



**LUPUS EUROPE**

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

**Norway**



Living with lupus in 2020 - Country level data

DATA FOR: **Norway**

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

COUNTRY: Norway

**DEMOGRAPHICS:**

	<u>Norway</u>	<u>EUROPE</u>	<u>Age</u>	<u>Norway</u>	<u>EUROPE</u>
Total number of responses	135	4375	Up to 25	3.7%	6.4%
			26 to 35	11.9%	17.9%
<u>Gender</u>	<u>Norway</u>	<u>EUROPE</u>	36 to 45	17.8%	27.4%
Man	1.5%	3.7%	46 to 55	40.7%	26.6%
Woman	97.0%	95.6%	56 to 65	19.3%	14.8%
Other / prefer not to answer	1.5%	0.7%	above 65	5.2%	5.1%
Total	100.0%	100.0%	NA	1.5%	1.8%
			Grand Total	100.0%	100.0%

**DIAGNOSIS**

<u>Diagnosis</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Norway</u>	<u>EUROPE</u>
SLE	95.6%	94.4%	Within the year	19.5%	26.5%
Child onset SLE	4.4%	5.6%	1 year	13.5%	21.1%
Grand Total	100.0%	100.0%	2 years	9.8%	11.5%
			3 years	7.5%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Norway</u>	<u>EUROPE</u>	4 years	6.8%	4.6%
None	47.4%	53.7%	5 years	3.8%	4.4%
UCTD/MCTD	1.5%	6.7%	6 years	2.3%	2.9%
Sjogren	9.6%	4.7%	7 years	1.5%	2.7%
APS	0.7%	2.4%	8 years	1.5%	2.4%
Other Autoimmune or Rheumatic	17.0%	13.8%	9 years	7.5%	2.3%
Fibromyalgia	14.1%	5.8%	10 to 20 years	13.5%	10.4%
Psychologic or mental disorder	11.9%	8.9%	More than 20 years	12.8%	5.5%
Other prior diagnosis	13.3%	16.5%	Grand Total	100.0%	100.0%
n=	133	4,275	n=	133	4,154



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**IMPACT ON STUDIES & CAREER**

<u>Education level</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Norway</u>	<u>EUROPE</u>
Basic	11.8%	3.7%	Employed full time	20.6%	34.6%
Secondary	45.7%	53.9%	Employed part time	21.4%	16.5%
Academic	42.5%	42.5%	Self-employed full time	0.8%	3.0%
n=	127	4,150	Self-employed part time	1.5%	2.4%
			Looking for employment	0.8%	5.1%
<u>Economic profile</u>	<u>Norway</u>	<u>EUROPE</u>	Stopped work for medical reason	37.4%	14.7%
No difficulties paying all bills	43.0%	46.9%	Retired	12.2%	11.6%
Occasional difficulties paying all bills.	29.6%	26.8%	Student	1.5%	4.0%
Often difficulties paying all bills	14.8%	10.4%	No paid employment / Full time home	3.8%	4.7%
Always difficulty paying all bills	5.9%	7.1%	Other / prefer not to answer	0.0%	3.5%
Did not respond	6.7%	8.9%	n=	131	4247
n=	135	4375			
<u>IMPACT ON STUDIES</u>	<u>Norway</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Norway</u>	<u>EUROPE</u>
Chose more relevant studies	3.0%	3.1%	No impact	11.0%	32.5%
could not do what they wanted	23.5%	11.1%	Changed career/ job	16.5%	13.5%
needed special support and received it	6.8%	4.6%	moved to Flexible hours	3.9%	8.1%
needed support but did NOT receive it	9.1%	2.9%	Reduced Work Schedule	26.8%	18.5%
Overall negative effect	15.2%	13.5%	Stopped work, gets social allowances	48.8%	18.5%
Overall positive effect	1.5%	1.4%	Missed promotion opportunities	7.9%	9.5%
No impact	54.5%	69.8%	Employment was terminated	6.3%	8.4%
n=	132	4240	Other negative impact	15.0%	20.8%
			Other positive impact	1.6%	1.8%
			Overall had negative impact	81.1%	57.9%
			n=	127	4024



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**IMPACT ON SOCIAL / FAMILY**

