



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Denmark



Living with lupus in 2020 - Country level data

DATA FOR: **Denmark**

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

COUNTRY: Denmark

DEMOGRAPHICS:

	<u>Denmark</u>	<u>EUROPE</u>	<u>Age</u>	<u>Denmark</u>	<u>EUROPE</u>
Total number of responses	110	4375	Up to 25	4.5%	6.4%
			26 to 35	13.6%	17.9%
<u>Gender</u>	<u>Denmark</u>	<u>EUROPE</u>	36 to 45	21.8%	27.4%
Man	4.5%	3.7%	46 to 55	27.3%	26.6%
Woman	94.5%	95.6%	56 to 65	26.4%	14.8%
Other / prefer not to answer	0.9%	0.7%	above 65	3.6%	5.1%
Total	100.0%	100.0%	NA	2.7%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Denmark</u>	<u>EUROPE</u>
SLE	100.0%	94.4%	Within the year	21.9%	26.5%
Child onset SLE	0.0%	5.6%	1 year	21.0%	21.1%
Grand Total	100.0%	100.0%	2 years	9.5%	11.5%
			3 years	9.5%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Denmark</u>	<u>EUROPE</u>	4 years	4.8%	4.6%
None	65.5%	53.7%	5 years	3.8%	4.4%
UCTD/MCTD	1.8%	6.7%	6 years	1.9%	2.9%
Sjogren	1.8%	4.7%	7 years	2.9%	2.7%
APS	5.5%	2.4%	8 years	4.8%	2.4%
Other Autoimmune or Rheumatic	12.7%	13.8%	9 years	1.9%	2.3%
Fibromyalgia	0.0%	5.8%	10 to 20 years	7.6%	10.4%
Psychologic or mental disorder	3.6%	8.9%	More than 20 years	10.5%	5.5%
Other prior diagnosis	17.3%	16.5%	Grand Total	100.0%	100.0%
n=	108	4,275	n=	105	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Denmark</u>	<u>EUROPE</u>
Basic	0.0%	3.7%	Employed full time	24.1%	34.6%
Secondary	39.6%	53.9%	Employed part time	25.0%	16.5%
Academic	60.4%	42.5%	Self-employed full time	0.0%	3.0%
n=	106	4,150	Self-employed part time	3.7%	2.4%
			Looking for employment	2.8%	5.1%
<u>Economic profile</u>	<u>Denmark</u>	<u>EUROPE</u>	Stopped work for medical reason	15.7%	14.7%
No difficulties paying all bills	70.0%	46.9%	Retired	19.4%	11.6%
Occasional difficulties paying all bills.	18.2%	26.8%	Student	6.5%	4.0%
Often difficulties paying all bills	3.6%	10.4%	No paid employment / Full time home	0.9%	4.7%
Always difficulty paying all bills	2.7%	7.1%	Other / prefer not to answer	1.9%	3.5%
Did not respond	5.5%	8.9%			
n=	110	4375	n=	108	4247
<u>IMPACT ON STUDIES</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Denmark</u>	<u>EUROPE</u>
Chose more relevant studies	3.7%	3.1%	No impact	20.0%	32.5%
could not do what they wanted	18.5%	11.1%	Changed career/ job	6.0%	13.5%
needed special support and received it	6.5%	4.6%	moved to Flexible hours	1.0%	8.1%
needed support but did NOT receive it	5.6%	2.9%	Reduced Work Schedule	33.0%	18.5%
Overall negative effect	17.6%	13.5%	Stopped work, gets social allowances	31.0%	18.5%
Overall positive effect	0.9%	1.4%	Missed promotion opportunities	9.0%	9.5%
No impact	62.0%	69.8%	Employment was terminated	7.0%	8.4%
n=	108	4240	Other negative impact	19.0%	20.8%
			Other positive impact	1.0%	1.8%
			Overall had negative impact	79.0%	57.9%
			n=	100	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Denmark</u>	<u>EUROPE</u>
Child/young with family	3.7%	4.5%	None	25.0%	32.8%
Single	15.0%	17.4%	One child	17.6%	23.8%
Married / with partner	71.0%	66.9%	2 or more children	53.7%	38.9%
Divorced	10.3%	9.2%	Child/young living with family	3.7%	4.5%
Widowed	0.0%	2.0%			
n=	107	4206	n=	108	4288
<u>Would have liked more children</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Denmark</u>	<u>EUROPE</u>
A. Yes	45.3%	37.6%	A. One miscarriage	16.8%	18.4%
B. No	37.9%	37.7%	B. Some miscarriages	10.5%	8.5%
C. don't know / prefer not to answer	16.8%	24.7%	C. Many miscarriages	1.1%	2.9%
n (women only) =	95	3,645	D. No miscarriage	71.6%	70.2%
			n (women only) =	95	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Denmark</u>	<u>EUROPE</u>
No Problem at all 1	8.3%	16.2%	Less active due to lupus	78.5%	72.6%
2	23.1%	32.3%	Equally active	12.1%	15.6%
3	38.9%	34.3%	More active due to lupus	1.9%	3.6%
4	24.1%	15.4%	I don't know	7.5%	8.1%
Fully Unable 5	5.6%	1.8%			
n=	108	4226	n=	107	4212
<u>Impact on Sexual/emotional life</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Denmark</u>	<u>EUROPE</u>
Negative impact	43.5%	38.2%	It created tensions	31.6%	33.2%
Mixed Positive and negative	35.2%	36.2%	It is difficult for me	79.7%	68.4%
No significant impact	21.3%	23.9%	It is difficult for my partner	30.4%	26.7%
Positive impact	0.0%	1.6%	I am concerned for my couple	19.0%	13.2%
n=	108	4,204	Our relationship ended	15.2%	16.6%
			n=	79	2875



