



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Portugal



Living with lupus in 2020 - Country level data

DATA FOR: **Portugal**

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

COUNTRY: Portugal

DEMOGRAPHICS:

	<u>Portugal</u>	<u>EUROPE</u>	<u>Age</u>	<u>Portugal</u>	<u>EUROPE</u>
Total number of responses	195	4375	Up to 25	4.1%	6.4%
			26 to 35	16.4%	17.9%
<u>Gender</u>	<u>Portugal</u>	<u>EUROPE</u>	36 to 45	39.0%	27.4%
Man	3.6%	3.7%	46 to 55	27.7%	26.6%
Woman	96.4%	95.6%	56 to 65	9.7%	14.8%
Other / prefer not to answer	0.0%	0.7%	above 65	2.6%	5.1%
Total	100.0%	100.0%	NA	0.5%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Portugal</u>	<u>EUROPE</u>
SLE	95.4%	94.4%	Within the year	27.8%	26.5%
Child onset SLE	4.6%	5.6%	1 year	29.4%	21.1%
Grand Total	100.0%	100.0%	2 years	9.6%	11.5%
			3 years	7.0%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Portugal</u>	<u>EUROPE</u>	4 years	1.6%	4.6%
None	57.4%	53.7%	5 years	4.8%	4.4%
UCTD/MCTD	1.0%	6.7%	6 years	3.7%	2.9%
Sjogren	1.5%	4.7%	7 years	3.2%	2.7%
APS	1.5%	2.4%	8 years	1.1%	2.4%
Other Autoimmune or Rheumatic	17.9%	13.8%	9 years	2.7%	2.3%
Fibromyalgia	4.6%	5.8%	10 to 20 years	7.0%	10.4%
Psychologic or mental disorder	6.7%	8.9%	More than 20 years	2.1%	5.5%
Other prior diagnosis	12.8%	16.5%	Grand Total	100.0%	100.0%
n=	189	4,275	n=	187	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Portugal</u>	<u>EUROPE</u>
Basic	2.7%	3.7%	Employed full time	56.6%	34.6%
Secondary	43.1%	53.9%	Employed part time	3.7%	16.5%
Academic	54.3%	42.5%	Self-employed full time	6.9%	3.0%
n=	188	4,150	Self-employed part time	1.6%	2.4%
			Looking for employment	7.9%	5.1%
<u>Economic profile</u>	<u>Portugal</u>	<u>EUROPE</u>	Stopped work for medical reason	8.5%	14.7%
No difficulties paying all bills	41.0%	46.9%	Retired	6.9%	11.6%
Occasional difficulties paying all bills.	34.4%	26.8%	Student	2.1%	4.0%
Often difficulties paying all bills	8.7%	10.4%	No paid employment / Full time home	1.6%	4.7%
Always difficulty paying all bills	9.7%	7.1%	Other / prefer not to answer	4.2%	3.5%
Did not respond	6.2%	8.9%	n=	189	4247
n=	195	4375			
<u>IMPACT ON STUDIES</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Portugal</u>	<u>EUROPE</u>
Chose more relevant studies	1.6%	3.1%	No impact	41.6%	32.5%
could not do what they wanted	8.5%	11.1%	Changed career/ job	11.9%	13.5%
needed special support and received it	2.1%	4.6%	moved to Flexible hours	9.2%	8.1%
needed support but did NOT receive it	2.6%	2.9%	Reduced Work Schedule	4.9%	18.5%
Overall negative effect	13.2%	13.5%	Stopped work, gets social allowances	10.3%	18.5%
Overall positive effect	1.1%	1.4%	Missed promotion opportunities	11.9%	9.5%
No impact	73.5%	69.8%	Employment was terminated	5.4%	8.4%
n=	189	4240	Other negative impact	28.1%	20.8%
			Other positive impact	0.5%	1.8%
			Overall had negative impact	47.0%	57.9%
			n=	185	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Portugal</u>	<u>EUROPE</u>
Child/young with family	1.6%	4.5%	None	36.0%	32.8%
Single	19.5%	17.4%	One child	31.2%	23.8%
Married / with partner	66.5%	66.9%	2 or more children	31.2%	38.9%
Divorced	9.2%	9.2%	Child/young living with family	1.6%	4.5%
Widowed	3.2%	2.0%			
n=	185	4206	n=	189	4288
<u>Would have liked more children</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Portugal</u>	<u>EUROPE</u>
A. Yes	38.5%	37.6%	A. One miscarriage	15.8%	18.4%
B. No	42.0%	37.7%	B. Some miscarriages	9.0%	8.5%
C. don't know / prefer not to answer	19.5%	24.7%	C. Many miscarriages	1.7%	2.9%
n (women only) =	174	3,645	D. No miscarriage	73.4%	70.2%
			n (women only) =	177	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Portugal</u>	<u>EUROPE</u>
No Problem at all 1	20.9%	16.2%	Less active due to lupus	67.6%	72.6%
2	36.9%	32.3%	Equally active	23.9%	15.6%
3	33.2%	34.3%	More active due to lupus	2.1%	3.6%
4	9.1%	15.4%	I don't know	6.4%	8.1%
Fully Unable 5	0.0%	1.8%			
n=	187	4226	n=	188	4212
<u>Impact on Sexual/emotional life</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Portugal</u>	<u>EUROPE</u>
Negative impact	33.9%	38.2%	It created tensions	35.7%	33.2%
Mixed Positive and negative	38.7%	36.2%	It is difficult for me	66.7%	68.4%
No significant impact	25.8%	23.9%	It is difficult for my partner	9.5%	26.7%
Positive impact	1.6%	1.6%	I am concerned for my couple	10.3%	13.2%
n=	186	4,204	Our relationship ended	15.1%	16.6%
			n=	126	2875



