



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Norway

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:

	Norway	EUROPE	Age	Norway	EUROPE
Total number of responses	238	4525	Up to 25	3.8%	5.5%
			26 to 35	5.9%	15.8%
<u>Gender</u>	<u>Norway</u>	<u>EUROPE</u>	36 to 45	13.4%	26.9%
Man	3.4%	4.1%	46 to 55	26.9%	28.0%
Woman	96.6%	95.5%	56 to 65	27.3%	16.0%
Other / prefer not to answer	0.0%	0.4%	above 65	19.7%	6.2%
Total	100.0%	100.0%	NA	2.9%	1.5%
			Grand Total	100.0%	100.0%
<u>Diagnosis</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Diagnosis</u>	<u>Norway</u>	<u>EUROPE</u>
SLE	93.7%	92.5%	Lupus Nephritis	17.6%	19.5%
Child onset SLE	6.3%	7.5%	APS	19.1%	19.2%
Grand Total	100.0%	100.0%	LN+APS	6.9%	6.2%
			None of the 2	56.4%	55.2%
			Grand Total	100.0%	100.0%

BURDEN

<u>Lupus under control past3mo</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Satisfied with current state</u>	<u>Norway</u>	<u>EUROPE</u>
Yes	86.2%	66.5%	Yes	55.3%	47.6%
No	13.8%	33.5%	No	38.9%	47.4%
n=	218	4360	Prefer not to answer	5.8%	5.0%
			n=	190	3957
<u>Flares over 5 years</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Burden</u>	<u>Norway</u>	<u>EUROPE</u>
A. Never	12.2%	7.9%	Overall burden of lupus on life	5.91	6.94
B. Once	16.2%	12.7%	activity of disease itself	5.54	6.63
C. Twice	8.1%	11.0%	physical conseq.of disease	6.35	7.41
D. 3 or 4 times	13.7%	13.3%	side effects of treatment	4.80	6.02
E. Annually	28.9%	9.7%	fatigue	6.92	7.95
F. Several times a year	20.3%	34.8%	Pain	5.39	6.79
G. Don't know	0.5%	10.6%	Psychological impact	5.50	6.99
n=	197	4124	Social impact	6.00	6.48
			Work / education impact	6.96	7.08
			Financial impact	6.46	6.46
			0= no burden at all / 10 = extreme burden		

<u>Lupus life Experience:</u>	<u>Norway</u>	<u>EUROPE</u>
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	8.7%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	1.5%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	10.8%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	4.1%	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	11.8%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life	13.3%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	19.5%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life	5.6%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life	10.3%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	11.3%	7.0%
K. Prefer not to answer	3.1%	1.9%
n=	195	4,057

Patient Doctor Communication

Most missing	Norway	EUROPE		
Time	33.0%	31.6%	Doctor takes into account my opinion when managing my treatment	7.40 7.44
Empathy	9.2%	14.0%	I am a key contributor to Sh. Dec. Mak.	
Communication within team	28.1%	22.3%	about my treatment mngt	7.19 6.96
Acknowledge the symptoms I mention	25.9%	22.9%	I have an active role in controlling my disease	7.31 7.47
Personalised info	15.7%	10.6%	I have a trustful relationship with my doctor	7.74 7.56
lay language	7.0%	6.4%	I say "the truth, all the truth and only the truth" to my HCP with regards to my	8.56 8.82
An invite to ask	3.8%	5.7%	I can share all my problems with my doctor	7.68 7.71
Answers	11.9%	8.3%	My doctor takes into account my psychological well-being	7.15 6.94
Consider non measurable	19.5%	25.0%		
What symptoms mean for my life	16.8%	16.7%		
Clear info on Meds	16.2%	21.2%		
Certainty I can talk anything	3.2%	4.3%		
Holistic approach	18.4%	17.9%		
Info on Clinical Trials	15.7%	15.5%		
Nothing	24.3%	23.7%		
Other	5.4%	3.5%	n=	113 3773
n=	185	3,841	0 = fully disagree : 10 = fully agree	
Satisfaction with HealthCare team	7.04	7.33	0 = fully unsatisfied / 10 = fully satisfied	

