



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Belgium

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:

	Belgium	EUROPE	Age	Belgium	EUROPE
Total number of responses	127	4525	Up to 25	3.9%	5.5%
			26 to 35	14.2%	15.8%
<u>Gender</u>	<u>Belgium</u>	<u>EUROPE</u>	36 to 45	27.6%	26.9%
Man	4.0%	4.1%	46 to 55	29.9%	28.0%
Woman	96.0%	95.5%	56 to 65	18.1%	16.0%
Other / prefer not to answer	0.0%	0.4%	above 65	4.7%	6.2%
Total	100.0%	100.0%	NA	1.6%	1.5%
			Grand Total	100.0%	100.0%
<u>Diagnosis</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Diagnosis</u>	<u>Belgium</u>	<u>EUROPE</u>
SLE	90.6%	92.5%	Lupus Nephritis	18.0%	19.5%
Child onset SLE	9.4%	7.5%	APS	15.6%	19.2%
Grand Total	100.0%	100.0%	LN+APS	7.4%	6.2%
			None of the 2	59.0%	55.2%
			Grand Total	100.0%	100.0%

BURDEN

<u>Lupus under control past3mo</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Satisfied with current state</u>	<u>Belgium</u>	<u>EUROPE</u>
Yes	66.7%	66.5%	Yes	47.4%	47.6%
No	33.3%	33.5%	No	47.4%	47.4%
n=	123	4360	Prefer not to answer	5.3%	5.0%
			n=	114	3957
<u>Flares over 5 years</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Burden</u>	<u>Belgium</u>	<u>EUROPE</u>
A. Never	11.7%	7.9%	Overall burden of lupus on life	6.50	6.94
B. Once	14.2%	12.7%	activity of disease itself	6.36	6.63
C. Twice	11.7%	11.0%	physical conseq.of disease	7.33	7.41
D. 3 or 4 times	13.3%	13.3%	side effects of treatment	5.77	6.02
E. Annually	4.2%	9.7%	fatigue	7.99	7.95
F. Several times a year	34.2%	34.8%	Pain	6.72	6.79
G. Don't know	10.8%	10.6%	Psychological impact	6.97	6.99
n=	120	4124	Social impact	6.59	6.48
			Work / education impact	6.83	7.08
			Financial impact	6.07	6.46
			0= no burden at all / 10 = extreme burden		

<u>Lupus life Experience:</u>	<u>Belgium</u>	<u>EUROPE</u>
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	4.2%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	5.9%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	11.9%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	5.1%	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	31.4%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life	13.6%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	14.4%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life	1.7%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life	5.9%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	1.7%	7.0%
K. Prefer not to answer	4.2%	1.9%
n=	118	4,057

Patient Doctor Communication

Most missing	Belgium	EUROPE			
Time	25.9%	31.6%	Doctor takes into account my opinion		
Empathy	14.7%	14.0%	when managing my treatment	7.66	7.44
Communication within team	15.5%	22.3%	I am a key contributor to Sh. Dec. Mak.		
Acknowledge the symptoms I mention	26.7%	22.9%	about my treatment mngt	7.04	6.96
Personalised info	6.9%	10.6%	I have an active role in controlling my		
lay language	10.3%	6.4%	disease	7.65	7.47
An invite to ask	7.8%	5.7%	I have a trustful relationship with my		
Answers	7.8%	8.3%	doctor	7.97	7.56
Consider non measurable	31.0%	25.0%	I say "the truth, all the truth and only the		
What symptoms mean for my life	19.8%	16.7%	truth" to my HCP with regards to my	8.86	8.82
Clear info on Meds	26.7%	21.2%	I can share all my problems with my		
Certainty I can talk anything	1.7%	4.3%	doctor	8.02	7.71
Holistic approach	16.4%	17.9%	My doctor takes into account my		
Info on Clinical Trials	14.7%	15.5%	psychological well-being	7.28	6.94
Nothing	20.7%	23.7%			
Other	2.6%	3.5%	n=	113	3773
n=	116	3,841	0 = fully disagree : 10 = fully agree		
Satisfaction with HealthCare team	7.57	7.33			
0 = fully unsatisfied / 10 = fully satisfied					

