



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Spain



Living with lupus in 2020 - Country level data

DATA FOR: **Spain**

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

COUNTRY: Spain

DEMOGRAPHICS:

	<u>Spain</u>	<u>EUROPE</u>	<u>Age</u>	<u>Spain</u>	<u>EUROPE</u>
Total number of responses	284	4375	Up to 25	5.3%	6.4%
			26 to 35	14.4%	17.9%
<u>Gender</u>	<u>Spain</u>	<u>EUROPE</u>	36 to 45	31.7%	27.4%
Man	3.9%	3.7%	46 to 55	32.0%	26.6%
Woman	93.7%	95.6%	56 to 65	12.3%	14.8%
Other / prefer not to answer	2.5%	0.7%	above 65	3.2%	5.1%
Total	100.0%	100.0%	NA	1.1%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Spain</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Spain</u>	<u>EUROPE</u>
SLE	94.4%	94.4%	Within the year	24.5%	26.5%
Child onset SLE	5.6%	5.6%	1 year	20.2%	21.1%
Grand Total	100.0%	100.0%	2 years	17.1%	11.5%
			3 years	5.8%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Spain</u>	<u>EUROPE</u>	4 years	6.6%	4.6%
None	47.9%	53.7%	5 years	4.3%	4.4%
UCTD/MCTD	2.8%	6.7%	6 years	2.3%	2.9%
Sjogren	5.3%	4.7%	7 years	2.3%	2.7%
APS	3.2%	2.4%	8 years	3.5%	2.4%
Other Autoimmune or Rheumatic	14.8%	13.8%	9 years	1.9%	2.3%
Fibromyalgia	4.6%	5.8%	10 to 20 years	8.6%	10.4%
Psychologic or mental disorder	9.9%	8.9%	More than 20 years	2.7%	5.5%
Other prior diagnosis	22.5%	16.5%	Grand Total	100.0%	100.0%
n=	269	4,275	n=	257	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Spain</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Spain</u>	<u>EUROPE</u>
Basic	12.5%	3.7%	Employed full time	33.1%	34.6%
Secondary	49.8%	53.9%	Employed part time	12.0%	16.5%
Academic	37.6%	42.5%	Self-employed full time	4.7%	3.0%
n=	271	4,150	Self-employed part time	0.0%	2.4%
			Looking for employment	10.2%	5.1%
<u>Economic profile</u>	<u>Spain</u>	<u>EUROPE</u>	Stopped work for medical reason	14.5%	14.7%
No difficulties paying all bills	50.0%	46.9%	Retired	12.0%	11.6%
Occasional difficulties paying all bills.	22.2%	26.8%	Student	4.0%	4.0%
Often difficulties paying all bills	9.5%	10.4%	No paid employment / Full time home	4.7%	4.7%
Always difficulty paying all bills	10.9%	7.1%	Other / prefer not to answer	4.7%	3.5%
Did not respond	7.4%	8.9%			
n=	284	4375	n=	275	4247
<u>IMPACT ON STUDIES</u>	<u>Spain</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Spain</u>	<u>EUROPE</u>
Chose more relevant studies	3.7%	3.1%	No impact	45.0%	32.5%
could not do what they wanted	9.2%	11.1%	Changed career/ job	7.1%	13.5%
needed special support and received it	1.5%	4.6%	moved to Flexible hours	7.1%	8.1%
needed support but did NOT receive it	3.3%	2.9%	Reduced Work Schedule	6.3%	18.5%
Overall negative effect	14.3%	13.5%	Stopped work, gets social allowances	13.9%	18.5%
Overall positive effect	1.5%	1.4%	Missed promotion opportunities	9.2%	9.5%
No impact	71.1%	69.8%	Employment was terminated	8.4%	8.4%
			Other negative impact	23.1%	20.8%
n=	273	4240	Other positive impact	2.9%	1.8%
			Overall had negative impact	47.9%	57.9%
			n=	238	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Spain</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Spain</u>	<u>EUROPE</u>
Child/young with family	4.1%	4.5%	None	34.4%	32.8%
Single	17.0%	17.4%	One child	26.1%	23.8%
Married / with partner	67.4%	66.9%	2 or more children	35.5%	38.9%
Divorced	10.0%	9.2%	Child/young living with family	4.0%	4.5%
Widowed	1.5%	2.0%			
n=	270	4206	n=	276	4288
<u>Would have liked more children</u>	<u>Spain</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Spain</u>	<u>EUROPE</u>
A. Yes	46.2%	37.6%	A. One miscarriage	15.0%	18.4%
B. No	30.7%	37.7%	B. Some miscarriages	5.3%	8.5%
C. don't know / prefer not to answer	23.1%	24.7%	C. Many miscarriages	1.2%	2.9%
n (women only) =	199	3,645	D. No miscarriage	78.5%	70.2%
			n (women only) =	246	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Spain</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Spain</u>	<u>EUROPE</u>
No Problem at all 1	18.5%	16.2%	Less active due to lupus	72.2%	72.6%
2	30.9%	32.3%	Equally active	14.3%	15.6%
3	33.8%	34.3%	More active due to lupus	4.8%	3.6%
4	14.2%	15.4%	I don't know	8.8%	8.1%
Fully Unable 5	2.5%	1.8%			
n=	275	4226	n=	273	4212
<u>Impact on Sexual/emotional life</u>	<u>Spain</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Spain</u>	<u>EUROPE</u>
Negative impact	40.9%	38.2%	It created tensions	36.0%	33.2%
Mixed Positive and negative	32.8%	36.2%	It is difficult for me	67.7%	68.4%
No significant impact	26.3%	23.9%	It is difficult for my partner	26.5%	26.7%
Positive impact	0.0%	1.6%	I am concerned for my couple	15.3%	13.2%
n=	274	4,204	Our relationship ended	12.2%	16.6%
			n=	189	2875



