



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Italy

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:

	Italy	EUROPE	Age	Italy	EUROPE
Total number of responses	442	4525	Up to 25	6.8%	5.5%
			26 to 35	18.8%	15.8%
<u>Gender</u>	Italy	EUROPE	36 to 45	29.0%	26.9%
Man	2.3%	4.1%	46 to 55	27.4%	28.0%
Woman	97.3%	95.5%	56 to 65	15.2%	16.0%
Other / prefer not to answer	0.5%	0.4%	above 65	1.6%	6.2%
Total	100.0%	100.0%	NA	1.4%	1.5%
			Grand Total	100.0%	100.0%
<u>Diagnosis</u>	Italy	EUROPE	<u>Diagnosis</u>	Italy	EUROPE
SLE	92.1%	92.5%	Lupus Nephritis	23.6%	19.5%
Child onset SLE	7.9%	7.5%	APS	24.8%	19.2%
Grand Total	100.0%	100.0%	LN+APS	10.1%	6.2%
			None of the 2	41.5%	55.2%
			Grand Total	100.0%	100.0%

BURDEN

<u>Lupus under control past3mo</u>	Italy	EUROPE	<u>Satisfied with current state</u>	Italy	EUROPE
Yes	80.7%	66.5%	Yes	58.7%	47.6%
No	19.3%	33.5%	No	34.5%	47.4%
n=	431	4360	Prefer not to answer	6.8%	5.0%
			n=	383	3957
<u>Flares over 5 years</u>	Italy	EUROPE	<u>Burden</u>	Italy	EUROPE
A. Never	13.6%	7.9%	Overall burden of lupus on life	7.40	6.94
B. Once	17.4%	12.7%	activity of disease itself	6.90	6.63
C. Twice	11.2%	11.0%	physical conseq.of disease	7.53	7.41
D. 3 or 4 times	8.9%	13.3%	side effects of treatment	6.62	6.02
E. Annually	6.9%	9.7%	fatigue	7.96	7.95
F. Several times a year	29.3%	34.8%	Pain	6.97	6.79
G. Don't know	12.7%	10.6%	Psychological impact	7.71	6.99
n=	403	4124	Social impact	6.67	6.48
			Work / education impact	6.97	7.08
			Financial impact	6.67	6.46
			0= no burden at all / 10 = extreme burden		

<u>Lupus life Experience:</u>	Italy	EUROPE
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	4.1%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	7.9%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	9.9%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	4.6%	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	8.9%	9.1%
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	21.1%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life	2.5%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life	9.9%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	12.7%	7.0%
K. Prefer not to answer	3.8%	1.9%
n=	394	4,057

Patient Doctor Communication

Most missing	Italy	EUROPE			
Time	34.8%	31.6%	Doctor takes into account my opinion		
Empathy	15.2%	14.0%	when managing my treatment	7.18	7.44
Communication within team	26.5%	22.3%	I am a key contributor to Sh. Dec. Mak.		
Acknowledge the symptoms I mention	14.4%	22.9%	about my treatment mngt	7.03	6.96
Personalised info	11.3%	10.6%	I have an active role in controlling my		
lay language	5.2%	6.4%	disease	7.64	7.47
An invite to ask	5.8%	5.7%	I have a trustful relationship with my		
Answers	8.8%	8.3%	doctor	7.82	7.56
Consider non measurable	18.2%	25.0%	I say "the truth, all the truth and only the		
What symptoms mean for my life	11.0%	16.7%	truth" to my HCP with regards to my	8.78	8.82
Clear info on Meds	26.0%	21.2%	I can share all my problems with my		
Certainty I can talk anything	5.0%	4.3%	doctor	7.90	7.71
Holistic approach	18.8%	17.9%	My doctor takes into account my		
Info on Clinical Trials	17.7%	15.5%	psychological well-being	6.87	6.94
Nothing	21.8%	23.7%			
Other	4.1%	3.5%	n=	113	3773
n=	362	3,841	0 = fully disagree : 10 = fully agree		
Satisfaction with HealthCare team	7.40	7.33			
0 = fully unsatisfied / 10 = fully satisfied					

