



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Spain

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:					
Total number of responses	Spain 695	EUROPE 4525	Age	Spain 5.5%	EUROPE 5.5%
			Up to 25		
			26 to 35	14.5%	15.8%
Gender	Spain	EUROPE	36 to 45	28.2%	26.9%
Man	4.9%	4.1%	46 to 55	31.7%	28.0%
Woman	94.9%	95.5%	56 to 65	15.7%	16.0%
Other / prefer not to answer	0.1%	0.4%	above 65	3.5%	6.2%
Total	100.0%	100.0%	NA	1.0%	1.5%
			Grand Total	100.0%	100.0%
Diagnosis	Spain	EUROPE	Diagnosis	Spain	EUROPE
SLE	93.7%	92.5%	Lupus Nephritis	19.2%	19.5%
Child onset SLE	6.3%	7.5%	APS	21.7%	19.2%
Grand Total	100.0%	100.0%	LN+APS	6.3%	6.2%
			None of the 2	52.8%	55.2%
			Grand Total	100.0%	100.0%
BURDEN					
<u>Lupus under control past3mo</u>	Spain 65.4%	EUROPE 66.5%	<u>Satisfied with current state</u>	Spain 41.8%	EUROPE 47.6%
Yes	34.6%	33.5%	Yes	53.3%	47.4%
No	667	4360	No	4.9%	5.0%
n=			Prefer not to answer	629	3957
<u>Flares over 5 years</u>	Spain	EUROPE	<u>Burden</u>	Spain	EUROPE
A. Never	10.4%	7.9%	Overall burden of lupus on life	7.33	6.94
B. Once	14.7%	12.7%	activity of disease itself	7.19	6.63
C. Twice	13.0%	11.0%	physical conseq.of disease	7.76	7.41
D. 3 or 4 times	12.1%	13.3%	side effects of treatment	6.67	6.02
E. Annually	4.8%	9.7%	fatigue	8.10	7.95
F. Several times a year	34.8%	34.8%	Pain	7.39	6.79
G. Don't know	10.4%	10.6%	Psychological impact	7.54	6.99
n=	647	4124	Social impact	6.81	6.48
			Work / education impact	7.51	7.08
			Financial impact	6.71	6.46
<i>0= no burden at all / 10 = extreme burden</i>					
<u>Lupus life Experience:</u>				Spain	EUROPE
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL				9.1%	9.7%
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL				10.6%	9.5%
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL				7.3%	11.0%
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL				5.5%	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				23.9%	19.6%
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life				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				17.5%	16.4%
H. Lupus not very aggressive, even when flaring, can live a normal life				3.4%	3.9%
I. Lupus rarely flaring. Most of the time, can live a normal life				6.1%	6.5%
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL				6.3%	7.0%
K. Prefer not to answer				1.4%	1.9%
n=	640	4,057			

### Patient Doctor Communication

<u>Most missing</u>	<b>Spain</b>	<b>EUROPE</b>				
Time	30.4%	31.6%	Doctor takes into account my opinion			
Empathy	17.5%	14.0%	when managing my treatment	7.51	7.44	
Communication within team	21.8%	22.3%	I am a key contributor to Sh. Dec. Mak.			
Acknwoledge the symptoms I mention	21.8%	22.9%	about my treatment mgnt	7.02	6.96	
Personalised info	14.3%	10.6%	I have an active role in controlling my			
lay language	4.5%	6.4%	disease	7.51	7.47	
An invite to ask	5.8%	5.7%	I have a trustful relationship with my			
Answers	7.6%	8.3%	doctor	7.38	7.56	
Consider non measurable	22.6%	25.0%	I say "the truth, all the truth and only the			
What symptoms mean for my life	19.0%	16.7%	truth" to my HCP with regards to my	9.28	8.82	
Clear info on Meds	24.0%	21.2%	I can share all my problems with my			
Certainty I can talk anything	3.6%	4.3%	doctor	7.69	7.71	
Holistic approach	16.1%	17.9%	My doctor takes into account my			
Info on Clinical Trials	17.2%	15.5%	psychological well-being	6.74	6.94	
Nothing	21.6%	23.7%				
Other	4.1%	3.5%				
n=	616	3,841	n=	113	3773	
			0 = fully disagree : 10 = fully agree			

