



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

France



Living with lupus in 2020 - Country level data

DATA FOR: **France**

Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

COUNTRY: France

DEMOGRAPHICS:

	<u>France</u>	<u>EUROPE</u>	<u>Age</u>	<u>France</u>	<u>EUROPE</u>
Total number of responses	680	4375	Up to 25	7.1%	6.4%
			26 to 35	19.7%	17.9%
<u>Gender</u>	<u>France</u>	<u>EUROPE</u>	36 to 45	28.4%	27.4%
Man	4.6%	3.7%	46 to 55	26.5%	26.6%
Woman	95.1%	95.6%	56 to 65	12.6%	14.8%
Other / prefer not to answer	0.3%	0.7%	above 65	4.1%	5.1%
Total	100.0%	100.0%	NA	1.6%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>France</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>France</u>	<u>EUROPE</u>
SLE	92.1%	94.4%	Within the year	31.8%	26.5%
Child onset SLE	7.9%	5.6%	1 year	26.0%	21.1%
Grand Total	100.0%	100.0%	2 years	9.6%	11.5%
			3 years	4.3%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>France</u>	<u>EUROPE</u>	4 years	4.5%	4.6%
None	61.0%	53.7%	5 years	4.9%	4.4%
UCTD/MCTD	3.4%	6.7%	6 years	2.5%	2.9%
Sjogren	3.1%	4.7%	7 years	1.9%	2.7%
APS	2.6%	2.4%	8 years	1.9%	2.4%
Other Autoimmune or Rheumatic	11.9%	13.8%	9 years	1.1%	2.3%
Fibromyalgia	5.6%	5.8%	10 to 20 years	7.7%	10.4%
Psychologic or mental disorder	10.1%	8.9%	More than 20 years	3.9%	5.5%
Other prior diagnosis	12.6%	16.5%	Grand Total	100.0%	100.0%
n=	665	4,275	n=	647	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>France</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>France</u>	<u>EUROPE</u>
Basic	1.2%	3.7%	Employed full time	37.1%	34.6%
Secondary	58.0%	53.9%	Employed part time	18.3%	16.5%
Academic	40.7%	42.5%	Self-employed full time	2.1%	3.0%
n=	641	4,150	Self-employed part time	1.2%	2.4%
			Looking for employment	6.2%	5.1%
<u>Economic profile</u>	<u>France</u>	<u>EUROPE</u>	Stopped work for medical reason	16.5%	14.7%
No difficulties paying all bills	42.4%	46.9%	Retired	8.3%	11.6%
Occasional difficulties paying all bills.	30.3%	26.8%	Student	3.9%	4.0%
Often difficulties paying all bills	11.3%	10.4%	No paid employment / Full time home	1.4%	4.7%
Always difficulty paying all bills	6.3%	7.1%	Other / prefer not to answer	5.0%	3.5%
Did not respond	9.7%	8.9%			
n=	680	4375	n=	661	4247
<u>IMPACT ON STUDIES</u>	<u>France</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>France</u>	<u>EUROPE</u>
Chose more relevant studies	3.3%	3.1%	No impact	32.4%	32.5%
could not do what they wanted	7.9%	11.1%	Changed career/ job	18.0%	13.5%
needed special support and received it	3.0%	4.6%	moved to Flexible hours	4.3%	8.1%
needed support but did NOT receive it	2.3%	2.9%	Reduced Work Schedule	20.7%	18.5%
Overall negative effect	10.8%	13.5%	Stopped work, gets social allowances	18.2%	18.5%
Overall positive effect	1.4%	1.4%	Missed promotion opportunities	10.5%	9.5%
No impact	77.9%	69.8%	Employment was terminated	4.5%	8.4%
n=	660	4240	Other negative impact	25.5%	20.8%
			Other positive impact	1.1%	1.8%
			Overall had negative impact	58.1%	57.9%
			n=	627	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>		<u>France</u>	<u>EUROPE</u>	<u>Have children</u>		<u>France</u>	<u>EUROPE</u>
Child/young with family		4.0%	4.5%	None		26.6%	32.8%
Single		20.2%	17.4%	One child		23.0%	23.8%
Married / with partner		65.3%	66.9%	2 or more children		46.5%	38.9%
Divorced		9.1%	9.2%	Child/young living with family		3.9%	4.5%
Widowed		1.4%	2.0%				
	n=	657	4206		n=	666	4288
<u>Would have liked more children</u>		<u>France</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>		<u>France</u>	<u>EUROPE</u>
A. Yes		32.5%	37.6%	A. One miscarriage		23.2%	18.4%
B. No		42.8%	37.7%	B. Some miscarriages		8.5%	8.5%
C. don't know / prefer not to answer		24.7%	24.7%	C. Many miscarriages		2.3%	2.9%
	n (women only) =	600	3,645	D. No miscarriage		65.9%	70.2%
					n (women only) =	598	3,756
<u>Difficulty to cope with Daily activities</u>		<u>France</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>		<u>France</u>	<u>EUROPE</u>
No Problem at all	1	14.7%	16.2%	Less active due to lupus		68.5%	72.6%
	2	31.6%	32.3%	Equally active		18.4%	15.6%
	3	37.3%	34.3%	More active due to lupus		3.6%	3.6%
	4	15.2%	15.4%	I don't know		9.4%	8.1%
Fully Unable	5	1.2%	1.8%				
	n=	659	4226		n=	658	4212
<u>Impact on Sexual/emotional life</u>		<u>France</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>		<u>France</u>	<u>EUROPE</u>
Negative impact		37.6%	38.2%	It created tensions		29.0%	33.2%
Mixed Positive and negative		36.1%	36.2%	It is difficult for me		73.2%	68.4%
No significant impact		24.4%	23.9%	It is difficult for my partner		28.3%	26.7%
Positive impact		2.0%	1.6%	I am concerned for my couple		12.9%	13.2%
	n=	657	4,204	Our relationship ended		17.9%	16.6%
					n=	448	2875