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DISEASE ACTIVITY

<u>Lupus was under control past 3 months</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>	<u>Denmark</u>	<u>EUROPE</u>
Yes	63%	72%	1	0.9%	1.6%
No	37%	28%	2	0.9%	2.1%
			3	6.5%	4.4%
n=	110	4347	4	3.7%	5.9%
			5	9.3%	6.1%
			6	4.7%	8.5%
	<u>Denmark</u>	<u>EUROPE</u>	7	9.3%	9.3%
<u>Average nr of symptoms (list of 23)</u>	9.1	8.8	8	9.3%	10.4%
n=	107	4197	9	8.4%	10.1%
			10	8.4%	9.3%
			11	11.2%	8.3%
	<u>Denmark</u>	<u>EUROPE</u>	12	5.6%	7.0%
<u>Median number of symptoms</u>	9	9	13	7.5%	5.8%
n=	107	4197	14	5.6%	4.4%
			15	2.8%	2.7%
			16	3.7%	2.1%
			17	0.9%	1.1%
			18	0.0%	0.4%
			19	0.9%	0.3%
			20	0.0%	0.0%
			n=	107	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Denmark	
	Regularly experience	Top 3 most bothersome
A. Rash	51%	10%
B. Sun sensitivity	69%	29%
C. Mouth ulcers	39%	4%
D. Dryness in the mouth or eyes	52%	11%
E. Dryness of the skin	57%	4%
F. Hair loss	52%	7%
G. Pain / swelling in joints	77%	47%
H. Jaccoud (hand deformation) or tendons a	11%	2%
I. Muscle Pain/Weakness	79%	35%
J. Headaches or migraine	51%	9%
K. Fatigue and weakness	93%	73%
L. Flu-like symptoms/Fevers	50%	13%
M. Shortness of breath	32%	3%
N. Depression or Anxiety	36%	16%
O. Haematologic problems incl. anemia	21%	2%
P. Poor circulation or Raynauds	36%	5%
Q. Kidney problems	16%	8%
R. Chest pain	31%	2%
S. High Blood pressure	26%	1%
T. Stroke, mini-stroke, Blood clots	13%	8%
U. Osteoporosis	21%	3%
n=	110	105

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>Denmark</u>	<u>EUROPE</u>		<u>Denmark</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	5.8	5.2	<u>Median number of medication (from list of 16)</u>	6	5
n=	106	4099	n=	106	4099
<u>Number of medications (list of 16)</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Denmark</u>	<u>EUROPE</u>
1	1.9%	5.4%	Non Steroids Anti-Inflammatory	25.5%	32.9%
2	5.7%	9.0%	Antimalarials	76.4%	75.0%
3	13.2%	12.5%	Oral Steroids	41.5%	52.4%
4	9.4%	14.1%	Immunosuppressants	57.5%	39.8%
5	13.2%	14.8%	Biologics	11.3%	10.9%
6	20.8%	13.9%	Painkillers	73.6%	50.1%
7	15.1%	11.8%	Antidepressant	15.1%	17.0%
8	9.4%	9.0%	Anxiolytic	3.8%	11.7%
9	6.6%	5.1%	Anticoagulants	24.5%	16.6%
10	0.9%	2.5%	Thyroid medication	10.4%	14.8%
11	1.9%	1.1%	Blood circulation and heart	19.8%	23.3%
12	0.9%	0.4%	Stomach protection	36.8%	47.0%
13	0.9%	0.2%	Statins	10.4%	5.9%
n=	106	4099	Calcium	63.2%	29.7%
			Vitamin D	68.9%	68.4%
			Vitamins (excl.D) / mineral complements	36.8%	25.4%