<u>Civil status</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Norway</u>	<u>EUROPE</u>
Child/young with family	2.4%	4.5%	None	15.4%	32.8%
Single	14.2%	17.4%	One child	20.0%	23.8%
Married / with partner	72.4%	66.9%	2 or more children	62.3%	38.9%
Divorced	8.7%	9.2%	Child/young living with family	2.3%	4.5%
Widowed	2.4%	2.0%			
n=	127	4206	n=	130	4288
<u>Would have liked more children</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Norway</u>	<u>EUROPE</u>
A. Yes	37.1%	37.6%	A. One miscarriage	21.0%	18.4%
B. No	48.4%	37.7%	B. Some miscarriages	15.3%	8.5%
C. don't know / prefer not to answer	14.5%	24.7%	C. Many miscarriages	7.3%	2.9%
n (women only) =	124	3,645	D. No miscarriage	56.5%	70.2%
			n (women only) =	124	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Norway</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Norway</u>	<u>EUROPE</u>
No Problem at all 1	9.9%	16.2%	Less active due to lupus	84.7%	72.6%
2	21.4%	32.3%	Equally active	9.2%	15.6%
3	42.7%	34.3%	More active due to lupus	3.8%	3.6%
4	22.9%	15.4%	I don't know	2.3%	8.1%
Fully Unable 5	3.1%	1.8%			
n=	131	4226	n=	131	4212
<u>Impact on Sexual/emotional life</u>	<u>Norway</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Norway</u>	<u>EUROPE</u>
Negative impact	41.2%	38.2%	It created tensions	29.9%	33.2%
Mixed Positive and negative	29.8%	36.2%	It is difficult for me	72.4%	68.4%
No significant impact	28.2%	23.9%	It is difficult for my partner	28.7%	26.7%
Positive impact	0.8%	1.6%	I am concerned for my couple	14.9%	13.2%
n=	131	4,204	Our relationship ended	21.8%	16.6%
			n=	87	2875



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DISEASE ACTIVITY						
<u>Lupus was under control past 3 months</u>		<u>Norway</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>		<u>Norway</u> <u>EUROPE</u>
Yes		66%	72%	1		0.0%      1.6%
No		34%	28%	2		0.8%      2.1%
	n=	134	4347	3		2.3%      4.4%
				4		5.3%      5.9%
				5		3.8%      6.1%
				6		9.2%      8.5%
				7		6.1%      9.3%
<u>Average nr of symptoms (list of 23)</u>		<u>Norway</u>	<u>EUROPE</u>	8		9.2%      10.4%
	n=	10.1	8.8	9		5.3%      10.1%
		131	4197	10		9.9%      9.3%
				11		8.4%      8.3%
				12		9.2%      7.0%
<u>Median number of symptoms</u>		<u>Norway</u>	<u>EUROPE</u>	13		10.7%      5.8%
	n=	10	9	14		7.6%      4.4%
		131	4197	15		4.6%      2.7%
				16		4.6%      2.1%
				17		1.5%      1.1%
				18		0.8%      0.4%
				19		0.0%      0.3%
				20		0.8%      0.0%
				n=		131      4197



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**Symptoms or Features experienced / Most bothersome**

Patient reported Symptoms or features	Norway	
	Regularly experience	Top 3 most bothersome
A. Rash	54%	7%
B. Sun sensitivity	<b>73%</b>	<b>27%</b>
C. Mouth ulcers	42%	0%
D. Dryness in the mouth or eyes	<b>68%</b>	12%
E. Dryness of the skin	66%	2%
F. Hair loss	56%	7%
G. Pain / swelling in joints	<b>81%</b>	<b>39%</b>
H. Jaccoud (hand deformation) or tendons a	15%	2%
I. Muscle Pain/Weakness	<b>80%</b>	<b>44%</b>
J. Headaches or migraine	63%	<b>23%</b>
K. Fatigue and weakness	<b>90%</b>	<b>62%</b>
L. Flu-like symptoms/Fevers	48%	5%
M. Shortness of breath	53%	5%
N. Depression or Anxiety	40%	13%
O. Haematologic problems incl. anemia	23%	2%
P. Poor circulation or Raynauds	50%	10%
Q. Kidney problems	17%	8%
R. Chest pain	37%	5%
S. High Blood pressure	26%	6%
T. Stroke, mini-stroke, Blood clots	11%	5%
U. Osteoporosis	18%	4%
n=	135	129

