



**LUPUS EUROPE**

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

**Italy**



Living with lupus in 2020 - Country level data

DATA FOR: **Italy**

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

COUNTRY: Italy

**DEMOGRAPHICS:**

	<u>Italy</u>	<u>EUROPE</u>	<u>Age</u>	<u>Italy</u>	<u>EUROPE</u>
Total number of responses	556	4375	Up to 25	7.2%	6.4%
			26 to 35	18.5%	17.9%
<u>Gender</u>	<u>Italy</u>	<u>EUROPE</u>	36 to 45	28.8%	27.4%
Man	4.5%	3.7%	46 to 55	25.9%	26.6%
Woman	94.6%	95.6%	56 to 65	15.5%	14.8%
Other / prefer not to answer	0.9%	0.7%	above 65	2.0%	5.1%
Total	100.0%	100.0%	NA	2.2%	1.8%
			Grand Total	100.0%	100.0%

**DIAGNOSIS**

<u>Diagnosis</u>	<u>Italy</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Italy</u>	<u>EUROPE</u>
SLE	93.2%	94.4%	Within the year	35.4%	26.5%
Child onset SLE	6.8%	5.6%	1 year	22.9%	21.1%
Grand Total	100.0%	100.0%	2 years	11.4%	11.5%
			3 years	6.1%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Italy</u>	<u>EUROPE</u>	4 years	2.3%	4.6%
None	54.9%	53.7%	5 years	3.0%	4.4%
UCTD/MCTD	16.2%	6.7%	6 years	2.3%	2.9%
Sjogren	4.0%	4.7%	7 years	1.7%	2.7%
APS	1.3%	2.4%	8 years	2.1%	2.4%
Other Autoimmune or Rheumatic	7.9%	13.8%	9 years	1.3%	2.3%
Fibromyalgia	4.7%	5.8%	10 to 20 years	8.6%	10.4%
Psychologic or mental disorder	7.4%	8.9%	More than 20 years	2.9%	5.5%
Other prior diagnosis	14.9%	16.5%	Grand Total	100.0%	100.0%
n=	542	4,275	n=	525	4,154



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**IMPACT ON STUDIES & CAREER**

<u>Education level</u>	<u>Italy</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Italy</u>	<u>EUROPE</u>
Basic	1.1%	3.7%	Employed full time	31.1%	34.6%
Secondary	73.0%	53.9%	Employed part time	15.3%	16.5%
Academic	25.8%	42.5%	Self-employed full time	4.9%	3.0%
n=	534	4,150	Self-employed part time	3.6%	2.4%
			Looking for employment	9.8%	5.1%
<u>Economic profile</u>	<u>Italy</u>	<u>EUROPE</u>	Stopped work for medical reason	7.5%	14.7%
No difficulties paying all bills	44.1%	46.9%	Retired	7.4%	11.6%
Occasional difficulties paying all bills.	24.1%	26.8%	Student	6.0%	4.0%
Often difficulties paying all bills	9.4%	10.4%	No paid employment / Full time home	8.9%	4.7%
Always difficulty paying all bills	7.9%	7.1%	Other / prefer not to answer	5.5%	3.5%
Did not respond	14.6%	8.9%			
n=	556	4375	n=	530	4247
<u>IMPACT ON STUDIES</u>	<u>Italy</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Italy</u>	<u>EUROPE</u>
Chose more relevant studies	2.1%	3.1%	No impact	40.4%	32.5%
could not do what they wanted	10.0%	11.1%	Changed career/ job	7.8%	13.5%
needed special support and received it	1.7%	4.6%	moved to Flexible hours	6.1%	8.1%
needed support but did NOT receive it	3.7%	2.9%	Reduced Work Schedule	13.3%	18.5%
Overall negative effect	10.6%	13.5%	Stopped work, gets social allowances	10.7%	18.5%
Overall positive effect	1.0%	1.4%	Missed promotion opportunities	3.9%	9.5%
No impact	72.8%	69.8%	Employment was terminated	9.4%	8.4%
n=	519	4240	Other negative impact	14.5%	20.8%
			Other positive impact	2.7%	1.8%
			Overall had negative impact	47.3%	57.9%
			n=	488	4024



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**IMPACT ON SOCIAL / FAMILY**