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DISEASE ACTIVITY

<u>Lupus was under control past 3 months</u>	<u>Spain</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>	<u>Spain</u>	<u>EUROPE</u>
Yes	77%	72%	1	1.5%	1.6%
No	23%	28%	2	1.1%	2.1%
			3	2.9%	4.4%
n=	281	4347	4	5.9%	5.9%
			5	9.2%	6.1%
			6	10.3%	8.5%
			7	9.9%	9.3%
<u>Average nr of symptoms (list of 23)</u>	<u>Spain</u>	<u>EUROPE</u>	8	11.0%	10.4%
	8.5	8.8	9	10.7%	10.1%
n=	272	4197	10	8.8%	9.3%
			11	8.5%	8.3%
			12	8.8%	7.0%
<u>Median number of symptoms</u>	<u>Spain</u>	<u>EUROPE</u>	13	4.0%	5.8%
	8	9	14	1.5%	4.4%
n=	272	4197	15	2.2%	2.7%
			16	1.5%	2.1%
			17	1.5%	1.1%
			18	0.7%	0.4%
			19	0.0%	0.3%
			20	0.0%	0.0%
			n=	272	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Spain	
	Regularly experience	Top 3 most bothersome
A. Rash	30%	5%
B. Sun sensitivity	69%	25%
C. Mouth ulcers	42%	6%
D. Dryness in the mouth or eyes	53%	9%
E. Dryness of the skin	55%	2%
F. Hair loss	55%	9%
G. Pain / swelling in joints	82%	56%
H. Jaccoud (hand deformation) or tendons a	16%	2%
I. Muscle Pain/Weakness	72%	38%
J. Headaches or migraine	49%	18%
K. Fatigue and weakness	78%	39%
L. Flu-like symptoms/Fevers	24%	4%
M. Shortness of breath	18%	6%
N. Depression or Anxiety	46%	17%
O. Haematologic problems incl. anemia	35%	5%
P. Poor circulation or Raynauds	44%	11%
Q. Kidney problems	22%	13%
R. Chest pain	23%	5%
S. High Blood pressure	17%	3%
T. Stroke, mini-stroke, Blood clots	6%	5%
U. Osteoporosis	17%	7%
n=	284	263

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>Spain</u>	<u>EUROPE</u>		<u>Spain</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	5.4	5.2	<u>Median number of medication (from list of 16)</u>	5	5
n=	261	4099	n=	261	4099
<u>Number of medications (list of 16)</u>	<u>Spain</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Spain</u>	<u>EUROPE</u>
1	4.2%	5.4%	Non Steroids Anti-Inflammatory	43.3%	32.9%
2	9.6%	9.0%	Antimalarials	80.8%	75.0%
3	10.7%	12.5%	Oral Steroids	51.3%	52.4%
4	13.8%	14.1%	Immunosuppressants	41.8%	39.8%
5	13.0%	14.8%	Biologics	15.3%	10.9%
6	12.6%	13.9%	Painkillers	51.7%	50.1%
7	12.6%	11.8%	Antidepressant	19.5%	17.0%
8	11.9%	9.0%	Anxiolytic	26.1%	11.7%
9	6.9%	5.1%	Anticoagulants	18.8%	16.6%
10	3.1%	2.5%	Thyroid medication	12.3%	14.8%
11	1.5%	1.1%	Blood circulation and heart	18.0%	23.3%
12	0.0%	0.4%	Stomach protection	57.5%	47.0%
13	0.0%	0.2%	Statins	4.6%	5.9%
n=	261	4099	Calcium	33.3%	29.7%
			Vitamin D	60.2%	68.4%
			Vitamins (excl.D) / mineral complements	10.3%	25.4%