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DISEASE ACTIVITY							
<u>Lupus was under control past 3 months</u>		<u>Portugal</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>		<u>Portugal</u>	<u>EUROPE</u>
Yes		73%	72%	1		3.2%	1.6%
No		27%	28%	2		2.7%	2.1%
	n=	192	4347	3		5.9%	4.4%
				4		6.4%	5.9%
				5		4.8%	6.1%
				6		10.7%	8.5%
				7		11.2%	9.3%
<u>Average nr of symptoms (list of 23)</u>		<u>Portugal</u>	<u>EUROPE</u>	8		8.6%	10.4%
	n=	8.2	8.8	9		10.7%	10.1%
		187	4197	10		7.5%	9.3%
				11		8.6%	8.3%
				12		5.3%	7.0%
<u>Median number of symptoms</u>		<u>Portugal</u>	<u>EUROPE</u>	13		8.6%	5.8%
	n=	8	9	14		2.1%	4.4%
		187	4197	15		1.6%	2.7%
				16		0.5%	2.1%
				17		1.6%	1.1%
				18		0.0%	0.4%
				19		0.0%	0.3%
				20		0.0%	0.0%
				n=		187	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Portugal	
	Regularly experience	Top 3 most bothersome
A. Rash	34%	11%
B. Sun sensitivity	66%	22%
C. Mouth ulcers	35%	6%
D. Dryness in the mouth or eyes	45%	3%
E. Dryness of the skin	46%	1%
F. Hair loss	60%	18%
G. Pain / swelling in joints	81%	50%
H. Jaccoud (hand deformation) or tendons a	28%	9%
I. Muscle Pain/Weakness	62%	34%
J. Headaches or migraine	45%	17%
K. Fatigue and weakness	78%	45%
L. Flu-like symptoms/Fevers	18%	1%
M. Shortness of breath	15%	2%
N. Depression or Anxiety	50%	20%
O. Haematologic problems incl. anemia	23%	5%
P. Poor circulation or Raynauds	43%	9%
Q. Kidney problems	20%	12%
R. Chest pain	16%	2%
S. High Blood pressure	20%	3%
T. Stroke, mini-stroke, Blood clots	14%	6%
U. Osteoporosis	19%	8%
n=	195	178

