



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Portugal

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,*  
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**DEMOGRAPHICS:**

	<u>Portugal</u>	<u>EUROPE</u>	<u>Age</u>	<u>Portugal</u>	<u>EUROPE</u>
Total number of responses	172	4525	Up to 25	4.1%	5.5%
			26 to 35	14.5%	15.8%
Gender	<u>Portugal</u>	<u>EUROPE</u>	36 to 45	32.6%	26.9%
Man	4.7%	4.1%	46 to 55	31.4%	28.0%
Woman	95.3%	95.5%	56 to 65	10.5%	16.0%
Other / prefer not to answer	0.0%	0.4%	above 65	5.2%	6.2%
Total	100.0%	100.0%	NA	1.7%	1.5%
			Grand Total	100.0%	100.0%
<b>Diagnosis</b>	<b>Portugal</b>	<b>EUROPE</b>	<b>Diagnosis</b>	<b>Portugal</b>	<b>EUROPE</b>
SLE	95.3%	92.5%	Lupus Nephritis	17.0%	19.5%
Child onset SLE	4.7%	7.5%	APS	11.3%	19.2%
Grand Total	100.0%	100.0%	LN+APS	5.0%	6.2%
			None of the 2	66.7%	55.2%
			Grand Total	100.0%	100.0%

**BURDEN**

<u>Lupus under control past3mo</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>Satisfied with current state</u>	<u>Portugal</u>	<u>EUROPE</u>
Yes	70.5%	66.5%	Yes	52.4%	47.6%
No	29.5%	33.5%	No	42.8%	47.4%
n=	166	4360	Prefer not to answer	4.8%	5.0%
			n=	145	3957
<b>Flares over 5 years</b>	<b>Portugal</b>	<b>EUROPE</b>	<b>Burden</b>	<b>Portugal</b>	<b>EUROPE</b>
A. Never	9.1%	7.9%	Overall burden of lupus on life	7.30	6.94
B. Once	13.6%	12.7%	activity of disease itself	7.19	6.63
C. Twice	12.3%	11.0%	physical conseq.of disease	7.65	7.41
D. 3 or 4 times	18.8%	13.3%	side effects of treatment	6.46	6.02
E. Annually	5.2%	9.7%	fatigue	8.33	7.95
F. Several times a year	27.9%	34.8%	Pain	7.44	6.79
G. Don't know	13.0%	10.6%	Psychological impact	7.52	6.99
n=	154	4124	Social impact	6.43	6.48
			Work / education impact	7.40	7.08
			Financial impact	6.79	6.46

0= no burden at all / 10 = extreme burden

<u>Lupus life Experience:</u>		<u>Portugal</u>	<u>EUROPE</u>
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL		7.3%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL		9.3%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL		8.6%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL		6.0%	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		21.9%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life		7.3%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL		21.2%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life		4.6%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life		10.6%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL		3.3%	7.0%
K. Prefer not to answer		0.0%	1.9%
n=	151	4,057	

Unmet needs					
<u>Unmet Needs</u>	Portugal	EUROPE	<u>Satisfaction with treatment:</u>	Portugal	EUROPE
A. effic Clinic measured	16.9%	13.9%	A. Satisfied, AND I believe this is the best that can be achieved for	48.8%	37.1%
B. Effic NON Measured sympt	26.2%	25.3%	B. Satisfied, BUT I believe better control could be achieved for my	28.3%	30.4%
C. reduc Steroids	30.0%	18.8%	C. Not satisfied, BUT I believe this is the best that can be	17.3%	18.4%
D. Lower side Eff	20.8%	23.7%	D. Not satisfied AND I believe better control could be achieved	5.5%	14.2%
E. less fatigue	50.8%	53.2%			
F. LT kidney prot.	28.5%	19.1%			
G. Easier to take	6.2%	5.4%			
H. Access to existing	2.3%	7.7%			
I. Access non Pharma treatm.	30.8%	32.0%			
J. edu & access to support	6.9%	9.5%			
K. Financial burd	17.7%	19.8%			
L. Other	2.3%	3.5%			
n=	130	3,502		n=	127
					3503

Symptoms or Features experienced / Most bothersome						
Portugal					Portugal	
Patient reported Symptoms or features	Regularly	most prevent	most worry	most worry	least taken into account	
	experience	live to the full	today	long term		
A.None	0.7%	0.7%	0.7%	0.0%	A.None	21.6%
B.Rash	27.7%	11.7%	7.4%	6.7%	B.Rash	12.0%
C.Sun	66.7%	34.3%	11.9%	10.4%	C.Sun	9.6%
D.Ulcers	28.4%	8.0%	6.7%	4.5%	D.Ulcers	8.0%
E.DryEyes	57.4%	13.1%	14.1%	9.7%	E.DryEyes	17.6%
F.dryskin	45.4%	3.6%	4.4%	3.0%	F.dryskin	11.2%
G.Hairloss	46.8%	12.4%	13.3%	10.4%	G.Hairloss	19.2%
H.Joints	65.2%	52.6%	37.0%	36.6%	H.Joints	9.6%
I.Jaccoud	11.3%	0.7%	2.2%	6.0%	I.Jaccoud	4.0%
J.Musclpain/weak	51.1%	25.5%	23.7%	24.6%	J.Musclpain/weak	6.4%
K.Headache	46.1%	16.8%	14.8%	11.2%	K.Headache	7.2%
L.Fatigue	87.9%	52.6%	41.5%	33.6%	L.Fatigue	24.8%
M.Flu-like	15.6%	1.5%	0.7%	0.7%	M.Flu-like	8.0%
N.Shot Breath	11.3%	2.2%	3.7%	2.2%	N.Shot Breath	6.4%
O.depres/anxiety	51.8%	11.7%	20.0%	15.7%	O.depres/anxiety	12.8%
P.Hematologic	17.7%	1.5%	3.7%	11.2%	P.Hematologic	2.4%
Q.Raynaud	21.3%	4.4%	2.2%	4.5%	Q.Raynaud	1.6%
R.Kidney	12.8%	4.4%	7.4%	23.9%	R.Kidney	0.0%
S.Chestpain	14.2%	1.5%	4.4%	2.2%	S.Chestpain	0.0%
T.Hiugh, Blood Pres	20.6%	1.5%	5.9%	4.5%	T.Hiugh, Blood Pres	6.4%
U.Cardiovasc	7.8%	1.5%	7.4%	23.9%	U.Cardiovasc	0.8%
V.Osteoporosis	19.9%	2.9%	5.2%	9.0%	V.Osteoporosis	3.2%
W.Brainfog	22.7%	7.3%	10.4%	11.2%	W.Brainfog	8.0%
n=	141	137	135	134	n=	125

**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: Portugal

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