



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

France

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,

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For more information, contact: secretariat@lupus-europe.org



DEMOGRAPHICS:					
Total number of responses	France	EUROPE	Age	France	EUROPE
	564	4525	Up to 25	4.1%	5.5%
			26 to 35	18.8%	15.8%
Gender	France	EUROPE	36 to 45	29.1%	26.9%
Man	3.9%	4.1%	46 to 55	30.9%	28.0%
Woman	95.6%	95.5%	56 to 65	11.0%	16.0%
Other / prefer not to answer	0.5%	0.4%	above 65	5.3%	6.2%
Total	100.0%	100.0%	NA	0.9%	1.5%
			Grand Total	100.0%	100.0%
Diagnosis	France	EUROPE	Diagnosis	France	EUROPE
SLE	91.8%	92.5%	Lupus Nephritis	11.8%	19.5%
Child onset SLE	8.2%	7.5%	APS	23.2%	19.2%
Grand Total	100.0%	100.0%	LN+APS	6.6%	6.2%
			None of the 2	58.4%	55.2%
			Grand Total	100.0%	100.0%
BURDEN					
<u>Lupus under control past3mo</u>	France	EUROPE	<u>Satisfied with current state</u>	France	EUROPE
Yes	56.8%	66.5%	Yes	43.3%	47.6%
No	43.2%	33.5%	No	53.0%	47.4%
n=	549	4360	Prefer not to answer	3.6%	5.0%
			n=	494	3957
<u>Flares over 5 years</u>	France	EUROPE	<u>Burden</u>	France	EUROPE
A. Never	4.0%	7.9%	Overall burden of lupus on life	6.89	6.94
B. Once	13.3%	12.7%	activity of disease itself	6.57	6.63
C. Twice	8.5%	11.0%	physical conseq.of disease	7.44	7.41
D. 3 or 4 times	11.9%	13.3%	side effects of treatment	5.69	6.02
E. Annually	9.8%	9.7%	fatigue	8.26	7.95
F. Several times a year	44.2%	34.8%	Pain	6.68	6.79
G. Don't know	8.3%	10.6%	Psychological impact	6.94	6.99
n=	520	4124	Social impact	6.29	6.48
			Work / education impact	7.17	7.08
			Financial impact	6.06	6.46
<i>0= no burden at all / 10 = extreme burden</i>					
<u>Lupus life Experience:</u>	France	EUROPE			
A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL	11.2%	9.7%			
B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL	10.8%	9.5%			
C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL	11.7%	11.0%			
D. Lupus story of flares and remission, flares are frequent and impact significantly QoL	7.4%	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	27.6%	19.6%			
F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life	10.6%	9.1%			
G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL	11.7%	16.4%			
H. Lupus not very aggressive, even when flaring, can live a normal life	2.9%	3.9%			
I. Lupus rarely flaring. Most of the time, can live a normal life	4.9%	6.5%			
J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL	0.0%	7.0%			
K. Prefer not to answer	1.2%	1.9%			
n=	511	4,057			

Patient Doctor Communication

<u>Most missing</u>	France	EUROPE				
Time	29.4%	31.6%	Doctor takes into account my opinion			
Empathy	14.1%	14.0%	when managing my treatment	7.83	7.44	
Communication within team	18.7%	22.3%	I am a key contributor to Sh. Dec. Mak.			
Acknwoledge the symptoms I mention	27.5%	22.9%	about my treatment mgnt	7.26	6.96	
Personalised info	8.0%	10.6%	I have an active role in controlling my			
lay language	8.0%	6.4%	disease	7.65	7.47	
An invite to ask	5.3%	5.7%	I have a trustful relationship with my			
Answers	6.3%	8.3%	doctor	8.04	7.56	
Consider non measurable	30.5%	25.0%	I say "the truth, all the truth and only the			
What symptoms mean for my life	14.9%	16.7%	truth" to my HCP with regards to my	8.87	8.82	
Clear info on Meds	19.1%	21.2%	I can share all my problems with my			
Certainty I can talk anything	4.6%	4.3%	doctor	7.90	7.71	
Holistic approach	16.0%	17.9%	My doctor takes into account my			
Info on Clinical Trials	21.0%	15.5%	psychological well-being	7.40	6.94	
Nothing	23.3%	23.7%				
Other	2.5%	3.5%				
n=	476	3,841	n=	113	3773	
			0 = fully disagree : 10 = fully agree			