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DISEASE ACTIVITY

<u>Lupus was under control past 3 months</u>	<u>France</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>	<u>France</u>	<u>EUROPE</u>
Yes	76%	72%	1	1.7%	1.6%
No	24%	28%	2	1.8%	2.1%
			3	3.7%	4.4%
n=	670	4347	4	6.7%	5.9%
			5	7.3%	6.1%
			6	9.3%	8.5%
			7	11.8%	9.3%
<u>Average nr of symptoms (list of 23)</u>	<u>France</u>	<u>EUROPE</u>	8	11.8%	10.4%
	8.3	8.8	9	10.4%	10.1%
n=	655	4197	10	9.9%	9.3%
			11	7.5%	8.3%
			12	5.8%	7.0%
<u>Median number of symptoms</u>	<u>France</u>	<u>EUROPE</u>	13	4.4%	5.8%
	8	9	14	3.1%	4.4%
n=	655	4197	15	2.1%	2.7%
			16	1.8%	2.1%
			17	0.5%	1.1%
			18	0.5%	0.4%
			19	0.0%	0.3%
			20	0.0%	0.0%
			n=	655	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	France	
	Regularly experience	Top 3 most bothersome
A. Rash	36%	10%
B. Sun sensitivity	76%	29%
C. Mouth ulcers	28%	1%
D. Dryness in the mouth or eyes	50%	9%
E. Dryness of the skin	52%	3%
F. Hair loss	54%	13%
G. Pain / swelling in joints	79%	57%
H. Jaccoud (hand deformation) or tendons a	14%	4%
I. Muscle Pain/Weakness	63%	34%
J. Headaches or migraine	52%	18%
K. Fatigue and weakness	88%	60%
L. Flu-like symptoms/Fevers	19%	1%
M. Shortness of breath	35%	5%
N. Depression or Anxiety	44%	16%
O. Haematologic problems incl. anemia	20%	2%
P. Poor circulation or Raynauds	51%	9%
Q. Kidney problems	15%	8%
R. Chest pain	23%	3%
S. High Blood pressure	14%	3%
T. Stroke, mini-stroke, Blood clots	10%	4%
U. Osteoporosis	11%	2%
n=	680	643

Patient reported Symptoms or features	EUROPE	
	Regularly experience	Top 3 most bothersome
A. Rash	40%	9%
B. Sun sensitivity	69%	23%
C. Mouth ulcers	35%	3%
D. Dryness in the mouth or eyes	55%	9%
E. Dryness of the skin	57%	4%
F. Hair loss	53%	14%
G. Pain / swelling in joints	77%	49%
H. Jaccoud (hand deformation) or tendor	14%	4%
I. Muscle Pain/Weakness	68%	33%
J. Headaches or migraine	51%	17%
K. Fatigue and weakness	85%	55%
L. Flu-like symptoms/Fevers	28%	4%
M. Shortness of breath	32%	6%
N. Depression or Anxiety	44%	17%
O. Haematologic problems incl. anemia	27%	4%
P. Poor circulation or Raynauds	45%	8%
Q. Kidney problems	20%	11%
R. Chest pain	24%	4%
S. High Blood pressure	23%	4%
T. Stroke, mini-stroke, Blood clots	9%	4%
U. Osteoporosis	19%	5%
n=	4375	4084