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

<u>I have appropriate access to</u>	<u>Denmark</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Denmark</u>	<u>EUROPE</u>
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)		
Experienced lupus doctors	4.00	3.81	Mobility	2.27	2.22
Multidisciplinary team	3.60	3.28	Self care	1.68	1.71
Specialised nurses that know lupus	3.63	2.92	Daily Activities	2.95	2.54
Prescribed medication	4.29	4.08	Pain or discomfort	3.10	3.14
Affordable treatments	3.94	3.77	Anxiety or depression	2.68	2.96
Social support and benefits	3.24	2.78	Average	2.54	2.51
Physiotherapy, Rehab, Occupational Thera	3.43	2.77			
Professional psychological support	2.70	2.68			
n min	86	3126	n min	108	4196
n max	103	3842	n max	108	4240
<u>Worry about lupus progressing?</u>	<u>Denmark</u>	<u>EUROPE</u>			
Very Low (1-2)	3.8%	3.6%			
Low (3-4)	10.6%	9.3%			
Mid (5-6)	20.2%	24.5%			
High (7-8)	50.0%	41.0%			
Very high (9-10)	15.4%	21.6%			
n=	104	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>Denmark</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	76%	54%	Mobility	73%	59%	
Self care	89%	73%	Self care	86%	73%	
Daily Activities	58%	39%	Daily Activities	66%	51%	
Pain or discomfort	55%	34%	Pain or discomfort	51%	35%	
Anxiety or depression	59%	56%	Anxiety or depression	54%	44%	
Average	67%	51%	Average	66%	52%	
	n min	69	39	n min	3011	1179
	n max	69	39	n max	3042	1194

	<u>Denmark</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	73.5%	87.2%	Less active due to lupus	68.6%	83.0%	
Equally active	13.2%	10.3%	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	10.3%	2.6%	I don't know	8.7%	6.7%	
	n=	68	39	n=	3018	1189

	<u>Denmark</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	42.0%	46.2%	Negative impact	34.0%	49.0%	
Mixed + and -	33.3%	38.5%	Mixed + and -	36.4%	35.7%	
No significant impact	24.6%	15.4%	No significant impact	27.8%	14.1%	
Positive impact	0.0%	0.0%	Positive impact	1.8%	1.2%	
	n=	69	39	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>Denmark</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	76%	59%	Mobility	75%	62%
Self care	86%	77%	Self care	86%	76%
Daily Activities	57%	46%	Daily Activities	67%	53%
Pain or discomfort	53%	39%	Pain or discomfort	52%	39%
Anxiety or depression	59%	61%	Anxiety or depression	52%	49%
Average	66%	57%	Average	66%	56%
	Difference	-9%		Difference	-10%
	of which - explained by age (*)	-4%		of which - explained by age	-3%
	n min	45		n min	1926
	n max	45		n max	1951
	average age:	40.6			41.2
		35			1239
		35			1249
		52.4			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