Unmet needs

Unmet Needs	Italy	EUROPE	Satisfaction with treatment:	Italy	EUROPE
A. effic Clinic measured	14.0%	13.9%	A. Satisfied, AND I believe this is		
B. Effic NON Measured sympt	18.8%	25.3%	the best that can be achieved for	39.2%	37.1%
C. reduc Steroids	21.0%	18.8%	B. Satisfied, BUT I believe better		
D. Lower side Eff	23.7%	23.7%	control could be achieved for my	34.0%	30.4%
E. less fatigue	41.0%	53.2%	C. Not satisfied, BUT I believe		
F. LT kidney prot.	22.5%	19.1%	this is the best that can be	13.4%	18.4%
G. Easier to take	5.5%	5.4%	D. Not satisfied AND I believe		
H. Access to existing	5.2%	7.7%	better control could be achieved	13.4%	14.2%
I. Access non Pharma treatm.	40.4%	32.0%			
J. edu & access to support	10.0%	9.5%	n=	329	3503
K. Financial burd	20.7%	19.8%			
L. Other	2.7%	3.5%			
n=	329	3,502			

Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Italy				Italy	
	Regularly	most prevent	most worry	most worry	least taken	
	experience	live to the full	today	long term	into account	
A.None	1.6%	0.5%	2.3%	1.9%	A.None	22.5%
B.Rash	38.7%	3.2%	2.8%	3.3%	B.Rash	12.0%
C.Sun	58.9%	33.3%	14.8%	12.3%	C.Sun	11.0%
D. Ulcers	30.5%	4.6%	2.3%	0.9%	D. Ulcers	11.0%
E.DryEyes	44.7%	14.6%	6.0%	3.8%	E.DryEyes	13.0%
F.dryskin	37.9%	3.2%	1.4%	0.9%	F.dryskin	11.5%
G.Hairloss	43.1%	16.4%	12.0%	8.5%	G.Hairloss	18.5%
H. Joints	61.3%	37.4%	26.4%	27.8%	H. Joints	7.0%
I.Jaccoud	7.9%	1.4%	2.8%	3.8%	I.Jaccoud	6.5%
J.Musclpain/weak	58.6%	29.7%	21.3%	23.1%	J.Musclpain/weak	9.5%
K. Headache	49.6%	18.3%	13.0%	10.4%	K. Headache	11.0%
L.Fatigue	79.3%	50.2%	29.6%	27.8%	L.Fatigue	18.0%
M. Flu-like	26.4%	2.7%	1.4%	1.4%	M. Flu-like	2.5%
N. Shrot Breath	30.0%	3.7%	6.0%	5.7%	N. Shrot Breath	6.5%
O. depres/anxiety	35.4%	12.3%	13.9%	17.5%	O. depres/anxiety	19.5%
P. Heamatologic	26.2%	4.6%	9.3%	11.3%	P. Heamatologic	2.5%
Q. Raynaud	27.8%	2.3%	1.4%	0.5%	Q. Raynaud	4.0%
R. Kidney	21.0%	8.2%	30.6%	35.8%	R. Kidney	3.0%
S. Chestpain	18.3%	2.3%	5.6%	2.8%	S. Chestpain	1.5%
T. Hiugh, Blood Pres	15.3%	1.8%	6.5%	4.2%	T. Hiugh, Blood Pres	2.0%
U. Cardiovasc	6.3%	3.2%	13.9%	27.4%	U. Cardiovasc	1.5%
V. Osteoporosis	18.0%	2.7%	7.4%	12.3%	V. Osteoporosis	1.5%
W. Brainfog	24.5%	5.0%	7.4%	9.4%	W. Brainfog	10.0%
n=	367	219	216	212	n=	200

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: Italy

For full text european analysis, please refer to:

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