



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Finland



Living with lupus in 2020 - Country level data

DATA FOR: **Finland**

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

COUNTRY: Finland

DEMOGRAPHICS:

	<u>Finland</u>	<u>EUROPE</u>	<u>Age</u>	<u>Finland</u>	<u>EUROPE</u>
Total number of responses	187	4375	Up to 25	4.8%	6.4%
			26 to 35	6.4%	17.9%
<u>Gender</u>	<u>Finland</u>	<u>EUROPE</u>	36 to 45	15.0%	27.4%
Man	3.2%	3.7%	46 to 55	28.3%	26.6%
Woman	96.3%	95.6%	56 to 65	24.6%	14.8%
Other / prefer not to answer	0.5%	0.7%	above 65	19.3%	5.1%
Total	100.0%	100.0%	NA	1.6%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Finland</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Finland</u>	<u>EUROPE</u>
SLE	94.1%	94.4%	Within the year	20.0%	26.5%
Child onset SLE	5.9%	5.6%	1 year	21.7%	21.1%
Grand Total	100.0%	100.0%	2 years	10.6%	11.5%
			3 years	4.4%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Finland</u>	<u>EUROPE</u>	4 years	3.9%	4.6%
None	62.6%	53.7%	5 years	5.0%	4.4%
UCTD/MCTD	7.5%	6.7%	6 years	6.1%	2.9%
Sjogren	5.9%	4.7%	7 years	3.3%	2.7%
APS	2.1%	2.4%	8 years	1.7%	2.4%
Other Autoimmune or Rheumatic	13.4%	13.8%	9 years	1.1%	2.3%
Fibromyalgia	3.7%	5.8%	10 to 20 years	14.4%	10.4%
Psychologic or mental disorder	4.8%	8.9%	More than 20 years	7.8%	5.5%
Other prior diagnosis	10.2%	16.5%	Grand Total	100.0%	100.0%
n=	183	4,275	n=	180	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Finland</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Finland</u>	<u>EUROPE</u>
Basic	0.0%	3.7%	Employed full time	35.5%	34.6%
Secondary	64.6%	53.9%	Employed part time	9.8%	16.5%
Academic	35.4%	42.5%	Self-employed full time	3.3%	3.0%
n=	178	4,150	Self-employed part time	2.2%	2.4%
			Looking for employment	2.2%	5.1%
<u>Economic profile</u>	<u>Finland</u>	<u>EUROPE</u>	Stopped work for medical reason	8.2%	14.7%
No difficulties paying all bills	52.9%	46.9%	Retired	27.9%	11.6%
Occasional difficulties paying all bills.	28.9%	26.8%	Student	4.9%	4.0%
Often difficulties paying all bills	9.1%	10.4%	No paid employment / Full time home	3.8%	4.7%
Always difficulty paying all bills	4.3%	7.1%	Other / prefer not to answer	2.2%	3.5%
Did not respond	4.8%	8.9%			
n=	187	4375	n=	183	4247
<u>IMPACT ON STUDIES</u>	<u>Finland</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Finland</u>	<u>EUROPE</u>
Chose more relevant studies	1.6%	3.1%	No impact	42.9%	32.5%
could not do what they wanted	14.8%	11.1%	Changed career/ job	20.0%	13.5%
needed special support and received it	7.1%	4.6%	moved to Flexible hours	7.1%	8.1%
needed support but did NOT receive it	1.6%	2.9%	Reduced Work Schedule	18.8%	18.5%
Overall negative effect	14.8%	13.5%	Stopped work, gets social allowances	10.6%	18.5%
Overall positive effect	2.7%	1.4%	Missed promotion opportunities	2.9%	9.5%
No impact	68.9%	69.8%	Employment was terminated	11.8%	8.4%
n=	183	4240	Other negative impact	22.9%	20.8%
			Other positive impact	4.7%	1.8%
			Overall had negative impact	45.3%	57.9%
			n=	170	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Finland</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Finland</u>	<u>EUROPE</u>
Child/young with family	0.5%	4.5%	None	25.4%	32.8%
Single	15.3%	17.4%	One child	20.0%	23.8%
Married / with partner	68.3%	66.9%	2 or more children	54.1%	38.9%
Divorced	13.7%	9.2%	Child/young living with family	0.5%	4.5%
Widowed	2.2%	2.0%			
n=	183	4206	n=	185	4288
<u>Would have liked more children</u>	<u>Finland</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Finland</u>	<u>EUROPE</u>
A. Yes	16.9%	37.6%	A. One miscarriage	20.3%	18.4%
B. No	54.4%	37.7%	B. Some miscarriages	8.7%	8.5%
C. don't know / prefer not to answer	28.7%	24.7%	C. Many miscarriages	4.3%	2.9%
n (women only) =	136	3,645	D. No miscarriage	66.7%	70.2%
			n (women only) =	138	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Finland</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Finland</u>	<u>EUROPE</u>
No Problem at all 1	20.3%	16.2%	Less active due to lupus	60.8%	72.6%
2	40.1%	32.3%	Equally active	22.7%	15.6%
3	28.0%	34.3%	More active due to lupus	4.4%	3.6%
4	11.5%	15.4%	I don't know	12.2%	8.1%
Fully Unable 5	0.0%	1.8%			
n=	182	4226	n=	181	4212
<u>Impact on Sexual/emotional life</u>	<u>Finland</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Finland</u>	<u>EUROPE</u>
Negative impact	34.5%	38.2%	It created tensions	33.3%	33.2%
Mixed Positive and negative	23.7%	36.2%	It is difficult for me	70.8%	68.4%
No significant impact	39.5%	23.9%	It is difficult for my partner	28.1%	26.7%
Positive impact	2.3%	1.6%	I am concerned for my couple	15.6%	13.2%
n=	177	4,204	Our relationship ended	17.7%	16.6%
			n=	96	2875