<u>Civil status</u>	<u>Italy</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Italy</u>	<u>EUROPE</u>
Child/young with family	7.1%	4.5%	None	44.6%	32.8%
Single	17.4%	17.4%	One child	26.4%	23.8%
Married / with partner	65.1%	66.9%	2 or more children	22.0%	38.9%
Divorced	8.1%	9.2%	Child/young living with family	7.0%	4.5%
Widowed	2.3%	2.0%			
n=	533	4206	n=	542	4288
<u>Would have liked more children</u>	<u>Italy</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Italy</u>	<u>EUROPE</u>
A. Yes	47.8%	37.6%	A. One miscarriage	16.4%	18.4%
B. No	21.1%	37.7%	B. Some miscarriages	7.0%	8.5%
C. don't know / prefer not to answer	31.1%	24.7%	C. Many miscarriages	3.0%	2.9%
n (women only) =	412	3,645	D. No miscarriage	73.6%	70.2%
			n (women only) =	470	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Italy</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Italy</u>	<u>EUROPE</u>
No Problem at all 1	19.2%	16.2%	Less active due to lupus	68.4%	72.6%
2	32.8%	32.3%	Equally active	18.9%	15.6%
3	33.6%	34.3%	More active due to lupus	3.0%	3.6%
4	12.3%	15.4%	I don't know	9.7%	8.1%
Fully Unable 5	2.1%	1.8%			
n=	527	4226	n=	525	4212
<u>Impact on Sexual/emotional life</u>	<u>Italy</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Italy</u>	<u>EUROPE</u>
Negative impact	26.9%	38.2%	It created tensions	19.3%	33.2%
Mixed Positive and negative	45.2%	36.2%	It is difficult for me	62.3%	68.4%
No significant impact	27.5%	23.9%	It is difficult for my partner	11.3%	26.7%
Positive impact	0.4%	1.6%	I am concerned for my couple	5.9%	13.2%
n=	524	4,204	Our relationship ended	18.4%	16.6%
			n=	353	2875



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**DISEASE ACTIVITY**

<u>Lupus was under control past 3 months</u>	<u>Italy</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>	<u>Italy</u>	<u>EUROPE</u>
Yes	79%	72%	1	3.8%	1.6%
No	21%	28%	2	4.6%	2.1%
			3	9.4%	4.4%
n=	552	4347	4	8.4%	5.9%
			5	6.9%	6.1%
			6	10.0%	8.5%
	<u>Italy</u>	<u>EUROPE</u>	7	8.2%	9.3%
<u>Average nr of symptoms (list of 23)</u>	7.5	8.8	8	9.2%	10.4%
n=	522	4197	9	9.0%	10.1%
			10	9.4%	9.3%
	<u>Italy</u>	<u>EUROPE</u>	11	6.3%	8.3%
<u>Median number of symptoms</u>	7	9	12	5.0%	7.0%
n=	522	4197	13	3.3%	5.8%
			14	1.9%	4.4%
			15	2.3%	2.7%
			16	1.5%	2.1%
			17	0.6%	1.1%
			18	0.0%	0.4%
			19	0.2%	0.3%
			20	0.0%	0.0%
			n=	522	4197



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**Symptoms or Features experienced / Most bothersome**

Patient reported Symptoms or features	Italy		Patient reported Symptoms or features	EUROPE	
	Regularly experience	Top 3 most bothersome		Regularly experience	Top 3 most bothersome
A. Rash	30%	11%	A. Rash	40%	9%
B. Sun sensitivity	<b>46%</b>	16%	B. Sun sensitivity	<b>69%</b>	<b>23%</b>
C. Mouth ulcers	25%	4%	C. Mouth ulcers	35%	3%
D. Dryness in the mouth or eyes	44%	10%	D. Dryness in the mouth or eyes	55%	9%
E. Dryness of the skin	<b>45%</b>	4%	E. Dryness of the skin	<b>57%</b>	4%
F. Hair loss	43%	15%	F. Hair loss	53%	14%
G. Pain / swelling in joints	<b>68%</b>	<b>43%</b>	G. Pain / swelling in joints	<b>77%</b>	<b>49%</b>
H. Jaccoud (hand deformation) or tendons a	11%	5%	H. Jaccoud (hand deformation) or tendor	14%	4%
I. Muscle Pain/Weakness	<b>67%</b>	<b>39%</b>	I. Muscle Pain/Weakness	<b>68%</b>	<b>33%</b>
J. Headaches or migraine	44%	18%	J. Headaches or migraine	51%	17%
K. Fatigue and weakness	<b>74%</b>	<b>40%</b>	K. Fatigue and weakness	<b>85%</b>	<b>55%</b>
L. Flu-like symptoms/Fevers	23%	2%	L. Flu-like symptoms/Fevers	28%	4%
M. Shortness of breath	25%	6%	M. Shortness of breath	32%	6%
N. Depression or Anxiety	42%	<b>21%</b>	N. Depression or Anxiety	44%	<b>17%</b>
O. Haematologic problems incl. anemia	28%	5%	O. Haematologic problems incl. anemia	27%	4%
P. Poor circulation or Raynauds	31%	5%	P. Poor circulation or Raynauds	45%	8%
Q. Kidney problems	23%	<b>19%</b>	Q. Kidney problems	20%	11%
R. Chest pain	17%	4%	R. Chest pain	24%	4%
S. High Blood pressure	24%	4%	S. High Blood pressure	23%	4%
T. Stroke, mini-stroke, Blood clots	9%	5%	T. Stroke, mini-stroke, Blood clots	9%	4%
U. Osteoporosis	27%	8%	U. Osteoporosis	19%	5%
n=	556	502	n=	4375	4084