Satisfaction with HealthCare team      7.79      7.33  
*0 = fully unsatisfied / 10 = fully satisfied*

### Unmet needs

<u>Unmet Needs</u>	<b>Spain</b>	<b>EUROPE</b>	<u>Satisfaction with treatment:</u>	<b>Spain</b>	<b>EUROPE</b>
A. effic Clinic measured	13.6%	13.9%	A. Satisfied, AND I believe this is		
B. Effic NON Measured sympt	30.7%	25.3%	the best that can be achieved for	37.2%	37.1%
C. reduc Steroids	19.6%	18.8%	B. Satisfied, BUT I believe better		
D. Lower side Eff	31.6%	23.7%	control could be achieved for my	30.8%	30.4%
E. less fatigue	44.1%	53.2%	C. Not satisfied, BUT I believe		
F. LT kidney prot.	20.3%	19.1%	this is the best that can be	17.0%	18.4%
G. Easier to take	3.6%	5.4%	D. Not satisfied AND I believe		
H. Access to existing	3.8%	7.7%	better control could be achieved	15.0%	14.2%
I. Access non Pharma treatm.	42.3%	32.0%			
J. edu & access to support	16.5%	9.5%	n=	559	3503
K. Financial burd	17.2%	19.8%			
L. Other	3.8%	3.5%			
n=	551	3,502			

### Symptoms or Features experienced / Most bothersome

<u>Patient reported Symptoms or features</u>	<b>Spain</b>				<b>Spain</b>	
	<u>Regularly</u> <u>experience</u>	<u>most prevent</u> <u>live to the full</u>	<u>most worry</u> <u>today</u>	<u>most worry</u> <u>long term</u>		
A.None	1.5%	5.5%	1.5%	0.9%	A.None	14.7%
B.Rash	42.1%	10.7%	8.5%	5.2%	B.Rash	10.3%
C.Sun	59.4%	27.3%	17.1%	10.2%	C.Sun	10.5%
D. Ulcers	42.9%	8.8%	4.4%	1.7%	D. Ulcers	13.6%
E.DryEyes	59.9%	11.5%	7.3%	7.9%	E.DryEyes	14.3%
F.dryskin	54.2%	5.8%	3.4%	0.7%	F.dryskin	15.6%
G.Hairloss	56.1%	11.5%	13.5%	9.7%	G.Hairloss	27.5%
H. Joints	77.8%	53.1%	40.3%	32.3%	H. Joints	5.8%
I.Jaccoud	11.3%	6.9%	5.5%	9.5%	I.Jaccoud	4.5%
J.Musclpain/weak	66.6%	37.5%	28.7%	26.8%	J.Musclpain/weak	8.9%
K. Headache	55.0%	22.2%	13.1%	8.6%	K. Headache	6.3%
L.Fatigue	82.7%	59.8%	38.6%	27.8%	L.Fatigue	29.0%
M. Flu-like	30.5%	5.7%	1.9%	1.2%	M. Flu-like	4.2%
N. Shrot Breath	20.4%	5.8%	4.8%	5.7%	N. Shrot Breath	2.4%
O. depres/anxiety	54.0%	19.1%	20.5%	19.2%	O. depres/anxiety	19.7%
P. Heamatologic	31.3%	6.0%	7.5%	10.7%	P. Heamatologic	1.6%
Q. Raynaud	27.2%	6.0%	3.4%	3.3%	Q. Raynaud	5.1%
R. Kidney	15.5%	6.2%	11.9%	28.8%	R. Kidney	2.4%
S. Chestpain	25.8%	5.2%	4.6%	2.2%	S. Chestpain	3.3%
T. Hiugh, Blood Pres	15.3%	3.8%	2.6%	3.3%	T. Hiugh, Blood Pres	2.2%
U. Cardiovasc	6.5%	5.3%	9.6%	26.6%	U. Cardiovasc	2.2%
V. Osteoporosis	15.7%	5.2%	4.8%	10.5%	V. Osteoporosis	3.6%
W. Brainfog	55.6%	14.9%	19.5%	22.6%	W. Brainfog	25.4%
n=	613	582	586	579	n=	552

**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: Spain

For full text european analysis, please refer to:

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