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DISEASE ACTIVITY

<u>Lupus was under control past 3 months</u>	<u>Finland</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>	<u>Finland</u>	<u>EUROPE</u>
Yes	68%	72%	1	0.0%	1.6%
No	32%	28%	2	2.2%	2.1%
			3	3.9%	4.4%
n=	186	4347	4	6.7%	5.9%
			5	7.3%	6.1%
			6	6.7%	8.5%
			7	10.1%	9.3%
<u>Average nr of symptoms (list of 23)</u>	<u>Finland</u>	<u>EUROPE</u>	8	14.5%	10.4%
	8.6	8.8	9	12.3%	10.1%
n=	179	4197	10	10.1%	9.3%
			11	8.4%	8.3%
			12	4.5%	7.0%
<u>Median number of symptoms</u>	<u>Finland</u>	<u>EUROPE</u>	13	4.5%	5.8%
	8	9	14	3.4%	4.4%
n=	179	4197	15	1.7%	2.7%
			16	2.2%	2.1%
			17	0.6%	1.1%
			18	0.6%	0.4%
			19	0.6%	0.3%
			20	0.0%	0.0%
			n=	179	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Finland	
	Regularly experience	Top 3 most bothersome
A. Rash	44%	8%
B. Sun sensitivity	79%	22%
C. Mouth ulcers	32%	6%
D. Dryness in the mouth or eyes	74%	18%
E. Dryness of the skin	64%	6%
F. Hair loss	34%	11%
G. Pain / swelling in joints	70%	42%
H. Jaccoud (hand deformation) or tendons a	16%	4%
I. Muscle Pain/Weakness	62%	32%
J. Headaches or migraine	42%	12%
K. Fatigue and weakness	79%	53%
L. Flu-like symptoms/Fevers	31%	6%
M. Shortness of breath	21%	6%
N. Depression or Anxiety	32%	15%
O. Haematologic problems incl. anemia	31%	4%
P. Poor circulation or Raynauds	53%	11%
Q. Kidney problems	11%	5%
R. Chest pain	11%	3%
S. High Blood pressure	36%	5%
T. Stroke, mini-stroke, Blood clots	12%	7%
U. Osteoporosis	25%	8%
n=	187	174

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>Finland</u>	<u>EUROPE</u>		<u>Finland</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	6.3	5.2	<u>Median number of medication (from list of 16)</u>	6	5
n=	177	4099	n=	177	4099
<u>Number of medications (list of 16)</u>	<u>Finland</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Finland</u>	<u>EUROPE</u>
1	1.1%	5.4%	Non Steroids Anti-Inflammatory	55.4%	32.9%
2	1.7%	9.0%	Antimalarials	71.2%	75.0%
3	11.3%	12.5%	Oral Steroids	49.7%	52.4%
4	10.7%	14.1%	Immunosuppressants	27.7%	39.8%
5	11.3%	14.8%	Biologics	10.7%	10.9%
6	15.3%	13.9%	Painkillers	63.3%	50.1%
7	18.1%	11.8%	Antidepressant	13.6%	17.0%
8	14.7%	9.0%	Anxiolytic	5.1%	11.7%
9	5.6%	5.1%	Anticoagulants	21.5%	16.6%
10	7.3%	2.5%	Thyroid medication	18.1%	14.8%
11	1.1%	1.1%	Blood circulation and heart	52.5%	23.3%
12	1.7%	0.4%	Stomach protection	47.5%	47.0%
13	0.0%	0.2%	Statins	15.3%	5.9%
n=	177	4099	Calcium	60.5%	29.7%
			Vitamin D	81.4%	68.4%
			Vitamins (excl.D) / mineral complements	37.3%	25.4%