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

<u>I have appropriate access to</u>	<u>Spain</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Spain</u>	<u>EUROPE</u>	
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)			
Experienced lupus doctors	4.02	3.81	Mobility	2.02	2.22	
Multidisciplinary team	3.51	3.28	Self care	1.60	1.71	
Specialised nurses that know lupus	2.71	2.92	Daily Activities	2.51	2.54	
Prescribed medication	4.53	4.08	Pain or discomfort	3.23	3.14	
Affordable treatments	4.20	3.77	Anxiety or depression	3.04	2.96	
Social support and benefits	2.63	2.78	Average	2.48	2.51	
Physiotherapy, Rehab, Occupational Thera	2.30	2.77				
Professional psychological support	2.75	2.68				
	n min	212	3126	n min	273	4196
	n max	241	3842	n max	276	4240
<u>Worry about lupus progressing?</u>	<u>Spain</u>	<u>EUROPE</u>				
Very Low (1-2)	2.7%	3.6%				
Low (3-4)	5.5%	9.3%				
Mid (5-6)	25.0%	24.5%				
High (7-8)	39.8%	41.0%				
Very high (9-10)	27.0%	21.6%				
	n=	256	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>Spain</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	77%	67%	Mobility	73%	59%	
Self care	87%	80%	Self care	86%	73%	
Daily Activities	65%	53%	Daily Activities	66%	51%	
Pain or discomfort	46%	37%	Pain or discomfort	51%	35%	
Anxiety or depression	53%	36%	Anxiety or depression	54%	44%	
Average	65%	54%	Average	66%	52%	
	n min	210	62	n min	3011	1179
	n max	211	64	n max	3042	1194

	<u>Spain</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	69.9%	79.4%	Less active due to lupus	68.6%	83.0%	
Equally active	16.3%	7.9%	Equally active	18.8%	7.6%	
More active due to lupus	4.8%	4.8%	More active due to lupus	4.0%	2.7%	
I don't know	9.1%	7.9%	I don't know	8.7%	6.7%	
	n=	209	63	n=	3018	1189

	<u>Spain</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	38.1%	50.8%	Negative impact	34.0%	49.0%	
Mixed + and -	32.9%	33.3%	Mixed + and -	36.4%	35.7%	
No significant impact	29.0%	15.9%	No significant impact	27.8%	14.1%	
Positive impact	0.0%	0.0%	Positive impact	1.8%	1.2%	
	n=	210	63	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>Spain</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	80%	67%	Mobility	75%	62%
Self care	89%	79%	Self care	86%	76%
Daily Activities	67%	53%	Daily Activities	67%	53%
Pain or discomfort	49%	35%	Pain or discomfort	52%	39%
Anxiety or depression	52%	42%	Anxiety or depression	52%	49%
Average	67%	55%	Average	66%	56%
	Difference	-12%		Difference	-10%
	of which - explained by age (*)	-2%		of which - explained by age	-3%
	n min	113		n min	1926
	n max	114		n max	1951
	average age:	42.8			41.2
		65			1239
		66			1249
		48.6			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



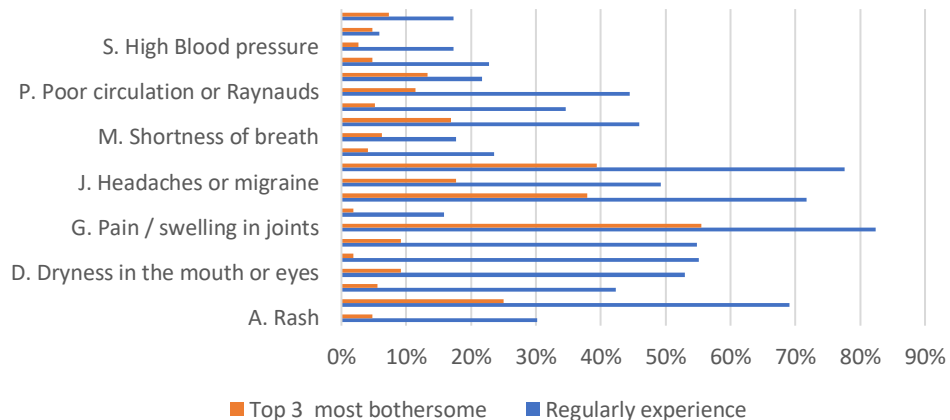
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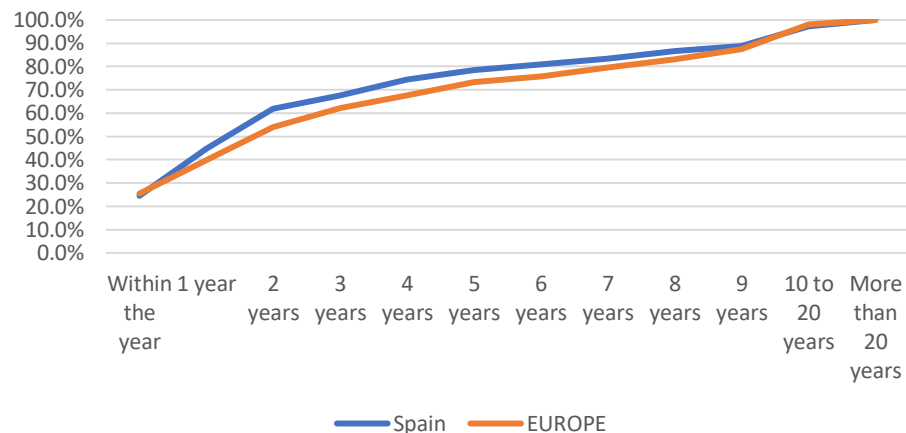
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