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**MEDICATION**

	<u>Italy</u>	<u>EUROPE</u>		<u>Italy</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	4.9	5.2	<u>Median number of medication (from list of 16)</u>	5	5
n=	507	4099	n=	507	4099
<u>Number of medications (list of 16)</u>	<u>Italy</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Italy</u>	<u>EUROPE</u>
1	6.1%	5.4%	Non Steroids Anti-Inflammatory	23.5%	32.9%
2	10.1%	9.0%	Antimalarials	<b>68.4%</b>	<b>75.0%</b>
3	13.0%	12.5%	Oral Steroids	<b>57.0%</b>	<b>52.4%</b>
4	15.8%	14.1%	Immunosuppressants	<b>39.6%</b>	39.8%
5	17.2%	14.8%	Biologics	13.6%	10.9%
6	14.6%	13.9%	Painkillers	37.7%	<b>50.1%</b>
7	8.5%	11.8%	Antidepressant	11.6%	17.0%
8	7.7%	9.0%	Anxiolytic	14.6%	11.7%
9	3.6%	5.1%	Anticoagulants	20.7%	16.6%
10	2.0%	2.5%	Thyroid medication	14.4%	14.8%
11	1.0%	1.1%	Blood circulation and heart	24.5%	23.3%
12	0.4%	0.4%	Stomach protection	<b>52.7%</b>	<b>47.0%</b>
13	0.2%	0.2%	Statins	5.7%	5.9%
n=	507	4099	Calcium	17.0%	29.7%
			Vitamin D	<b>76.5%</b>	<b>68.4%</b>
			Vitamins (excl.D) / mineral complements	15.0%	25.4%



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

<u>I have appropriate access to</u>	<u>Italy</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Italy</u>	<u>EUROPE</u>	
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)			
Experienced lupus doctors	3.65	3.81	Mobility	2.09	2.22	
Multidisciplinary team	3.15	3.28	Self care	1.61	1.71	
Specialised nurses that know lupus	2.86	2.92	Daily Activities	2.45	2.54	
Prescribed medication	3.87	4.08	Pain or discomfort	3.10	3.14	
Affordable treatments	3.64	3.77	Anxiety or depression	3.18	2.96	
Social support and benefits	2.73	2.78	Average	2.49	2.51	
Physiotherapy, Rehab, Occupational Thera	2.57	2.77				
Professional psychological support	2.53	2.68				
	n min	328	3126	n min	525	4196
	n max	448	3842	n max	532	4240
<u>Worry about lupus progressing?</u>	<u>Italy</u>	<u>EUROPE</u>				
Very Low (1-2)	1.4%	3.6%				
Low (3-4)	5.5%	9.3%				
Mid (5-6)	18.6%	24.5%				
High (7-8)	39.8%	41.0%				
Very high (9-10)	34.7%	21.6%				
	n=	495	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>Italy</u>			<u>EUROPE</u>		
	<u>lupus under control</u>	<u>not under control</u>		<u>lupus under control</u>	<u>not under control</u>	
Mobility	75%	63%	Mobility	73%	59%	
Self care	87%	76%	Self care	86%	73%	
Daily Activities	66%	54%	Daily Activities	66%	51%	
Pain or discomfort	51%	36%	Pain or discomfort	51%	35%	
Anxiety or depression	46%	42%	Anxiety or depression	54%	44%	
Average	65%	54%	Average	66%	52%	
	n min	416	108	n min	3011	1179
	n max	421	110	n max	3042	1194