Unmet needs

Unmet Needs	Belgium	EUROPE	Satisfaction with treatment:	Belgium	EUROPE
A. effic Clinic measured	10.6%	13.9%	A. Satisfied, AND I believe this is		
B. Effic NON Measured sympt	19.2%	25.3%	the best that can be achieved for	43.3%	37.1%
C. reduc Steroids	16.3%	18.8%	B. Satisfied, BUT I believe better		
D. Lower side Eff	19.2%	23.7%	control could be achieved for my	18.3%	30.4%
E. less fatigue	64.4%	53.2%	C. Not satisfied, BUT I believe		
F. LT kidney prot.	18.3%	19.1%	this is the best that can be	28.8%	18.4%
G. Easier to take	0.0%	5.4%	D. Not satisfied AND I believe		
H. Access to existing	6.7%	7.7%	better control could be achieved	9.6%	14.2%
I. Access non Pharma treatm.	28.8%	32.0%			
J. edu & access to support	7.7%	9.5%	n=	104	3503
K. Financial burd	15.4%	19.8%			
L. Other	6.7%	3.5%			
n=	104	3,502			

Symptoms or Features experienced / Most bothersome

	Belgium				Belgium	
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	0.9%	0.9%	1.8%	0.0%	A.None	16.0%
B.Rash	41.4%	8.8%	9.6%	8.8%	B.Rash	9.4%
C.Sun	57.8%	18.4%	10.5%	9.7%	C.Sun	11.3%
D. Ulcers	31.9%	1.8%	0.9%	0.9%	D. Ulcers	12.3%
E.DryEyes	50.0%	8.8%	5.3%	7.1%	E.DryEyes	18.9%
F.dryskin	37.9%	3.5%	1.8%	0.0%	F.dryskin	10.4%
G.Hairloss	46.6%	10.5%	14.9%	8.0%	G.Hairloss	19.8%
H. Joints	75.9%	50.9%	31.6%	36.3%	H. Joints	10.4%
I.Jaccoud	15.5%	5.3%	7.0%	3.5%	I.Jaccoud	4.7%
J.Musclpain/weak	63.8%	37.7%	34.2%	29.2%	J.Musclpain/weak	16.0%
K. Headache	43.1%	20.2%	12.3%	13.3%	K. Headache	10.4%
L.Fatigue	89.7%	57.9%	43.0%	35.4%	L.Fatigue	43.4%
M. Flu-like	24.1%	2.6%	0.0%	0.9%	M. Flu-like	0.9%
N. Shrot Breath	38.8%	6.1%	13.2%	9.7%	N. Shrot Breath	7.5%
O. depres/anxiety	46.6%	14.0%	11.4%	14.2%	O. depres/anxiety	16.0%
P. Heamatologic	18.1%	0.9%	2.6%	5.3%	P. Heamatologic	0.9%
Q. Raynaud	37.1%	1.8%	1.8%	1.8%	Q. Raynaud	3.8%
R. Kidney	15.5%	4.4%	9.6%	19.5%	R. Kidney	0.9%
S. Chestpain	25.9%	2.6%	7.0%	7.1%	S. Chestpain	2.8%
T. Hiugh, Blood Pres	20.7%	2.6%	2.6%	8.0%	T. Hiugh, Blood Pres	1.9%
U. Cardiovasc	10.3%	0.9%	5.3%	11.5%	U. Cardiovasc	0.0%
V. Osteoporosis	12.9%	0.9%	3.5%	8.8%	V. Osteoporosis	1.9%
W. Brainfog	33.6%	9.6%	12.3%	13.3%	W. Brainfog	11.3%
n=	116	114	114	113	n=	106

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: Belgium

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>.

For more informatioin, contact: secretariat@lupus-europe.org