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MEDICATION

	<u>France</u>	<u>EUROPE</u>		<u>France</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	4.3	5.2	<u>Median number of medication (from list of 16)</u>	4	5
n=	634	4099	n=	634	4099
<u>Number of medications (list of 16)</u>	<u>France</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>France</u>	<u>EUROPE</u>
1	8.2%	5.4%	Non Steroids Anti-Inflammatory	22.7%	32.9%
2	16.7%	9.0%	Antimalarials	77.8%	75.0%
3	17.5%	12.5%	Oral Steroids	42.9%	52.4%
4	13.9%	14.1%	Immunosuppressants	30.6%	39.8%
5	15.3%	14.8%	Biologics	8.0%	10.9%
6	11.4%	13.9%	Painkillers	48.1%	50.1%
7	9.0%	11.8%	Antidepressant	17.5%	17.0%
8	3.5%	9.0%	Anxiolytic	17.4%	11.7%
9	2.4%	5.1%	Anticoagulants	17.8%	16.6%
10	1.1%	2.5%	Thyroid medication	9.0%	14.8%
11	0.5%	1.1%	Blood circulation and heart	13.7%	23.3%
12	0.6%	0.4%	Stomach protection	33.3%	47.0%
13	0.0%	0.2%	Statins	3.3%	5.9%
n=	634	4099	Calcium	15.5%	29.7%
			Vitamin D	55.4%	68.4%
			Vitamins (excl.D) / mineral complements	17.2%	25.4%



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ACCESS / Quality of life (scale of 1 to 5)

<u>I have appropriate access to</u>	<u>France</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>France</u>	<u>EUROPE</u>	
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)			
Experienced lupus doctors	4.19	3.81	Mobility	2.19	2.22	
Multidisciplinary team	3.48	3.28	Self care	1.67	1.71	
Specialised nurses that know lupus	2.73	2.92	Daily Activities	2.57	2.54	
Prescribed medication	4.32	4.08	Pain or discomfort	3.14	3.14	
Affordable treatments	4.31	3.77	Anxiety or depression	2.98	2.96	
Social support and benefits	2.53	2.78	Average	2.51	2.51	
Physiotherapy, Rehab, Occupational Thera	2.35	2.77				
Professional psychological support	2.45	2.68				
	n min	434	3126	n min	652	4196
	n max	599	3842	n max	660	4240
<u>Worry about lupus progressing?</u>	<u>France</u>	<u>EUROPE</u>				
Very Low (1-2)	3.9%	3.6%				
Low (3-4)	11.2%	9.3%				
Mid (5-6)	32.8%	24.5%				
High (7-8)	40.8%	41.0%				
Very high (9-10)	11.3%	21.6%				
	n=	635	4042			



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Impact of lupus not being under control over past 3 months

% of Health Related QoL Maintained vs 100% = FULL HEALTH/ABILITY TO PERFORM

	<u>France</u>			<u>EUROPE</u>		
	<u>lupus under</u>	<u>not under</u>		<u>lupus under</u>	<u>not under</u>	
	<u>control</u>	<u>control</u>		<u>control</u>	<u>control</u>	
Mobility	73%	61%	Mobility	73%	59%	
Self care	86%	74%	Self care	86%	73%	
Daily Activities	64%	50%	Daily Activities	66%	51%	
Pain or discomfort	50%	36%	Pain or discomfort	51%	35%	
Anxiety or depression	52%	46%	Anxiety or depression	54%	44%	
Average	65%	54%	Average	66%	52%	
	n min	491	158	n min	3011	1179
	n max	498	161	n max	3042	1194

	<u>France</u>			<u>EUROPE</u>		
	<u>lupus under</u>	<u>not under</u>		<u>lupus under</u>	<u>not under</u>	
	<u>control</u>	<u>control</u>		<u>control</u>	<u>control</u>	
<u>More or less active than others of same age</u>			<u>More or less active than others of same age</u>			
Less active due to lupus	65.1%	78.9%	Less active due to lupus	68.6%	83.0%	
Equally active	20.8%	11.2%	Equally active	18.8%	7.6%	
More active due to lupus	3.8%	3.1%	More active due to lupus	4.0%	2.7%	
I don't know	10.3%	6.8%	I don't know	8.7%	6.7%	
	n=	495	161	n=	3018	1189