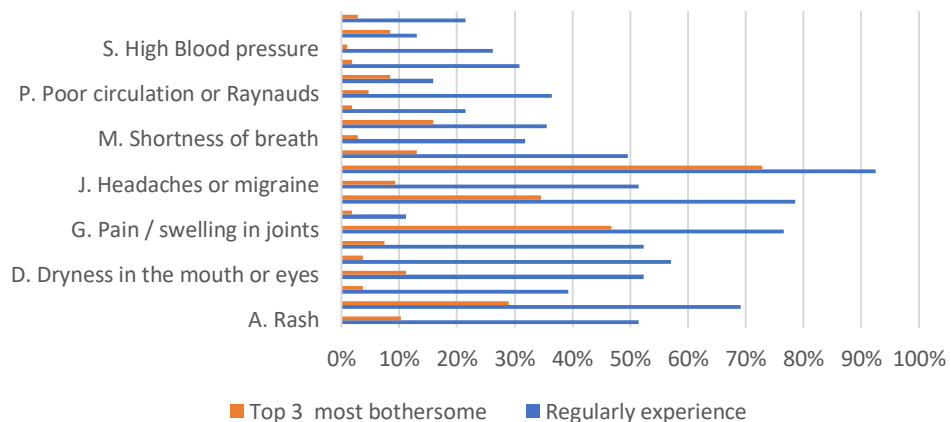
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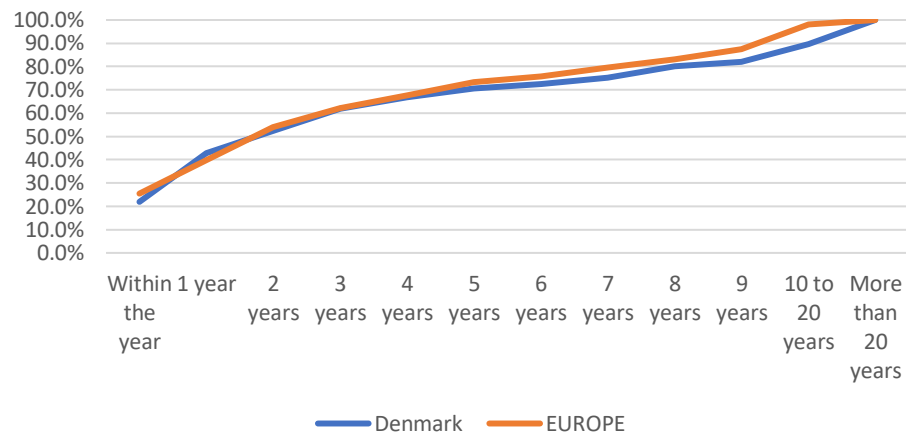
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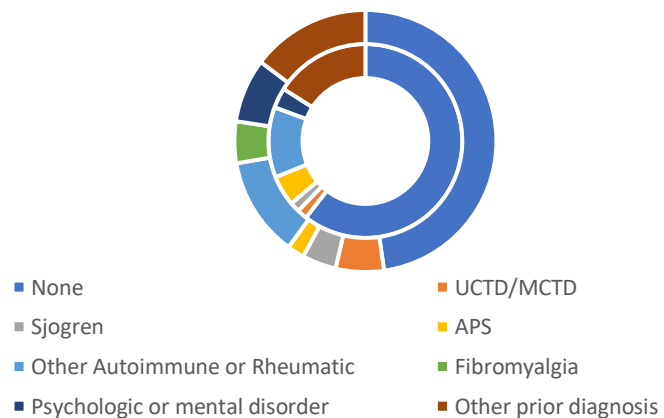
Patient reported symptoms and features



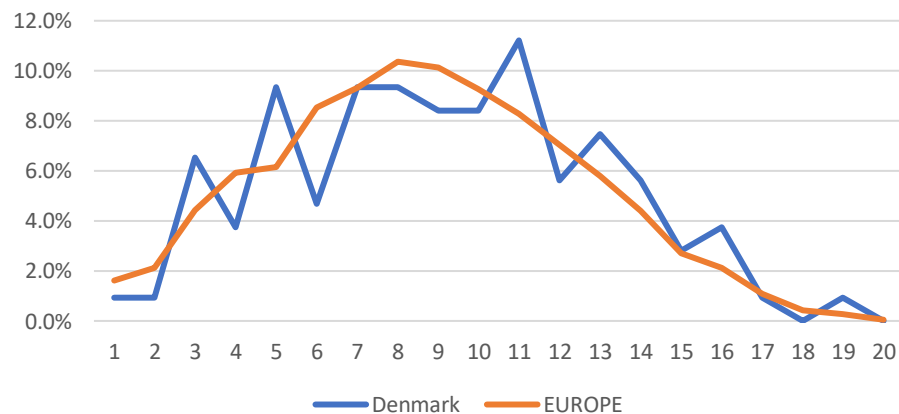
Patient time to diagnosis



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



Number of symptoms experienced





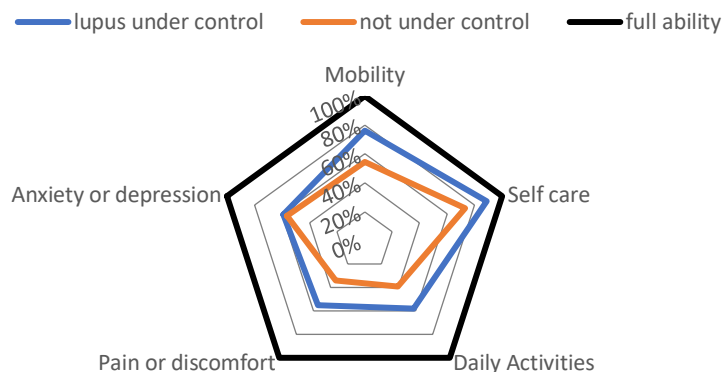
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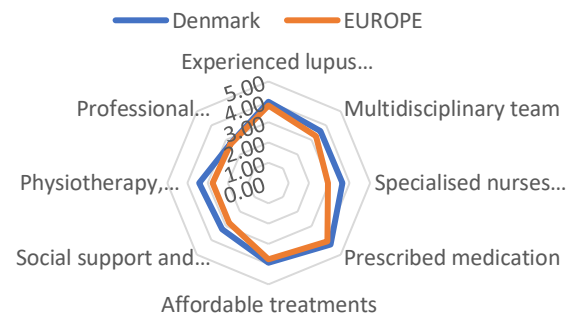
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

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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