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>Portugal</u>	<u>EUROPE</u>		<u>Portugal</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	5.5	5.2	<u>Median number of medication (from list of 16)</u>	5	5
n=	179	4099	n=	179	4099
<u>Number of medications (list of 16)</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Portugal</u>	<u>EUROPE</u>
1	5.6%	5.4%	Non Steroids Anti-Inflammatory	44.1%	32.9%
2	6.7%	9.0%	Antimalarials	74.3%	75.0%
3	10.6%	12.5%	Oral Steroids	69.8%	52.4%
4	14.5%	14.1%	Immunosuppressants	41.9%	39.8%
5	14.0%	14.8%	Biologics	9.5%	10.9%
6	14.0%	13.9%	Painkillers	46.9%	50.1%
7	11.7%	11.8%	Antidepressant	30.2%	17.0%
8	11.7%	9.0%	Anxiolytic	27.9%	11.7%
9	6.7%	5.1%	Anticoagulants	21.8%	16.6%
10	1.7%	2.5%	Thyroid medication	7.8%	14.8%
11	2.2%	1.1%	Blood circulation and heart	18.4%	23.3%
12	0.0%	0.4%	Stomach protection	50.8%	47.0%
13	0.6%	0.2%	Statins	4.5%	5.9%
n=	179	4099	Calcium	30.2%	29.7%
			Vitamin D	59.2%	68.4%
			Vitamins (excl.D) / mineral complements	10.1%	25.4%



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

<u>I have appropriate access to</u>	<u>Portugal</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Portugal</u>	<u>EUROPE</u>
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)		
Experienced lupus doctors	3.97	3.81	Mobility	2.25	2.22
Multidisciplinary team	3.38	3.28	Self care	1.74	1.71
Specialised nurses that know lupus	2.84	2.92	Daily Activities	2.30	2.54
Prescribed medication	4.41	4.08	Pain or discomfort	3.23	3.14
Affordable treatments	3.75	3.77	Anxiety or depression	3.20	2.96
Social support and benefits	2.78	2.78	Average	2.54	2.51
Physiotherapy, Rehab, Occupational Thera	2.55	2.77			
Professional psychological support	2.67	2.68			
n min	119	3126	n min	186	4196
n max	172	3842	n max	188	4240
<u>Worry about lupus progressing?</u>	<u>Portugal</u>	<u>EUROPE</u>			
Very Low (1-2)	1.1%	3.6%			
Low (3-4)	5.0%	9.3%			
Mid (5-6)	21.8%	24.5%			
High (7-8)	44.7%	41.0%			
Very high (9-10)	27.4%	21.6%			
n=	179	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>Portugal</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	72%	60%	Mobility	73%	59%	
Self care	85%	72%	Self care	86%	73%	
Daily Activities	70%	59%	Daily Activities	66%	51%	
Pain or discomfort	48%	35%	Pain or discomfort	51%	35%	
Anxiety or depression	48%	38%	Anxiety or depression	54%	44%	
Average	65%	53%	Average	66%	52%	
	n min	137	49	n min	3011	1179
	n max	138	50	n max	3042	1194

	<u>Portugal</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	63.8%	78.0%	Less active due to lupus	68.6%	83.0%	
Equally active	28.3%	12.0%	Equally active	18.8%	7.6%	
More active due to lupus	2.9%	0.0%	More active due to lupus	4.0%	2.7%	
I don't know	5.1%	10.0%	I don't know	8.7%	6.7%	
	n=	138	50	n=	3018	1189

	<u>Portugal</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	31.4%	40.8%	Negative impact	34.0%	49.0%	
Mixed + and -	36.5%	44.9%	Mixed + and -	36.4%	35.7%	
No significant impact	30.7%	12.2%	No significant impact	27.8%	14.1%	
Positive impact	1.5%	2.0%	Positive impact	1.8%	1.2%	
	n=	137	49	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>Portugal</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	70%	63%	Mobility	75%	62%
Self care	83%	76%	Self care	86%	76%
Daily Activities	71%	58%	Daily Activities	67%	53%
Pain or discomfort	48%	36%	Pain or discomfort	52%	39%
Anxiety or depression	43%	42%	Anxiety or depression	52%	49%
Average	63%	55%	Average	66%	56%
	Difference	-8%		Difference	-10%
	of which - explained by age (*)	-3%		of which - explained by age	-3%
	n min	105		n min	1926
	n max	106		n max	1951
	average age:	40.2			41.2
		45			1239
		46			1249
		48.2			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