	<u>France</u>			<u>EUROPE</u>		
	<u>lupus under</u>	<u>not under</u>		<u>lupus under</u>	<u>not under</u>	
	<u>control</u>	<u>control</u>		<u>control</u>	<u>control</u>	
<u>Impact on Sexual/emotional life</u>			<u>Impact on Sexual/emotional life</u>			
Negative impact	34.3%	47.2%	Negative impact	34.0%	49.0%	
Mixed + and -	35.9%	37.1%	Mixed + and -	36.4%	35.7%	
No significant impact	27.8%	13.8%	No significant impact	27.8%	14.1%	
Positive impact	2.0%	1.9%	Positive impact	1.8%	1.2%	
	n=	496	159	n=	3018	1181



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IMPACT OF A PROMPT DIAGNOSIS

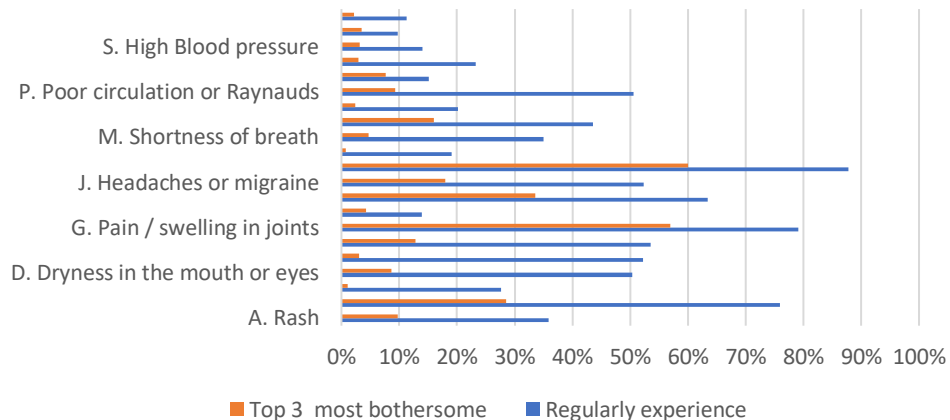
% of Health Related QoL Maintained vs 100% = FULL HEALTH/ABILITY TO PERFORM

	<u>France</u>			<u>EUROPE</u>	
	<u>Diagnosed within 2 years</u>	<u>Diagnosed after more than 5 years</u>		<u>Diagnosed within 2 years</u>	<u>Diagnosed after more than 5 years</u>
Mobility	75%	62%	Mobility	75%	62%
Self care	87%	75%	Self care	86%	76%
Daily Activities	65%	53%	Daily Activities	67%	53%
Pain or discomfort	50%	41%	Pain or discomfort	52%	39%
Anxiety or depression	53%	46%	Anxiety or depression	52%	49%
Average	66%	55%	Average	66%	56%
	Difference	-11%		Difference	-10%
	of which - explained by age (*)	-2%		of which - explained by age	-3%
	n min	364		n min	1926
	n max	369		n max	1951
	average age:	41.3			41.2
					49.0

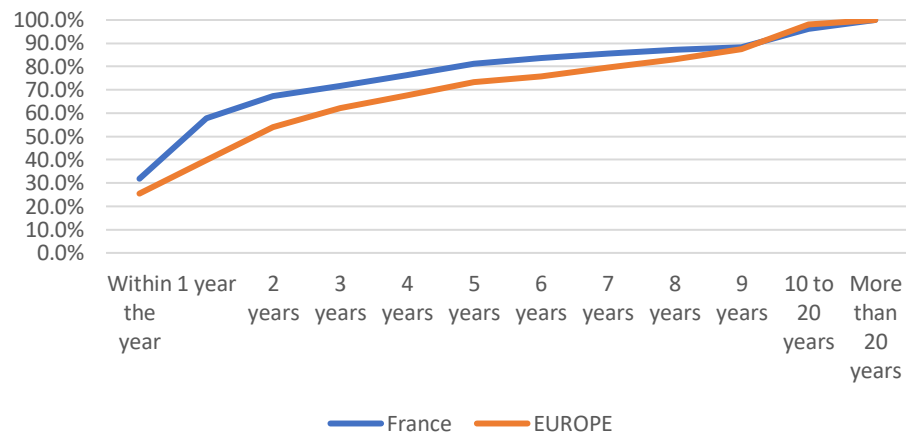
(*) in our overall study, we found that from age 28 to age 63 HrQoL drops from 69.1% to 56.0% i.e. 3.7% per decade