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

<u>I have appropriate access to</u>	<u>Finland</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Finland</u>	<u>EUROPE</u>	
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)			
Experienced lupus doctors	3.07	3.81	Mobility	2.30	2.22	
Multidisciplinary team	2.73	3.28	Self care	1.54	1.71	
Specialised nurses that know lupus	3.08	2.92	Daily Activities	2.31	2.54	
Prescribed medication	4.10	4.08	Pain or discomfort	3.06	3.14	
Affordable treatments	3.30	3.77	Anxiety or depression	2.57	2.96	
Social support and benefits	2.54	2.78	Average	2.35	2.51	
Physiotherapy, Rehab, Occupational Thera	2.81	2.77				
Professional psychological support	2.85	2.68				
	n min	126	3126	n min	181	4196
	n max	169	3842	n max	183	4240
<u>Worry about lupus progressing?</u>	<u>Finland</u>	<u>EUROPE</u>				
Very Low (1-2)	9.4%	3.6%				
Low (3-4)	9.9%	9.3%				
Mid (5-6)	29.2%	24.5%				
High (7-8)	40.4%	41.0%				
Very high (9-10)	11.1%	21.6%				
	n=	171	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>Finland</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%	52%	Mobility	73%	59%	
Self care	90%	79%	Self care	86%	73%	
Daily Activities	74%	54%	Daily Activities	66%	51%	
Pain or discomfort	53%	38%	Pain or discomfort	51%	35%	
Anxiety or depression	66%	50%	Anxiety or depression	54%	44%	
Average	72%	55%	Average	66%	52%	
	n min	123	57	n min	3011	1179
	n max	125	57	n max	3042	1194

	<u>Finland</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	52.0%	78.9%	Less active due to lupus	68.6%	83.0%	
Equally active	30.9%	5.3%	Equally active	18.8%	7.6%	
More active due to lupus	4.9%	3.5%	More active due to lupus	4.0%	2.7%	
I don't know	12.2%	12.3%	I don't know	8.7%	6.7%	
	n=	123	57	n=	3018	1189

	<u>Finland</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	27.5%	50.0%	Negative impact	34.0%	49.0%	
Mixed + and -	20.8%	28.6%	Mixed + and -	36.4%	35.7%	
No significant impact	48.3%	21.4%	No significant impact	27.8%	14.1%	
Positive impact	3.3%	0.0%	Positive impact	1.8%	1.2%	
	n=	120	56	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>Finland</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	71%	63%	Mobility	75%	62%
Self care	89%	83%	Self care	86%	76%
Daily Activities	70%	64%	Daily Activities	67%	53%
Pain or discomfort	58%	43%	Pain or discomfort	52%	39%
Anxiety or depression	63%	59%	Anxiety or depression	52%	49%
Average	70%	63%	Average	66%	56%
	Difference	-7%		Difference	-10%
	of which - explained by age (*)	-3%		of which - explained by age	-3%
	n min	72		n min	1926
	n max	74		n max	1951
	average age:	48.9			41.2
		56.0			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



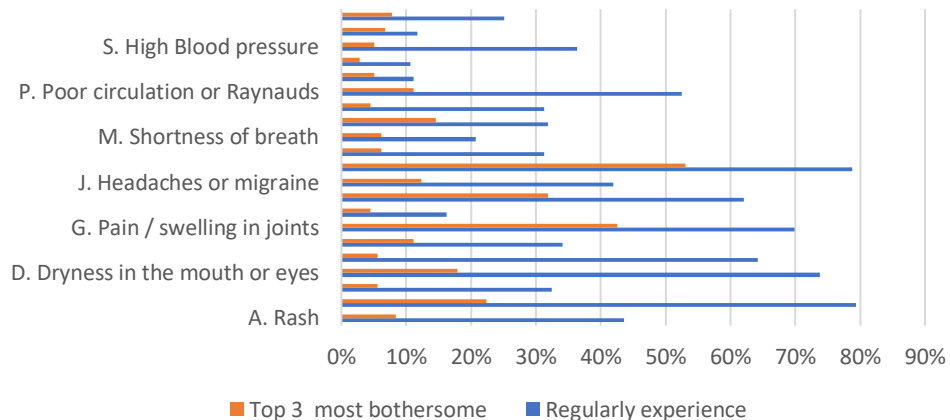
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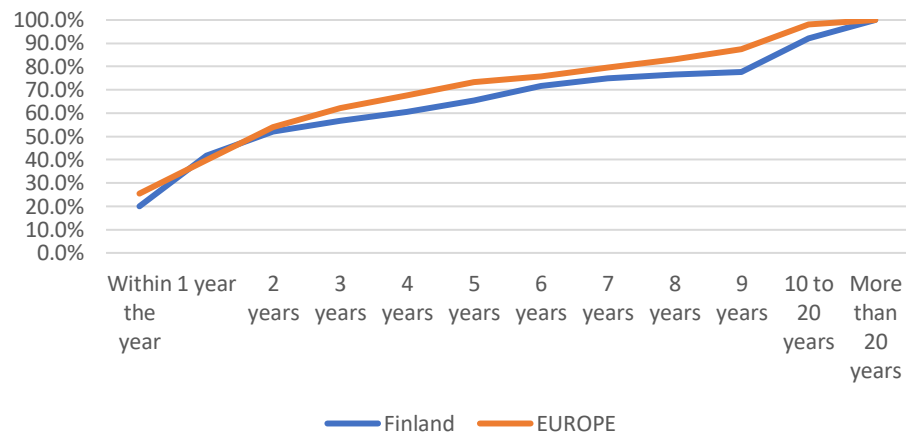
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

