



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Germany



Living with lupus in 2020 - Country level data

DATA FOR: **Germany**

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

COUNTRY: Germany

DEMOGRAPHICS:

	<u>Germany</u>	<u>EUROPE</u>	<u>Age</u>	<u>Germany</u>	<u>EUROPE</u>
Total number of responses	301	4375	Up to 25	8.0%	6.4%
			26 to 35	19.9%	17.9%
<u>Gender</u>	<u>Germany</u>	<u>EUROPE</u>	36 to 45	25.2%	27.4%
Man	3.7%	3.7%	46 to 55	29.9%	26.6%
Woman	96.0%	95.6%	56 to 65	12.3%	14.8%
Other / prefer not to answer	0.3%	0.7%	above 65	3.0%	5.1%
Total	100.0%	100.0%	NA	1.7%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Germany</u>	<u>EUROPE</u>
SLE	95.0%	94.4%	Within the year	26.9%	26.5%
Child onset SLE	5.0%	5.6%	1 year	17.5%	21.1%
Grand Total	100.0%	100.0%	2 years	11.9%	11.5%
			3 years	5.9%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Germany</u>	<u>EUROPE</u>	4 years	4.5%	4.6%
None	47.2%	53.7%	5 years	3.8%	4.4%
UCTD/MCTD	2.0%	6.7%	6 years	3.1%	2.9%
Sjogren	4.3%	4.7%	7 years	2.8%	2.7%
APS	1.3%	2.4%	8 years	2.4%	2.4%
Other Autoimmune or Rheumatic	15.0%	13.8%	9 years	1.7%	2.3%
Fibromyalgia	6.0%	5.8%	10 to 20 years	12.9%	10.4%
Psychologic or mental disorder	16.3%	8.9%	More than 20 years	6.3%	5.5%
Other prior diagnosis	19.6%	16.5%	Grand Total	100.0%	100.0%
n=	291	4,275	n=	286	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Germany</u>	<u>EUROPE</u>
Basic	9.8%	3.7%	Employed full time	29.5%	34.6%
Secondary	69.5%	53.9%	Employed part time	27.8%	16.5%
Academic	20.7%	42.5%	Self-employed full time	0.7%	3.0%
n=	285	4,150	Self-employed part time	1.4%	2.4%
			Looking for employment	2.0%	5.1%
<u>Economic profile</u>	<u>Germany</u>	<u>EUROPE</u>	Stopped work for medical reason	13.2%	14.7%
No difficulties paying all bills	53.2%	46.9%	Retired	12.2%	11.6%
Occasional difficulties paying all bills.	21.3%	26.8%	Student	4.1%	4.0%
Often difficulties paying all bills	8.6%	10.4%	No paid employment / Full time home	6.1%	4.7%
Always difficulty paying all bills	5.6%	7.1%	Other / prefer not to answer	3.1%	3.5%
Did not respond	11.3%	8.9%			
n=	301	4375	n=	295	4247
<u>IMPACT ON STUDIES</u>	<u>Germany</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Germany</u>	<u>EUROPE</u>
Chose more relevant studies	1.7%	3.1%	No impact	25.9%	32.5%
could not do what they wanted	12.9%	11.1%	Changed career/ job	12.9%	13.5%
needed special support and received it	4.7%	4.6%	moved to Flexible hours	8.6%	8.1%
needed support but did NOT receive it	3.1%	2.9%	Reduced Work Schedule	26.3%	18.5%
Overall negative effect	15.3%	13.5%	Stopped work, gets social allowances	15.5%	18.5%
Overall positive effect	1.0%	1.4%	Missed promotion opportunities	18.0%	9.5%
No impact	70.5%	69.8%	Employment was terminated	7.2%	8.4%
n=	295	4240	Other negative impact	30.2%	20.8%
			Other positive impact	1.4%	1.8%
			Overall had negative impact	68.0%	57.9%
			n=	278	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Germany</u>	<u>EUROPE</u>
Child/young with family	5.6%	4.5%	None	43.8%	32.8%
Single	15.7%	17.4%	One child	22.2%	23.8%
Married / with partner	67.2%	66.9%	2 or more children	28.6%	38.9%
Divorced	9.4%	9.2%	Child/young living with family	5.4%	4.5%
Widowed	2.1%	2.0%			
n=	287	4206	n=	297	4288
<u>Would have liked more children</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Germany</u>	<u>EUROPE</u>
A. Yes	33.8%	37.6%	A. One miscarriage	12.2%	18.4%
B. No	42.9%	37.7%	B. Some miscarriages	4.2%	8.5%
C. don't know / prefer not to answer	23.3%	24.7%	C. Many miscarriages	1.5%	2.9%
			D. No miscarriage	82.1%	70.2%
n (women only) =	266	3,645	n (women only) =	263	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Germany</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Germany</u>	<u>EUROPE</u>
No Problem at all 1	15.9%	16.2%	Less active due to lupus	76.3%	72.6%
2	29.8%	32.3%	Equally active	11.5%	15.6%
3	40.1%	34.3%	More active due to lupus	4.5%	3.6%
4	12.8%	15.4%	I don't know	7.7%	8.1%
Fully Unable 5	1.4%	1.8%			
n=	289	4226	n=	287	4212
<u>Impact on Sexual/emotional life</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Germany</u>	<u>EUROPE</u>
Negative impact	41.3%	38.2%	It created tensions	50.0%	33.2%
Mixed Positive and negative	39.9%	36.2%	It is difficult for me	67.6%	68.4%
No significant impact	18.1%	23.9%	It is difficult for my partner	41.9%	26.7%
Positive impact	0.7%	1.6%	I am concerned for my couple	18.1%	13.2%
n=	288	4,204	Our relationship ended	16.2%	16.6%
			n=	210	2875