DATA FOR: 0

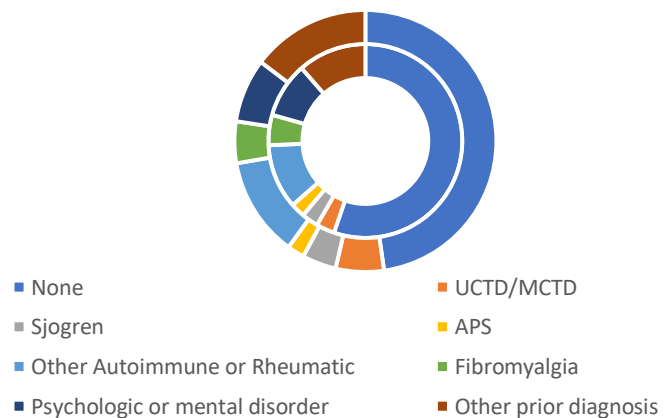
Patient reported symptoms and features



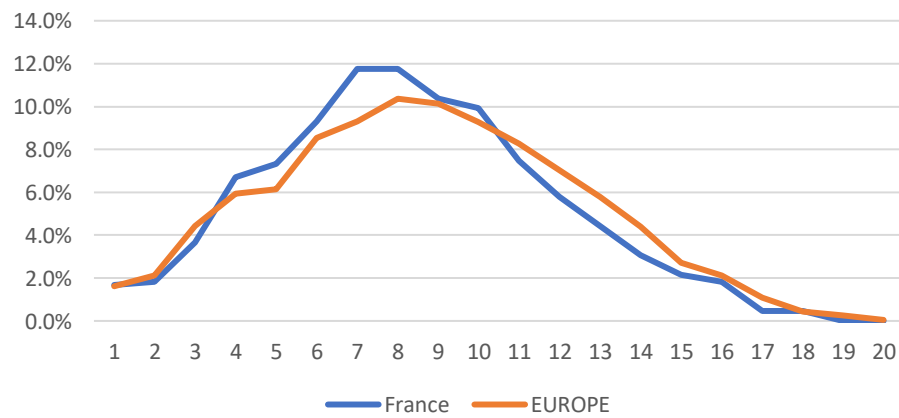
Patient time to diagnosis



Prior Diagnosis - Country (inside) vs. Europe (outside)



Number of symptoms experienced





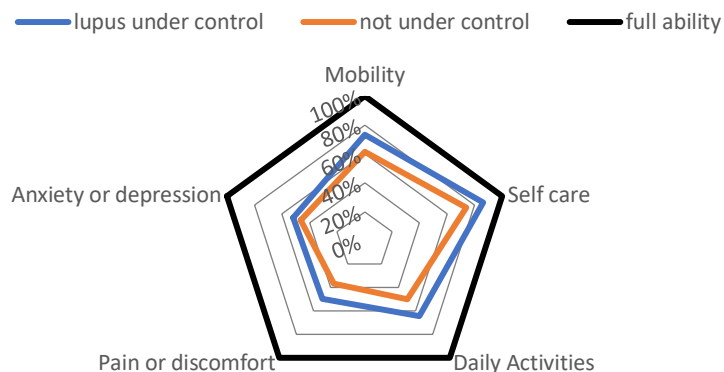
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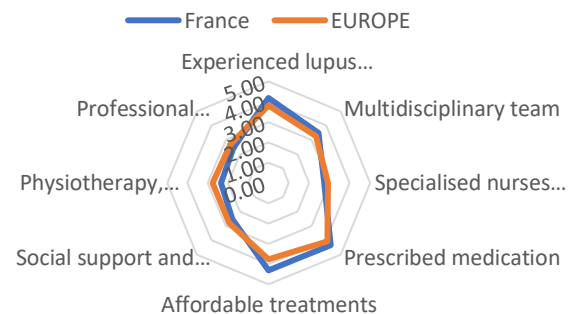
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

DATA FOR: 0

% residual HRQoL



Access - I have appropriate access to...



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DATA FOR: 0

For full text european analysis, please refer to:

Cornet A, Andersen J, Myllys K, et al. Living with systemic lupus erythematosus in 2020: a European patient survey. Lupus Science & Medicine 2021;8:e000469. doi:10.1136/lupus-2020-000469

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