Patient reported Symptoms or features	EUROPE	
	Regularly experience	Top 3 most bothersome
A. Rash	40%	9%
B. Sun sensitivity	<b>69%</b>	<b>23%</b>
C. Mouth ulcers	35%	3%
D. Dryness in the mouth or eyes	55%	9%
E. Dryness of the skin	<b>57%</b>	4%
F. Hair loss	53%	14%
G. Pain / swelling in joints	<b>77%</b>	<b>49%</b>
H. Jaccoud (hand deformation) or tendor	14%	4%
I. Muscle Pain/Weakness	<b>68%</b>	<b>33%</b>
J. Headaches or migraine	51%	17%
K. Fatigue and weakness	<b>85%</b>	<b>55%</b>
L. Flu-like symptoms/Fevers	28%	4%
M. Shortness of breath	32%	6%
N. Depression or Anxiety	44%	<b>17%</b>
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>Norway</u>	<u>EUROPE</u>		<u>Norway</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=	130	4099	n=	130	4099
<u>Number of medications (list of 16)</u>	<u>Norway</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Norway</u>	<u>EUROPE</u>
1	3.1%	5.4%	Non Steroids Anti-Inflammatory	19.2%	32.9%
2	10.0%	9.0%	Antimalarials	<b>83.1%</b>	<b>75.0%</b>
3	11.5%	12.5%	Oral Steroids	<b>60.8%</b>	<b>52.4%</b>
4	17.7%	14.1%	Immunosuppressants	26.9%	39.8%
5	15.4%	14.8%	Biologics	9.2%	10.9%
6	13.8%	13.9%	Painkillers	<b>72.3%</b>	<b>50.1%</b>
7	12.3%	11.8%	Antidepressant	8.5%	17.0%
8	3.8%	9.0%	Anxiolytic	12.3%	11.7%
9	7.7%	5.1%	Anticoagulants	14.6%	16.6%
10	2.3%	2.5%	Thyroid medication	15.4%	14.8%
11	2.3%	1.1%	Blood circulation and heart	20.8%	23.3%
12	0.0%	0.4%	Stomach protection	32.3%	<b>47.0%</b>
13	0.0%	0.2%	Statins	5.4%	5.9%
n=	130	4099	Calcium	<b>46.2%</b>	29.7%
			Vitamin D	<b>64.6%</b>	<b>68.4%</b>
			Vitamins (excl.D) / mineral complements	31.5%	25.4%



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

<u>I have appropriate access to</u>	<u>Norway</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Norway</u>	<u>EUROPE</u>
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)		
Experienced lupus doctors	3.17	3.81	Mobility	2.31	2.22
Multidisciplinary team	2.79	3.28	Self care	1.64	1.71
Specialised nurses that know lupus	2.77	2.92	Daily Activities	2.88	2.54
Prescribed medication	3.91	4.08	Pain or discomfort	3.34	3.14
Affordable treatments	3.15	3.77	Anxiety or depression	2.68	2.96
Social support and benefits	2.99	2.78	Average	2.57	2.51
Physiotherapy, Rehab, Occupational Thera	2.87	2.77			
Professional psychological support	2.45	2.68			
	n min	97		n min	130
	n max	119		n max	131
		3126			4196
		3842			4240
<u>Worry about lupus progressing?</u>	<u>Norway</u>	<u>EUROPE</u>			
Very Low (1-2)	4.7%	3.6%			
Low (3-4)	10.9%	9.3%			
Mid (5-6)	31.0%	24.5%			
High (7-8)	40.3%	41.0%			
Very high (9-10)	13.2%	21.6%			
	n=	129			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>Norway</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%	58%	Mobility	73%	59%	
Self care	88%	77%	Self care	86%	73%	
Daily Activities	57%	46%	Daily Activities	66%	51%	
Pain or discomfort	44%	37%	Pain or discomfort	51%	35%	
Anxiety or depression	60%	54%	Anxiety or depression	54%	44%	
Average	64%	54%	Average	66%	52%	
	n min	84	45	n min	3011	1179
	n max	85	46	n max	3042	1194

	<u>Norway</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	81.2%	91.3%	Less active due to lupus	68.6%	83.0%	
Equally active	10.6%	6.5%	Equally active	18.8%	7.6%	
More active due to lupus	4.7%	2.2%	More active due to lupus	4.0%	2.7%	
I don't know	3.5%	0.0%	I don't know	8.7%	6.7%	
	n=	85	46	n=	3018	1189

	<u>Norway</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	36.5%	50.0%	Negative impact	34.0%	49.0%	
Mixed + and -	32.9%	23.9%	Mixed + and -	36.4%	35.7%	
No significant impact	29.4%	26.1%	No significant impact	27.8%	14.1%	
Positive impact	1.2%	0.0%	Positive impact	1.8%	1.2%	
	n=	85	46	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>Norway</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	78%	60%	Mobility	75%	62%
Self care	92%	79%	Self care	86%	76%
Daily Activities	62%	45%	Daily Activities	67%	53%
Pain or discomfort	51%	35%	Pain or discomfort	52%	39%
Anxiety or depression	59%	55%	Anxiety or depression	52%	49%
Average	68%	55%	Average	66%	56%
	Difference	-14%		Difference	-10%
	of which - explained by age (*)	-3%		of which - explained by age	-3%
	n min	41		n min	1926
	n max	42		n max	1951
	average age:	44.7			41.2
		56			1239
		57			1249
		52.0			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



