



**LUPUS EUROPE**

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

**Poland**



Living with lupus in 2020 - Country level data

DATA FOR: **Poland**

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

COUNTRY: Poland

**DEMOGRAPHICS:**

	<u>Poland</u>	<u>EUROPE</u>	<u>Age</u>	<u>Poland</u>	<u>EUROPE</u>
Total number of responses	120	4375	Up to 25	9.2%	6.4%
			26 to 35	29.2%	17.9%
<u>Gender</u>	<u>Poland</u>	<u>EUROPE</u>	36 to 45	40.8%	27.4%
Man	0.8%	3.7%	46 to 55	11.7%	26.6%
Woman	98.3%	95.6%	56 to 65	7.5%	14.8%
Other / prefer not to answer	0.8%	0.7%	above 65	0.8%	5.1%
Total	100.0%	100.0%	NA	0.8%	1.8%
			Grand Total	100.0%	100.0%

**DIAGNOSIS**

<u>Diagnosis</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Poland</u>	<u>EUROPE</u>
SLE	95.0%	94.4%	Within the year	27.2%	26.5%
Child onset SLE	5.0%	5.6%	1 year	24.6%	21.1%
Grand Total	100.0%	100.0%	2 years	12.3%	11.5%
			3 years	5.3%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Poland</u>	<u>EUROPE</u>	4 years	6.1%	4.6%
None	49.2%	53.7%	5 years	0.0%	4.4%
UCTD/MCTD	16.7%	6.7%	6 years	3.5%	2.9%
Sjogren	2.5%	4.7%	7 years	2.6%	2.7%
APS	2.5%	2.4%	8 years	4.4%	2.4%
Other Autoimmune or Rheumatic	20.0%	13.8%	9 years	4.4%	2.3%
Fibromyalgia	3.3%	5.8%	10 to 20 years	7.0%	10.4%
Psychologic or mental disorder	7.5%	8.9%	More than 20 years	2.6%	5.5%
Other prior diagnosis	17.5%	16.5%	Grand Total	100.0%	100.0%
n=	118	4,275	n=	114	4,154



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**IMPACT ON STUDIES & CAREER**

<u>Education level</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Poland</u>	<u>EUROPE</u>
Basic	0.0%	3.7%	Employed full time	44.9%	34.6%
Secondary	44.4%	53.9%	Employed part time	5.9%	16.5%
Academic	55.6%	42.5%	Self-employed full time	5.1%	3.0%
n=	117	4,150	Self-employed part time	0.8%	2.4%
			Looking for employment	5.9%	5.1%
<u>Economic profile</u>	<u>Poland</u>	<u>EUROPE</u>	Stopped work for medical reason	19.5%	14.7%
No difficulties paying all bills	45.0%	46.9%	Retired	2.5%	11.6%
Occasional difficulties paying all bills.	26.7%	26.8%	Student	5.9%	4.0%
Often difficulties paying all bills	13.3%	10.4%	No paid employment / Full time home	5.1%	4.7%
Always difficulty paying all bills	6.7%	7.1%	Other / prefer not to answer	4.2%	3.5%
Did not respond	8.3%	8.9%	n=	118	4247
n=	120	4375			
<u>IMPACT ON STUDIES</u>	<u>Poland</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Poland</u>	<u>EUROPE</u>
Chose more relevant studies	7.6%	3.1%	No impact	36.9%	32.5%
could not do what they wanted	16.9%	11.1%	Changed career/ job	13.5%	13.5%
needed special support and received it	5.1%	4.6%	moved to Flexible hours	9.0%	8.1%
needed support but did NOT receive it	6.8%	2.9%	Reduced Work Schedule	16.2%	18.5%
Overall negative effect	9.3%	13.5%	Stopped work, gets social allowances	17.1%	18.5%
Overall positive effect	0.8%	1.4%	Missed promotion opportunities	3.6%	9.5%
No impact	61.9%	69.8%	Employment was terminated	15.3%	8.4%
n=	118	4240	Other negative impact	15.3%	20.8%
			Other positive impact	1.8%	1.8%
			Overall had negative impact	51.4%	57.9%
			n=	111	4024



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**IMPACT ON SOCIAL / FAMILY**