	<u>Italy</u>			<u>EUROPE</u>		
	<u>lupus under control</u>	<u>not under control</u>		<u>lupus under control</u>	<u>not under 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	65.5%	79.8%	Less active due to lupus	68.6%	83.0%	
Equally active	21.7%	7.3%	Equally active	18.8%	7.6%	
More active due to lupus	3.4%	1.8%	More active due to lupus	4.0%	2.7%	
I don't know	9.4%	11.0%	I don't know	8.7%	6.7%	
	n=	415	109	n=	3018	1189

	<u>Italy</u>			<u>EUROPE</u>		
	<u>lupus under control</u>	<u>not under control</u>		<u>lupus under control</u>	<u>not under control</u>	
<u>Impact on Sexual/emotional life</u>			<u>Impact on Sexual/emotional life</u>			
Negative impact	25.2%	33.6%	Negative impact	34.0%	49.0%	
Mixed + and -	45.7%	43.9%	Mixed + and -	36.4%	35.7%	
No significant impact	28.6%	22.4%	No significant impact	27.8%	14.1%	
Positive impact	0.5%	0.0%	Positive impact	1.8%	1.2%	
	n=	416	107	n=	3018	1181



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**IMPACT OF A PROMPT DIAGNOSIS**

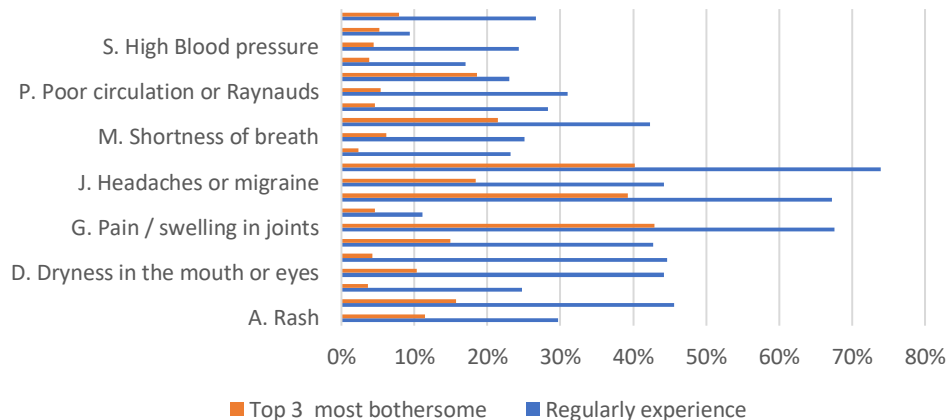
**% of Health Related QoL Maintained vs 100% = FULL HEALTH/ABILITY TO PERFORM**

	<u>Italy</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	77%	63%	Mobility	75%	62%
Self care	88%	77%	Self care	86%	76%
Daily Activities	68%	55%	Daily Activities	67%	53%
Pain or discomfort	51%	39%	Pain or discomfort	52%	39%
Anxiety or depression	44%	44%	Anxiety or depression	52%	49%
Average	66%	55%	Average	66%	56%
	Difference	-10%		Difference	-10%
	of which - explained by age (*)	-3%		of which - explained by age	-3%
	n min	296		n min	1926
	n max	299		n max	1951
	average age:	40.6			41.2
		108			1239
		110			1249
		47.9			49.0

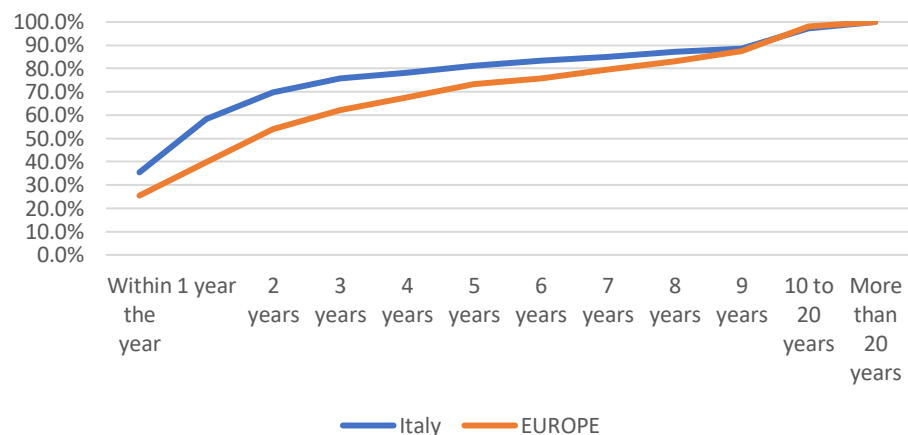
(\*) in our overall study, we found that from age 28 to age 63 HrQoL drops from 69.1% to 56.0% i.e. 3.7% per decade