Unmet needs

Unmet Needs	Norway	EUROPE	Satisfaction with treatment:	Norway	EUROPE
A. effic Clinic measured	8.3%	13.9%	A. Satisfied, AND I believe this is the best that can be achieved for	43.9%	37.1%
B. Effic NON Measured sympt	30.8%	25.3%	B. Satisfied, BUT I believe better control could be achieved for my	28.3%	30.4%
C. reduc Steroids	8.3%	18.8%	C. Not satisfied, BUT I believe this is the best that can be	15.0%	18.4%
D. Lower side Eff	19.5%	23.7%	D. Not satisfied AND I believe better control could be achieved	12.7%	14.2%
E. less fatigue	63.9%	53.2%			
F. LT kidney prot.	15.4%	19.1%			
G. Easier to take	3.0%	5.4%			
H. Access to existing	9.5%	7.7%			
I. Access non Pharma treatm.	23.1%	32.0%			
J. edu & access to support	4.1%	9.5%	n=	173	3503
K. Financial burd	23.1%	19.8%			
L. Other	5.9%	3.5%			
n=	169	3,502			

Symptoms or Features experienced / Most bothersome

	Norway				Norway	
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	4.2%	6.7%	8.6%	5.6%	A.None	22.8%
B.Rash	33.9%	5.1%	4.0%	5.1%	B.Rash	3.6%
C.Sun	56.1%	24.7%	13.1%	7.9%	C.Sun	13.8%
D. Ulcers	29.6%	1.7%	0.6%	1.7%	D. Ulcers	6.6%
E.DryEyes	63.5%	10.7%	9.1%	8.4%	E.DryEyes	11.4%
F.dryskin	47.6%	2.8%	2.3%	1.1%	F.dryskin	6.6%
G.Hairloss	33.3%	3.9%	6.9%	6.2%	G.Hairloss	13.8%
H. Joints	64.6%	31.5%	24.0%	19.7%	H. Joints	9.0%
I.Jaccoud	8.5%	3.9%	4.0%	3.9%	I.Jaccoud	0.6%
J.Musclpain/weak	58.2%	30.9%	26.3%	26.4%	J.Musclpain/weak	15.0%
K. Headache	39.2%	18.0%	14.3%	13.5%	K. Headache	9.6%
L.Fatigue	82.0%	61.8%	38.3%	33.7%	L.Fatigue	31.7%
M. Flu-like	40.7%	10.1%	8.0%	5.6%	M. Flu-like	8.4%
N. Shrot Breath	32.3%	7.3%	10.3%	5.1%	N. Shrot Breath	2.4%
O. depres/anxiety	18.0%	7.9%	8.6%	10.1%	O. depres/anxiety	10.8%
P. Heamatologic	10.6%	2.2%	5.1%	7.3%	P. Heamatologic	1.8%
Q. Raynaud	30.7%	2.2%	0.0%	0.0%	Q. Raynaud	3.6%
R. Kidney	12.7%	2.8%	14.9%	24.2%	R. Kidney	3.0%
S. Chestpain	21.2%	1.7%	6.3%	7.9%	S. Chestpain	3.0%
T. Hiugh, Blood Pres	18.0%	0.6%	6.9%	7.9%	T. Hiugh, Blood Pres	3.0%
U. Cardiovasc	5.3%	1.1%	9.1%	24.2%	U. Cardiovasc	4.2%
V. Osteoporosis	15.9%	3.4%	5.7%	10.1%	V. Osteoporosis	1.2%
W. Brainfog	29.1%	6.2%	8.6%	10.1%	W. Brainfog	15.6%
n=	189	178	175	178	n=	167

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: Norway

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