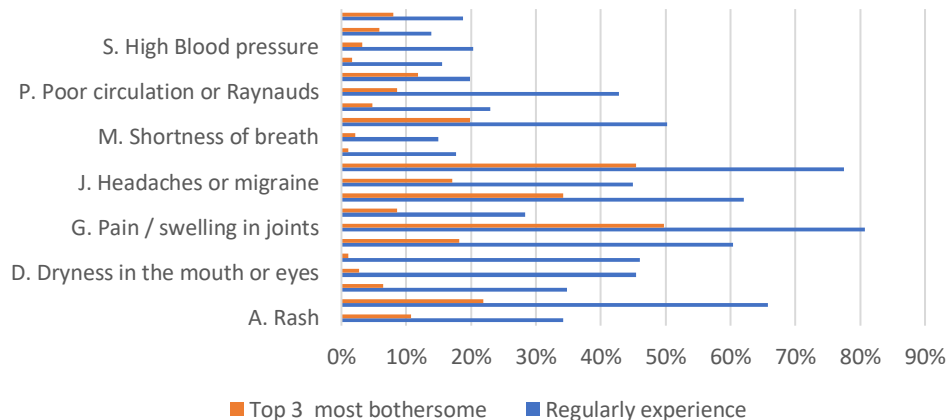
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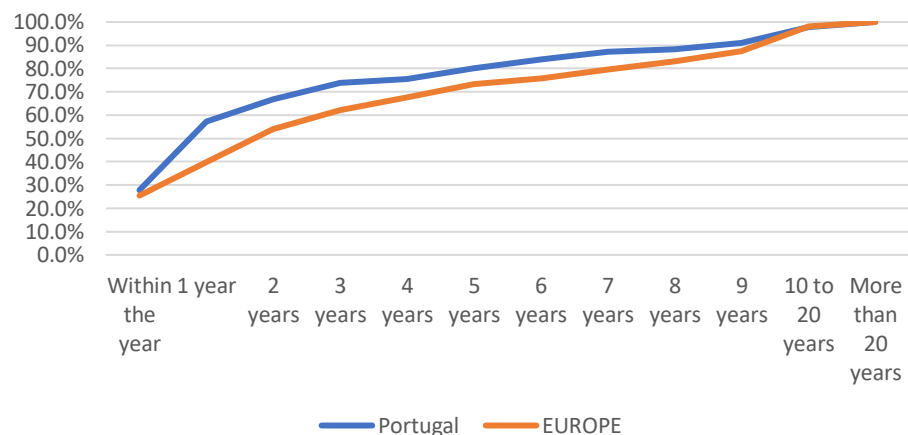
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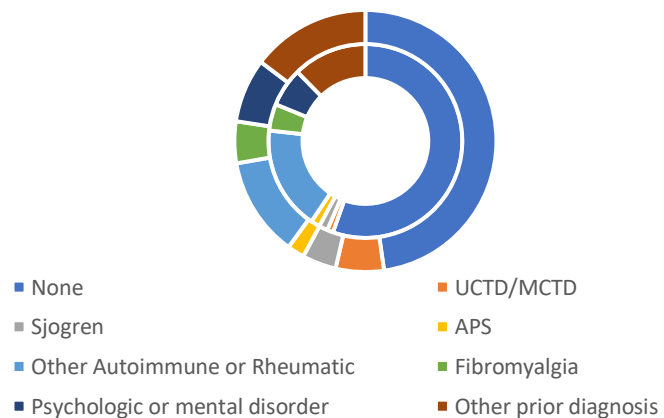
Patient reported symptoms and features



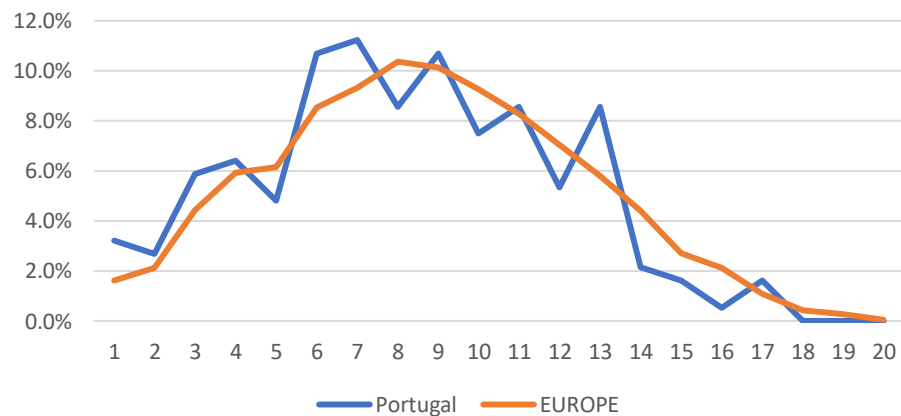
Patient time to diagnosis



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



Number of symptoms experienced



DATA FOR: 0