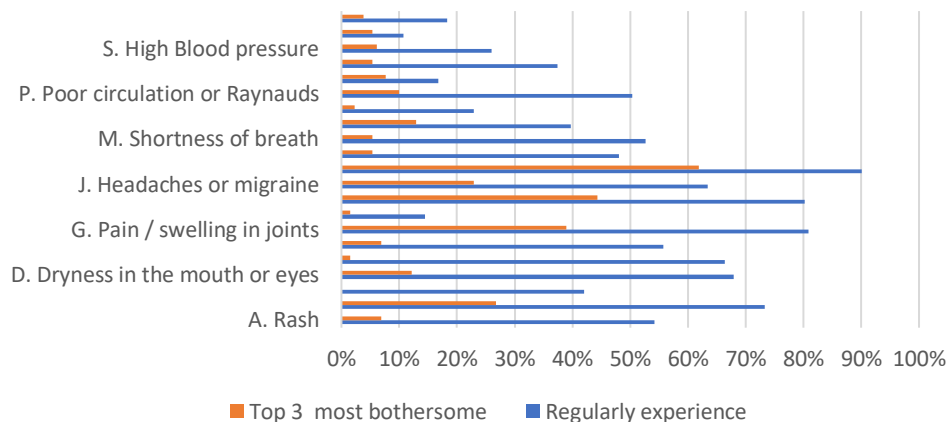
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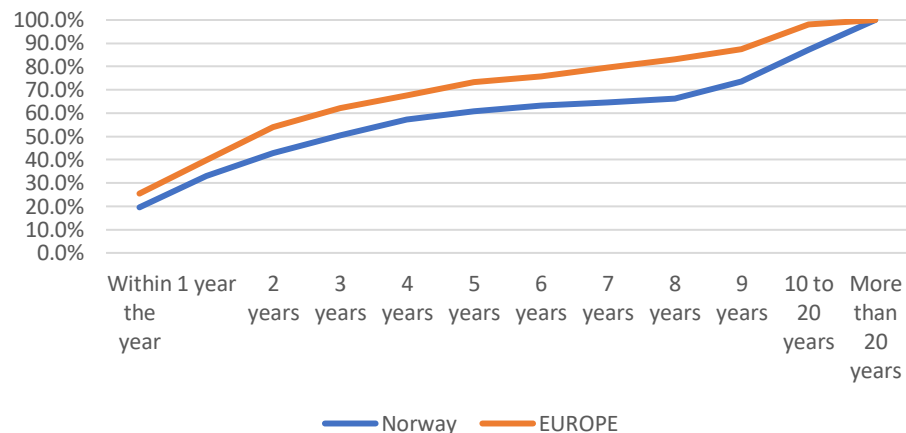
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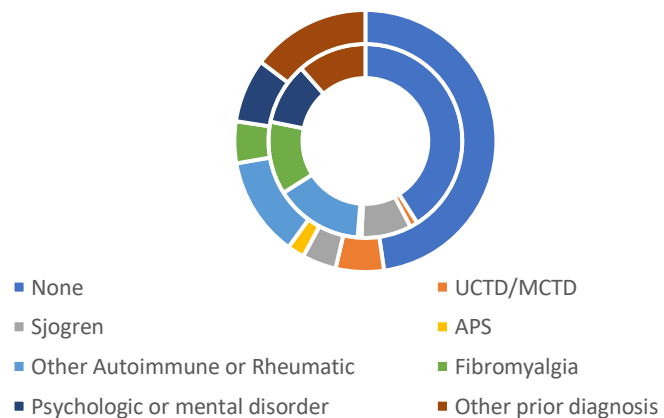
## Patient reported symptoms and features



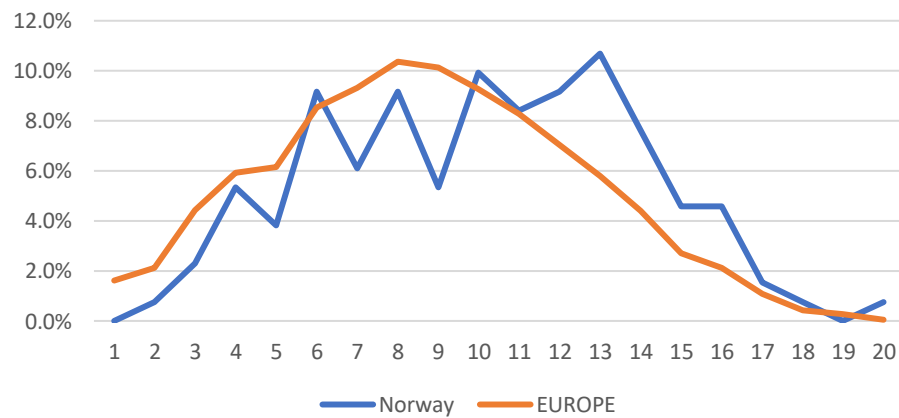
## Patient time to diagnosis



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



## Number of symptoms experienced



DATA FOR: Norway