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DISEASE ACTIVITY

<u>Lupus was under control past 3 months</u>	<u>Germany</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>	<u>Germany</u>	<u>EUROPE</u>
Yes	69%	72%	1	0.7%	1.6%
No	31%	28%	2	2.8%	2.1%
			3	2.1%	4.4%
n=	301	4347	4	4.6%	5.9%
			5	5.6%	6.1%
			6	6.3%	8.5%
			7	11.2%	9.3%
<u>Average nr of symptoms (list of 23)</u>	<u>Germany</u>	<u>EUROPE</u>	8	13.0%	10.4%
n=	8.9	8.8	9	11.9%	10.1%
	285	4197	10	10.5%	9.3%
			11	9.1%	8.3%
			12	5.3%	7.0%
<u>Median number of symptoms</u>	<u>Germany</u>	<u>EUROPE</u>	13	6.3%	5.8%
n=	9	9	14	7.7%	4.4%
	285	4197	15	1.4%	2.7%
			16	1.1%	2.1%
			17	0.4%	1.1%
			18	0.0%	0.4%
			19	0.0%	0.3%
			20	0.0%	0.0%
			n=	285	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Germany	
	Regularly experience	Top 3 most bothersome
A. Rash	37%	10%
B. Sun sensitivity	74%	26%
C. Mouth ulcers	22%	1%
D. Dryness in the mouth or eyes	62%	9%
E. Dryness of the skin	67%	3%
F. Hair loss	51%	12%
G. Pain / swelling in joints	80%	48%
H. Jaccoud (hand deformation) or tendons a	12%	2%
I. Muscle Pain/Weakness	70%	33%
J. Headaches or migraine	53%	16%
K. Fatigue and weakness	90%	59%
L. Flu-like symptoms/Fevers	25%	6%
M. Shortness of breath	38%	7%
N. Depression or Anxiety	41%	19%
O. Haematologic problems incl. anemia	23%	5%
P. Poor circulation or Raynauds	43%	7%
Q. Kidney problems	27%	13%
R. Chest pain	19%	3%
S. High Blood pressure	28%	6%
T. Stroke, mini-stroke, Blood clots	7%	2%
U. Osteoporosis	20%	2%
n=	301	279

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>Germany</u>	<u>EUROPE</u>		<u>Germany</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	5.2	5.2	<u>Median number of medication (from list of 16)</u>	5	5
n=	278	4099	n=	278	4099
<u>Number of medications (list of 16)</u>	<u>Germany</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Germany</u>	<u>EUROPE</u>
1	5.4%	5.4%	Non Steroids Anti-Inflammatory	41.0%	32.9%
2	7.6%	9.0%	Antimalarials	71.6%	75.0%
3	10.1%	12.5%	Oral Steroids	58.3%	52.4%
4	14.7%	14.1%	Immunosuppressants	54.3%	39.8%
5	17.6%	14.8%	Biologics	14.4%	10.9%
6	14.0%	13.9%	Painkillers	37.8%	50.1%
7	14.0%	11.8%	Antidepressant	12.2%	17.0%
8	9.0%	9.0%	Anxiolytic	4.0%	11.7%
9	5.4%	5.1%	Anticoagulants	6.5%	16.6%
10	1.8%	2.5%	Thyroid medication	27.3%	14.8%
11	0.4%	1.1%	Blood circulation and heart	39.2%	23.3%
12	0.0%	0.4%	Stomach protection	41.4%	47.0%
13	0.0%	0.2%	Statins	1.1%	5.9%
n=	278	4099	Calcium	9.7%	29.7%
			Vitamin D	81.3%	68.4%
			Vitamins (excl.D) / mineral complements	22.7%	25.4%