Satisfaction with HealthCare team 7.55 7.33
0 = fully unsatisfied / 10 = fully satisfied

Unmet needs

<u>Unmet Needs</u>	France	EUROPE	<u>Satisfaction with treatment:</u>	France	EUROPE
A. effic Clinic measured	12.4%	13.9%	A. Satisfied, AND I believe this is		
B. Effic NON Measured sympt	25.0%	25.3%	the best that can be achieved for	38.0%	37.1%
C. reduc Steroids	15.7%	18.8%	B. Satisfied, BUT I believe better		
D. Lower side Eff	22.2%	23.7%	control could be achieved for my	25.1%	30.4%
E. less fatigue	67.3%	53.2%	C. Not satisfied, BUT I believe		
F. LT kidney prot.	17.5%	19.1%	this is the best that can be	29.1%	18.4%
G. Easier to take	5.8%	5.4%	D. Not satisfied AND I believe		
H. Access to existing	2.1%	7.7%	better control could be achieved	7.7%	14.2%
I. Access non Pharma treatm.	31.8%	32.0%			
J. edu & access to support	7.5%	9.5%	n=	426	3503
K. Financial burd	17.8%	19.8%			
L. Other	2.1%	3.5%			
n=	428	3,502			

Symptoms or Features experienced / Most bothersome

	France					France	
	<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>		<u>least taken</u> <u>into account</u>	
<u>Patient reported Symptoms or features</u>							
A.None	0.4%	2.1%	2.4%	1.5%	A.None	11.6%	
B.Rash	45.2%	9.4%	9.9%	9.0%	B.Rash	9.6%	
C.Sun	65.3%	30.8%	14.4%	12.4%	C.Sun	17.4%	
D. Ulcers	37.6%	1.5%	1.5%	1.3%	D. Ulcers	7.4%	
E.DryEyes	52.0%	7.9%	6.5%	4.6%	E.DryEyes	12.8%	
F.dryskin	54.8%	2.4%	1.1%	1.5%	F.dryskin	10.3%	
G.Hairloss	50.7%	8.4%	10.8%	9.6%	G.Hairloss	23.0%	
H. Joints	81.6%	50.7%	38.6%	34.3%	H. Joints	11.2%	
I.Jaccoud	11.8%	4.1%	3.9%	6.1%	I.Jaccoud	3.4%	
J.Musclpain/weak	60.5%	31.0%	26.9%	23.6%	J.Musclpain/weak	12.5%	
K. Headache	53.7%	14.8%	10.8%	7.0%	K. Headache	9.8%	
L.Fatigue	92.8%	64.0%	56.9%	46.3%	L.Fatigue	51.0%	
M. Flu-like	24.7%	1.7%	1.3%	1.3%	M. Flu-like	1.8%	
N. Shrot Breath	40.0%	8.1%	8.4%	7.0%	N. Shrot Breath	6.7%	
O. depres/anxiety	50.5%	10.5%	15.3%	13.5%	O. depres/anxiety	16.3%	
P. Heamatologic	21.6%	1.3%	4.5%	7.9%	P. Heamatologic	0.9%	
Q. Raynaud	37.6%	3.6%	3.0%	2.8%	Q. Raynaud	6.5%	
R. Kidney	14.6%	4.5%	10.3%	18.3%	R. Kidney	1.1%	
S. Chestpain	23.7%	3.2%	5.4%	6.8%	S. Chestpain	2.7%	
T. Hiugh, Blood Pres	16.5%	1.1%	3.9%	4.4%	T. Hiugh, Blood Pres	0.9%	
U. Cardiovasc	9.3%	2.4%	5.0%	15.1%	U. Cardiovasc	2.2%	
V. Osteoporosis	13.3%	0.9%	4.3%	7.4%	V. Osteoporosis	2.5%	
W. Brainfog	33.4%	6.2%	10.8%	13.1%	W. Brainfog	15.9%	
n=	473	467	464	458	n=	447	

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: France

For full text european analysis, please refer to:

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