	control could be achieved for my	29.2%	30.4%
E. less fatigue	46.2%	53.2%	C. Not satisfied, BUT I believe		
F. LT kidney prot.	19.2%	19.1%	this is the best that can be	19.8%	18.4%
G. Easier to take	4.8%	5.4%	D. Not satisfied AND I believe		
H. Access to existing	3.8%	7.7%	better control could be achieved	9.4%	14.2%
I. Access non Pharma treatm.	28.8%	32.0%			
J. edu & access to support	11.5%	9.5%	n=	106	3503
K. Financial burd	20.2%	19.8%			
L. Other	1.9%	3.5%			
n=	104	3,502			

Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Czech Rep				Czech Rep	
	Regularly experience	most prevent live to the full	most worry today	most worry long term	least taken into account	
A.None	1.7%	7.6%	3.5%	3.6%	A.None	21.5%
B.Rash	32.8%	7.6%	8.8%	8.2%	B.Rash	5.6%
C.Sun	57.1%	24.6%	10.6%	8.2%	C.Sun	12.1%
D. Ulcers	17.6%	0.8%	1.8%	0.9%	D. Ulcers	2.8%
E.DryEyes	42.9%	11.0%	10.6%	7.3%	E.DryEyes	9.3%
F.dryskin	52.1%	3.4%	6.2%	2.7%	F.dryskin	11.2%
G.Hairloss	49.6%	11.0%	9.7%	12.7%	G.Hairloss	23.4%
H. Joints	66.4%	44.9%	38.1%	45.5%	H. Joints	9.3%
I.Jaccoud	9.2%	1.7%	1.8%	2.7%	I.Jaccoud	0.9%
J.Musclpain/weak	59.7%	35.6%	23.9%	26.4%	J.Musclpain/weak	11.2%
K. Headache	34.5%	10.2%	9.7%	15.5%	K. Headache	2.8%
L.Fatigue	84.0%	52.5%	58.4%	46.4%	L.Fatigue	35.5%
M. Flu-like	19.3%	3.4%	3.5%	2.7%	M. Flu-like	3.7%
N. Shrot Breath	23.5%	2.5%	7.1%	6.4%	N. Shrot Breath	3.7%
O. depres/anxiety	37.8%	14.4%	13.3%	15.5%	O. depres/anxiety	15.9%
P. Heamatologic	29.4%	5.9%	5.3%	10.0%	P. Heamatologic	0.9%
Q. Raynaud	26.1%	5.1%	6.2%	5.5%	Q. Raynaud	2.8%
R. Kidney	19.3%	3.4%	3.5%	9.1%	R. Kidney	1.9%
S. Chestpain	16.0%	0.8%	1.8%	2.7%	S. Chestpain	0.0%
T. Hiugh, Blood Pres	26.1%	0.8%	2.7%	2.7%	T. Hiugh, Blood Pres	1.9%
U. Cardiovasc	5.9%	2.5%	0.9%	4.5%	U. Cardiovasc	0.0%
V. Osteoporosis	22.7%	2.5%	1.8%	4.5%	V. Osteoporosis	5.6%
W. Brainfog	22.7%	5.1%	7.1%	5.5%	W. Brainfog	12.1%
n=	119	118	113	110	n=	107

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: Czech Rep

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