DATA FOR: 0

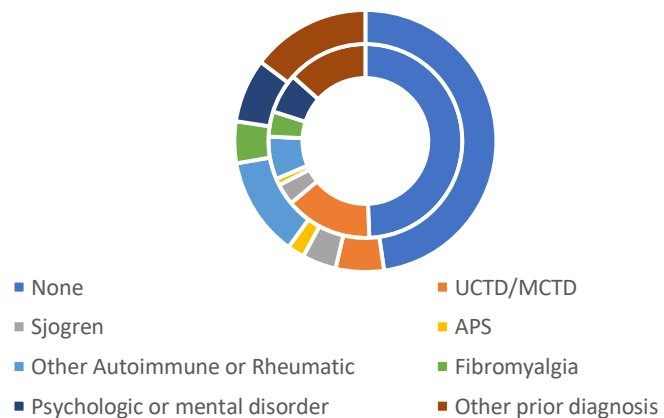
### Patient reported symptoms and features



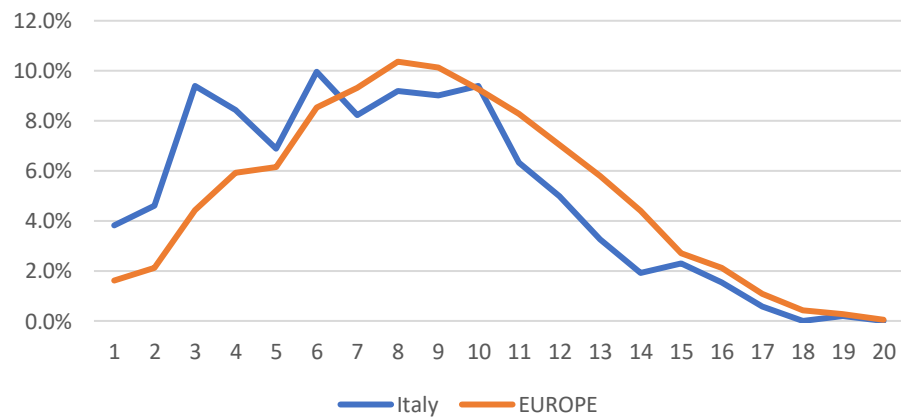
### Patient time to diagnosis



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



### Number of symptoms experienced





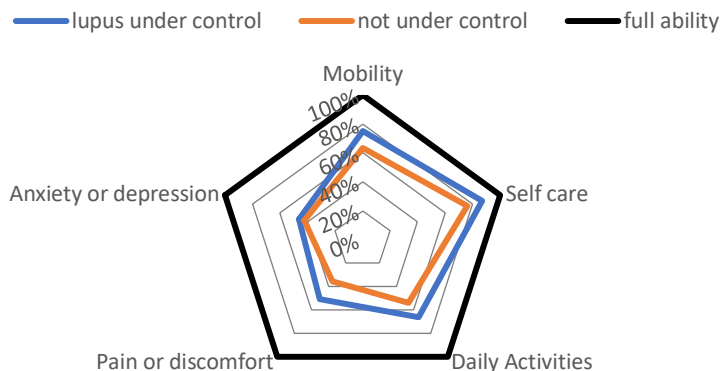
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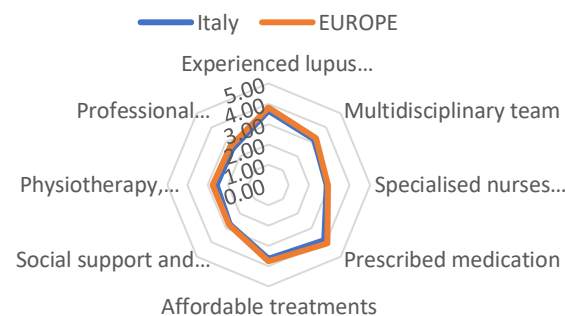
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

DATA FOR: 0

## % residual HRQoL



## Access - I have appropriate access to...



## Living with lupus in 2020 - Country level data

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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