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

<u>I have appropriate access to</u>	<u>Germany</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Germany</u>	<u>EUROPE</u>
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)		
Experienced lupus doctors	3.69	3.81	Mobility	2.19	2.22
Multidisciplinary team	3.36	3.28	Self care	1.59	1.71
Specialised nurses that know lupus	2.79	2.92	Daily Activities	2.54	2.54
Prescribed medication	4.10	4.08	Pain or discomfort	3.04	3.14
Affordable treatments	3.51	3.77	Anxiety or depression	2.71	2.96
Social support and benefits	3.02	2.78	Average	2.41	2.51
Physiotherapy, Rehab, Occupational Thera	3.17	2.77			
Professional psychological support	2.99	2.68			
n min	218	3126	n min	287	4196
n max	267	3842	n max	291	4240
<u>Worry about lupus progressing?</u>	<u>Germany</u>	<u>EUROPE</u>			
Very Low (1-2)	5.5%	3.6%			
Low (3-4)	16.8%	9.3%			
Mid (5-6)	32.2%	24.5%			
High (7-8)	33.3%	41.0%			
Very high (9-10)	12.1%	21.6%			
n=	273	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>Germany</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	75%	60%	Mobility	73%	59%	
Self care	89%	76%	Self care	86%	73%	
Daily Activities	67%	49%	Daily Activities	66%	51%	
Pain or discomfort	54%	37%	Pain or discomfort	51%	35%	
Anxiety or depression	60%	51%	Anxiety or depression	54%	44%	
Average	69%	55%	Average	66%	52%	
	n min	201	86	n min	3011	1179
	n max	203	88	n max	3042	1194

	<u>Germany</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	72.9%	84.1%	Less active due to lupus	68.6%	83.0%	
Equally active	14.1%	5.7%	Equally active	18.8%	7.6%	
More active due to lupus	4.5%	4.5%	More active due to lupus	4.0%	2.7%	
I don't know	8.5%	5.7%	I don't know	8.7%	6.7%	
	n=	199	88	n=	3018	1189

	<u>Germany</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	35.5%	54.5%	Negative impact	34.0%	49.0%	
Mixed + and -	43.0%	33.0%	Mixed + and -	36.4%	35.7%	
No significant impact	20.5%	12.5%	No significant impact	27.8%	14.1%	
Positive impact	1.0%	0.0%	Positive impact	1.8%	1.2%	
	n=	200	88	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>Germany</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%	63%	Mobility	75%	62%
Self care	87%	82%	Self care	86%	76%
Daily Activities	68%	54%	Daily Activities	67%	53%
Pain or discomfort	53%	44%	Pain or discomfort	52%	39%
Anxiety or depression	61%	54%	Anxiety or depression	52%	49%
Average	69%	59%	Average	66%	56%
	Difference	-10%		Difference	-10%
	of which - explained by age (*)	-3%		of which - explained by age	-3%
	n min	122		n min	1926
	n max	125		n max	1951
	average age:	40.2			41.2
		91			1239
		92			1249
		47.7			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