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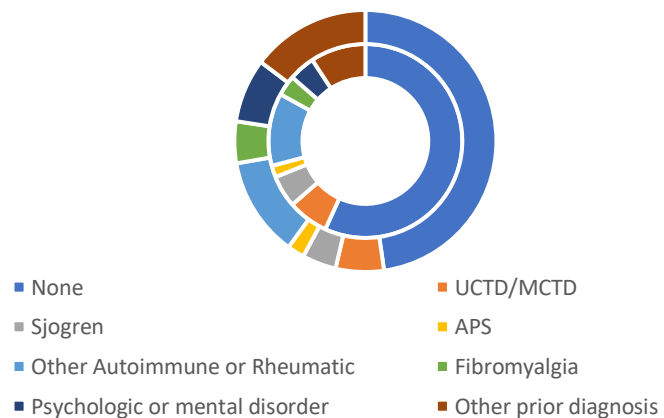
Patient reported symptoms and features



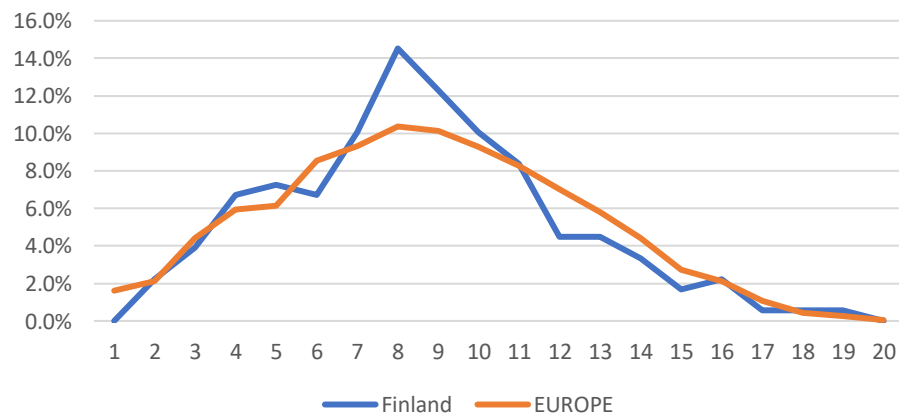
Patient time to diagnosis



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



Number of symptoms experienced





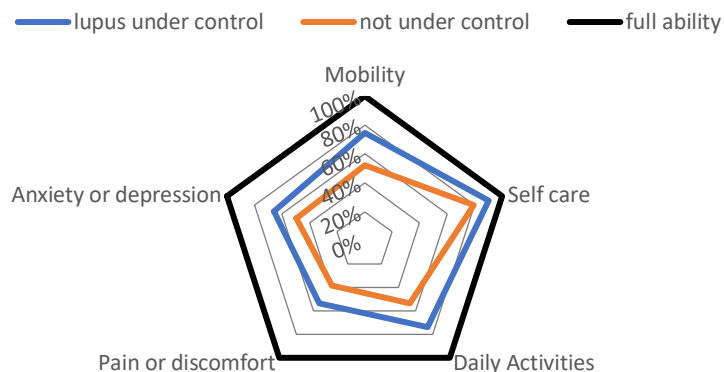
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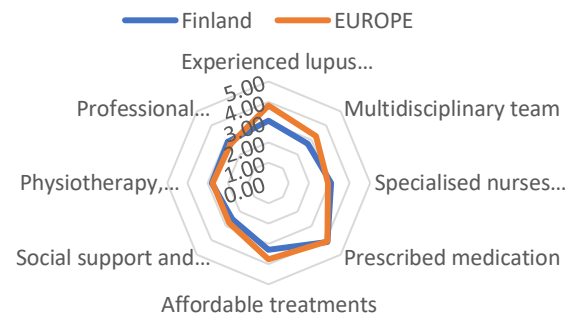
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

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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