



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Germany

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:

	Germany	EUROPE	Age	Germany	EUROPE
Total number of responses	227	4525	Up to 25	6.2%	5.5%
			26 to 35	22.9%	15.8%
<u>Gender</u>	<u>Germany</u>	<u>EUROPE</u>	36 to 45	26.0%	26.9%
Man	1.8%	4.1%	46 to 55	24.2%	28.0%
Woman	97.3%	95.5%	56 to 65	15.4%	16.0%
Other / prefer not to answer	0.9%	0.4%	above 65	3.5%	6.2%
Total	100.0%	100.0%	NA	1.8%	1.5%
			Grand Total	100.0%	100.0%
<u>Diagnosis</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Diagnosis</u>	<u>Germany</u>	<u>EUROPE</u>
SLE	95.6%	92.5%	Lupus Nephritis	22.2%	19.5%
Child onset SLE	4.4%	7.5%	APS	18.9%	19.2%
Grand Total	100.0%	100.0%	LN+APS	7.5%	6.2%
			None of the 2	51.4%	55.2%
			Grand Total	100.0%	100.0%

BURDEN

<u>Lupus under control past3mo</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Satisfied with current state</u>	<u>Germany</u>	<u>EUROPE</u>
Yes	61.1%	66.5%	Yes	46.5%	47.6%
No	38.9%	33.5%	No	49.5%	47.4%
n=	221	4360	Prefer not to answer	4.0%	5.0%
			n=	200	3957
<u>Flares over 5 years</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Burden</u>	<u>Germany</u>	<u>EUROPE</u>
A. Never	3.9%	7.9%	Overall burden of lupus on life	6.62	6.94
B. Once	10.2%	12.7%	activity of disease itself	5.96	6.63
C. Twice	10.7%	11.0%	physical conseq.of disease	6.74	7.41
D. 3 or 4 times	12.7%	13.3%	side effects of treatment	5.42	6.02
E. Annually	7.3%	9.7%	fatigue	7.15	7.95
F. Several times a year	40.5%	34.8%	Pain	6.25	6.79
G. Don't know	14.6%	10.6%	Psychological impact	6.54	6.99
n=	205	4124	Social impact	6.19	6.48
			Work / education impact	6.71	7.08
			Financial impact	5.89	6.46
			0= no burden at all / 10 = extreme burden		

<u>Lupus life Experience:</u>	<u>Germany</u>	<u>EUROPE</u>
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	10.3%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	11.8%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	14.8%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	1.5%	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	15.3%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life	6.4%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	19.7%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life	3.0%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life	8.4%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	5.9%	7.0%
K. Prefer not to answer	3.0%	1.9%
n=	203	4,057

Patient Doctor Communication

Most missing	Germany	EUROPE		
Time	34.9%	31.6%	Doctor takes into account my opinion	
Empathy	21.0%	14.0%	when managing my treatment	7.19 7.44
Communication within team	25.1%	22.3%	I am a key contributor to Sh. Dec. Mak.	
Acknowledge the symptoms I mention	30.3%	22.9%	about my treatment mngt	6.89 6.96
Personalised info	8.7%	10.6%	I have an active role in controlling my	
lay language	5.6%	6.4%	disease	7.11 7.47
An invite to ask	6.2%	5.7%	I have a trustful relationship with my	
Answers	8.2%	8.3%	doctor	7.17 7.56
Consider non measurable	37.4%	25.0%	I say "the truth, all the truth and only the	
What symptoms mean for my life	13.3%	16.7%	truth" to my HCP with regards to my	8.89 8.82
Clear info on Meds	23.6%	21.2%	I can share all my problems with my	
Certainty I can talk anything	6.2%	4.3%	doctor	7.17 7.71
Holistic approach	27.2%	17.9%	My doctor takes into account my	
Info on Clinical Trials	19.5%	15.5%	psychological well-being	6.44 6.94
Nothing	21.0%	23.7%		
Other	3.1%	3.5%	n=	113 3773
n=	195	3,841	0 = fully disagree : 10 = fully agree	
Satisfaction with HealthCare team	6.85	7.33		
0 = fully unsatisfied / 10 = fully satisfied				