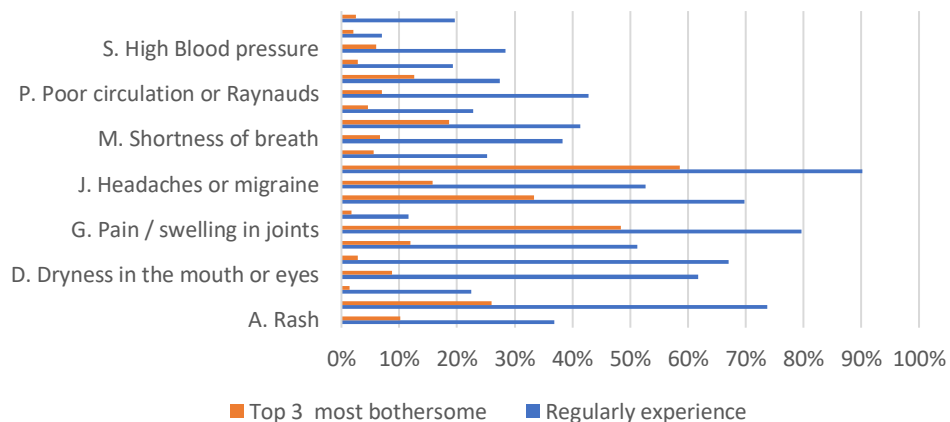
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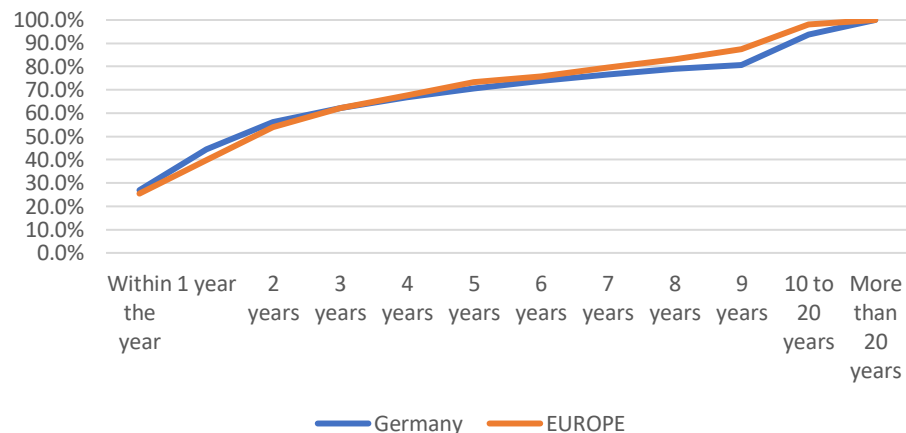
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DATA FOR: 0

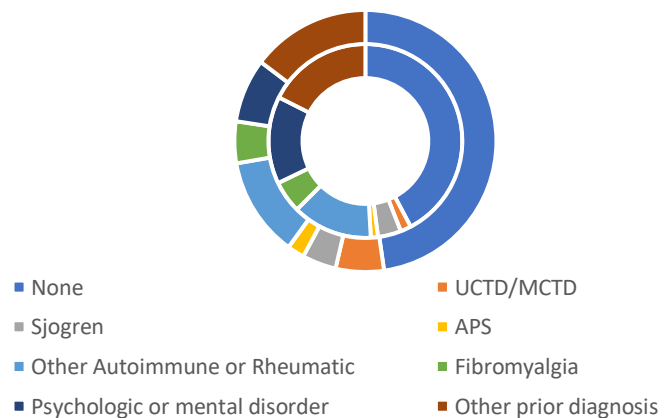
Patient reported symptoms and features



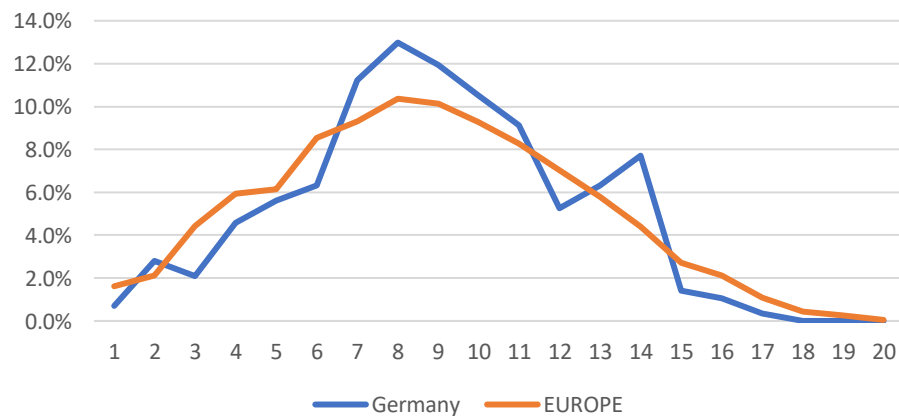
Patient time to diagnosis



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



Number of symptoms experienced



DATA FOR: 0

