



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:

	<u>Czech Rep</u>	<u>EUROPE</u>	<u>Age</u>	<u>Czech Rep</u>	<u>EUROPE</u>
Total number of responses	141	4525	Up to 25	6.4%	5.5%
			26 to 35	17.7%	15.8%
Gender	<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%
Diagnosis	<u>Czech Rep</u>	<u>EUROPE</u>	Diagnosis	<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
Flares over 5 years	<u>Czech Rep</u>	<u>EUROPE</u>	Burden	<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

<u>Most missing</u>	<u>Czech Rep</u>	<u>EUROPE</u>				
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.			
Acknwoledge the symptoms I mention	16.9%	22.9%	about my treatment mgmt	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=	118	3,841	n=	113	3773	
			0 = fully disagree : 10 = fully agree			

Satisfaction with HealthCare team 7.69 7.33
0 = fully unsatisfied / 10 = fully satisfied

Unmet needs

<u>Unmet Needs</u>	<u>Czech Rep</u>	<u>EUROPE</u>	<u>Satisfaction with treatment:</u>	<u>Czech Rep</u>	<u>EUROPE</u>
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

<u>Patient reported Symptoms or features</u>	<u>Czech Rep</u>				<u>Czech Rep</u>	
	<u>Regularly</u> <u>experience</u>	<u>most prevent</u> <u>live to the full</u>	<u>most worry</u> <u>today</u>	<u>most worry</u> <u>long term</u>		
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

<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: 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, <https://doi.org/10.1016/j.autrev.2025.103838>.

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