Unmet needs

Unmet Needs	Germany	EUROPE	Satisfaction with treatment:	Germany	EUROPE
A. effic Clinic measured	11.6%	13.9%	A. Satisfied, AND I believe this is		
B. Effic NON Measured sympt	29.3%	25.3%	the best that can be achieved for	32.2%	37.1%
C. reduc Steroids	21.0%	18.8%	B. Satisfied, BUT I believe better		
D. Lower side Eff	21.5%	23.7%	control could be achieved for my	27.9%	30.4%
E. less fatigue	54.1%	53.2%	C. Not satisfied, BUT I believe		
F. LT kidney prot.	18.2%	19.1%	this is the best that can be	21.3%	18.4%
G. Easier to take	3.3%	5.4%	D. Not satisfied AND I believe		
H. Access to existing	5.0%	7.7%	better control could be achieved	18.6%	14.2%
I. Access non Pharma treatm.	34.3%	32.0%			
J. edu & access to support	5.5%	9.5%	n=	183	3503
K. Financial burd	21.0%	19.8%			
L. Other	4.4%	3.5%			
n=	181	3,502			

Symptoms or Features experienced / Most bothersome

	Germany				Germany	
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	1.5%	2.6%	5.4%	3.7%	A.None	16.1%
B.Rash	37.6%	7.9%	7.5%	5.9%	B.Rash	8.9%
C.Sun	51.8%	26.7%	9.1%	11.2%	C.Sun	14.4%
D. Ulcers	29.9%	4.7%	3.2%	1.6%	D. Ulcers	3.9%
E.DryEyes	48.7%	5.8%	4.8%	2.7%	E.DryEyes	12.8%
F.dryskin	45.7%	0.5%	1.1%	1.1%	F.dryskin	11.1%
G.Hairloss	41.6%	8.9%	12.4%	8.6%	G.Hairloss	23.3%
H. Joints	67.5%	37.7%	24.2%	25.7%	H. Joints	5.0%
I.Jaccoud	5.1%	2.1%	2.2%	1.6%	I.Jaccoud	2.2%
J.Musclpain/weak	62.4%	37.7%	28.5%	23.0%	J.Musclpain/weak	17.8%
K. Headache	47.2%	16.8%	12.9%	2.7%	K. Headache	11.1%
L.Fatigue	75.1%	50.3%	32.8%	24.6%	L.Fatigue	38.9%
M. Flu-like	32.0%	5.8%	4.8%	2.7%	M. Flu-like	2.8%
N. Shrot Breath	28.4%	4.2%	8.1%	2.7%	N. Shrot Breath	3.3%
O. depres/anxiety	39.1%	13.6%	17.7%	14.4%	O. depres/anxiety	21.7%
P. Heamatologic	23.4%	3.7%	9.7%	5.9%	P. Heamatologic	3.3%
Q. Raynaud	34.0%	9.9%	6.5%	3.2%	Q. Raynaud	7.2%
R. Kidney	18.8%	3.1%	11.8%	19.8%	R. Kidney	1.7%
S. Chestpain	22.3%	2.1%	5.9%	3.7%	S. Chestpain	3.3%
T. Hiugh, Blood Pres	25.4%	2.6%	6.5%	5.3%	T. Hiugh, Blood Pres	3.3%
U. Cardiovasc	5.1%	1.0%	5.4%	10.7%	U. Cardiovasc	2.8%
V. Osteoporosis	13.2%	2.1%	3.2%	4.8%	V. Osteoporosis	2.2%
W. Brainfog	34.0%	11.0%	12.4%	5.9%	W. Brainfog	17.8%
n=	197	191	186	187	n=	180

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: Germany

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