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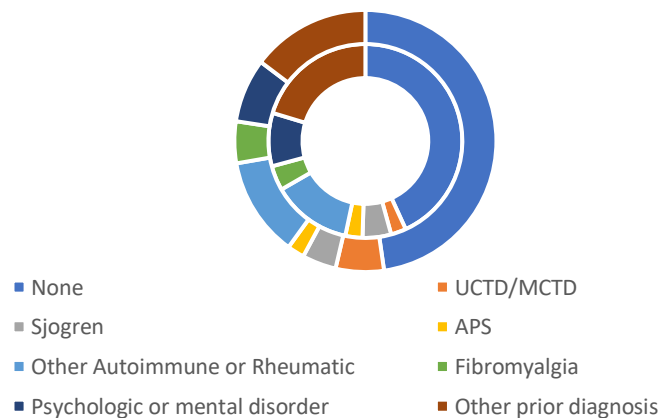
Patient reported symptoms and features



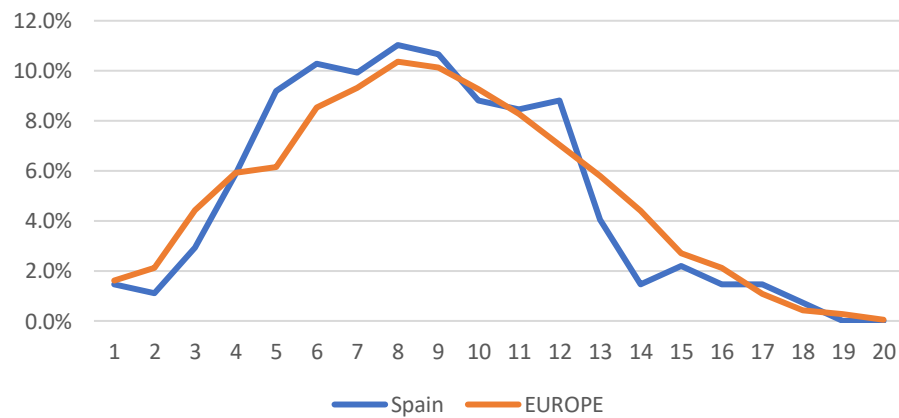
Patient time to diagnosis



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



Number of symptoms experienced





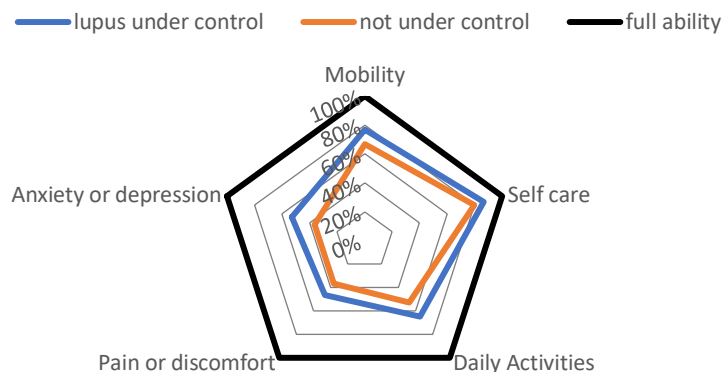
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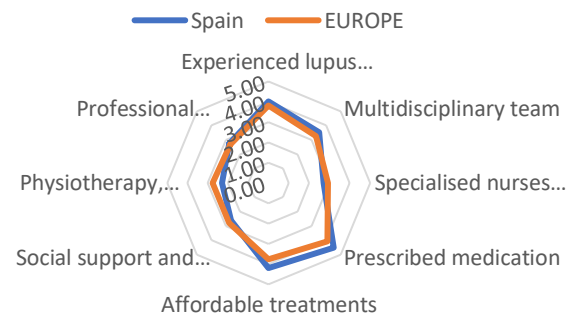
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

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

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