



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

UK

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:

	UK	EUROPE	Age	UK	EUROPE
Total number of responses	617	4525	Up to 25	7.1%	5.5%
			26 to 35	16.0%	15.8%
Gender	UK	EUROPE	36 to 45	22.4%	26.9%
Man	3.8%	4.1%	46 to 55	23.8%	28.0%
Woman	95.4%	95.5%	56 to 65	19.9%	16.0%
Other / prefer not to answer	0.8%	0.4%	above 65	9.6%	6.2%
Total	100.0%	100.0%	NA	1.1%	1.5%
			Grand Total	100.0%	100.0%
Diagnosis	UK	EUROPE	Diagnosis	UK	EUROPE
SLE	92.9%	92.5%	Lupus Nephritis	18.0%	19.5%
Child onset SLE	7.1%	7.5%	APS	18.1%	19.2%
Grand Total	100.0%	100.0%	LN+APS	4.2%	6.2%
			None of the 2	59.7%	55.2%
			Grand Total	100.0%	100.0%

BURDEN

<u>Lupus under control past3mo</u>	UK	EUROPE	<u>Satisfied with current state</u>	UK	EUROPE
Yes	51.2%	66.5%	Yes	36.0%	47.6%
No	48.8%	33.5%	No	60.0%	47.4%
n=	603	4360	Prefer not to answer	4.0%	5.0%
			n=	550	3957
<u>Flares over 5 years</u>	UK	EUROPE	<u>Burden</u>	UK	EUROPE
A. Never	3.0%	7.9%	Overall burden of lupus on life	7.21	6.94
B. Once	7.0%	12.7%	activity of disease itself	6.96	6.63
C. Twice	7.1%	11.0%	physical conseq.of disease	7.93	7.41
D. 3 or 4 times	18.6%	13.3%	side effects of treatment	5.99	6.02
E. Annually	5.1%	9.7%	fatigue	8.51	7.95
F. Several times a year	49.1%	34.8%	Pain	7.48	6.79
G. Don't know	10.1%	10.6%	Psychological impact	7.46	6.99
n=	574	4124	Social impact	7.34	6.48
			Work / education impact	7.46	7.08
			Financial impact	6.58	6.46

0= no burden at all / 10 = extreme burden

<u>Lupus life Experience:</u>	UK	EUROPE
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	16.3%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	15.8%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	15.4%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	6.7%	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	14.7%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life	9.0%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	10.3%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life	2.3%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life	4.1%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	5.0%	7.0%
K. Prefer not to answer	0.4%	1.9%
n=	564	4,057

Unmet needs					
Unmet Needs	UK	EUROPE	Satisfaction with treatment:	UK	EUROPE
A. effic Clinic measured	17.8%	13.9%	A. Satisfied, AND I believe this is the best that can be achieved for	28.0%	37.1%
B. Effic NON Measured sympt	31.7%	25.3%	B. Satisfied, BUT I believe better control could be achieved for my	35.9%	30.4%
C. reduc Steroids	8.4%	18.8%	C. Not satisfied, BUT I believe this is the best that can be	15.5%	18.4%
D. Lower side Eff	17.4%	23.7%	D. Not satisfied AND I believe better control could be achieved	20.6%	14.2%
E. less fatigue	61.3%	53.2%			
F. LT kidney prot.	18.0%	19.1%			
G. Easier to take	7.4%	5.4%			
H. Access to existing	9.4%	7.7%			
I. Access non Pharma treatm.	29.7%	32.0%			
J. edu & access to support	11.2%	9.5%			
K. Financial burd	20.4%	19.8%			
L. Other	4.5%	3.5%			
n=	489	3,502		n=	485
					3503

Symptoms or Features experienced / Most bothersome						
Patient reported Symptoms or features	UK				UK	
	Regularly experience	most prevent live to the full	most worry today	most worry long term	least taken into account	
A.None	0.2%	0.8%	2.3%	0.8%	A.None	11.0%
B.Rash	62.1%	8.6%	8.4%	3.7%	B.Rash	14.6%
C.Sun	64.2%	15.3%	8.3%	7.2%	C.Sun	13.4%
D.Ulcers	56.8%	4.0%	1.7%	1.0%	D.Ulcers	10.5%
E.DryEyes	66.6%	8.2%	6.1%	3.9%	E.DryEyes	14.0%
F.dryskin	54.0%	2.3%	1.7%	1.4%	F.dryskin	5.9%
G.Hairloss	50.9%	8.0%	12.3%	8.9%	G.Hairloss	21.9%
H.Joints	83.0%	49.8%	35.3%	37.2%	H.Joints	13.0%
I.Jaccoud	8.5%	1.3%	2.5%	2.1%	I.Jaccoud	4.5%
J.Musclpain/weak	73.2%	38.5%	26.5%	28.5%	J.Musclpain/weak	12.6%
K.Headache	58.5%	16.8%	13.6%	10.1%	K.Headache	10.8%
L.Fatigue	93.4%	69.5%	49.3%	44.4%	L.Fatigue	36.3%
M.Flu-like	41.5%	4.2%	5.2%	2.7%	M.Flu-like	4.7%
N.Shot Breath	43.0%	6.7%	11.5%	9.5%	N.Shot Breath	7.3%
O.depres/anxiety	53.0%	12.4%	15.7%	13.4%	O.depres/anxiety	21.9%
P.Hematologic	21.9%	2.1%	4.2%	6.8%	P.Hematologic	2.8%
Q.Raynaud	53.0%	5.9%	4.2%	3.3%	Q.Raynaud	7.9%
R.Kidney	17.2%	5.0%	13.1%	22.1%	R.Kidney	3.6%
S.Chestpain	28.5%	3.4%	7.5%	6.8%	S.Chestpain	3.9%
T.Hiugh, Blood Pres	24.9%	1.9%	5.2%	9.7%	T.Hiugh, Blood Pres	2.6%
U.Cardiovasc	8.9%	1.9%	7.1%	20.2%	U.Cardiovasc	3.4%
V.Osteoporosis	17.0%	1.9%	3.8%	9.3%	V.Osteoporosis	4.5%
W.Brainfog	73.2%	15.3%	19.2%	18.6%	W.Brainfog	26.4%
n=	530	524	521	516	n=	507

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: UK

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