<u>Civil status</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Poland</u>	<u>EUROPE</u>
Child/young with family	4.5%	4.5%	None	36.4%	32.8%
Single	15.3%	17.4%	One child	22.9%	23.8%
Married / with partner	72.1%	66.9%	2 or more children	36.4%	38.9%
Divorced	5.4%	9.2%	Child/young living with family	4.2%	4.5%
Widowed	2.7%	2.0%			
n=	111	4206	n=	118	4288
<u>Would have liked more children</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Poland</u>	<u>EUROPE</u>
A. Yes	34.2%	37.6%	A. One miscarriage	15.3%	18.4%
B. No	38.7%	37.7%	B. Some miscarriages	8.1%	8.5%
C. don't know / prefer not to answer	27.0%	24.7%	C. Many miscarriages	0.9%	2.9%
n (women only) =	111	3,645	D. No miscarriage	75.7%	70.2%
			n (women only) =	111	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Poland</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Poland</u>	<u>EUROPE</u>
No Problem at all 1	24.6%	16.2%	Less active due to lupus	72.0%	72.6%
2	39.0%	32.3%	Equally active	20.3%	15.6%
3	25.4%	34.3%	More active due to lupus	2.5%	3.6%
4	9.3%	15.4%	I don't know	5.1%	8.1%
Fully Unable 5	1.7%	1.8%			
n=	118	4226	n=	118	4212
<u>Impact on Sexual/emotional life</u>	<u>Poland</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Poland</u>	<u>EUROPE</u>
Negative impact	39.8%	38.2%	It created tensions	33.7%	33.2%
Mixed Positive and negative	36.4%	36.2%	It is difficult for me	62.8%	68.4%
No significant impact	23.7%	23.9%	It is difficult for my partner	20.9%	26.7%
Positive impact	0.0%	1.6%	I am concerned for my couple	19.8%	13.2%
n=	118	4,204	Our relationship ended	20.9%	16.6%
			n=	86	2875



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DISEASE ACTIVITY							
<u>Lupus was under control past 3 months</u>		<u>Poland</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>		<u>Poland</u>	<u>EUROPE</u>
Yes		71%	72%	1		2.6%	1.6%
No		29%	28%	2		4.3%	2.1%
	n=	120	4347	3		5.1%	4.4%
				4		5.1%	5.9%
				5		4.3%	6.1%
				6		11.1%	8.5%
				7		6.8%	9.3%
<u>Average nr of symptoms (list of 23)</u>		<u>Poland</u>	<u>EUROPE</u>	8		9.4%	10.4%
	n=	8.4	8.8	9		11.1%	10.1%
		117	4197	10		8.5%	9.3%
				11		12.0%	8.3%
				12		7.7%	7.0%
<u>Median number of symptoms</u>		<u>Poland</u>	<u>EUROPE</u>	13		3.4%	5.8%
	n=	9	9	14		3.4%	4.4%
		117	4197	15		1.7%	2.7%
				16		2.6%	2.1%
				17		0.9%	1.1%
				18		0.0%	0.4%
				19		0.0%	0.3%
				20		0.0%	0.0%
				n=		117	4197



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**Symptoms or Features experienced / Most bothersome**

Patient reported Symptoms or features	Poland	
	Regularly experience	Top 3 most bothersome
A. Rash	26%	6%
B. Sun sensitivity	<b>67%</b>	18%
C. Mouth ulcers	29%	4%
D. Dryness in the mouth or eyes	44%	7%
E. Dryness of the skin	<b>64%</b>	6%
F. Hair loss	<b>68%</b>	<b>21%</b>
G. Pain / swelling in joints	<b>68%</b>	<b>56%</b>
H. Jaccoud (hand deformation) or tendons a	6%	3%
I. Muscle Pain/Weakness	53%	<b>21%</b>
J. Headaches or migraine	60%	<b>24%</b>
K. Fatigue and weakness	<b>88%</b>	<b>50%</b>
L. Flu-like symptoms/Fevers	25%	4%
M. Shortness of breath	17%	4%
N. Depression or Anxiety	39%	11%
O. Haematologic problems incl. anemia	33%	6%
P. Poor circulation or Raynauds	38%	8%
Q. Kidney problems	32%	18%
R. Chest pain	32%	4%
S. High Blood pressure	24%	6%
T. Stroke, mini-stroke, Blood clots	6%	3%
U. Osteoporosis	22%	4%
n=	120	113

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>Poland</u>	<u>EUROPE</u>		<u>Poland</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=	113	4099	n=	113	4099
<u>Number of medications (list of 16)</u>	<u>Poland</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Poland</u>	<u>EUROPE</u>
1	3.5%	5.4%	Non Steroids Anti-Inflammatory	27.4%	32.9%
2	9.7%	9.0%	Antimalarials	<b>76.1%</b>	<b>75.0%</b>
3	4.4%	12.5%	Oral Steroids	<b>67.3%</b>	<b>52.4%</b>
4	15.9%	14.1%	Immunosuppressants	44.2%	39.8%
5	15.0%	14.8%	Biologics	3.5%	10.9%
6	8.8%	13.9%	Painkillers	46.9%	<b>50.1%</b>
7	11.5%	11.8%	Antidepressant	9.7%	17.0%
8	15.9%	9.0%	Anxiolytic	4.4%	11.7%
9	8.0%	5.1%	Anticoagulants	17.7%	16.6%
10	4.4%	2.5%	Thyroid medication	21.2%	14.8%
11	1.8%	1.1%	Blood circulation and heart	23.0%	23.3%
12	0.9%	0.4%	Stomach protection	<b>57.5%</b>	<b>47.0%</b>
13	0.0%	0.2%	Statins	6.2%	5.9%
n=	113	4099	Calcium	<b>47.8%</b>	29.7%
			Vitamin D	<b>84.1%</b>	<b>68.4%</b>
			Vitamins (excl.D) / mineral complements	45.1%	25.4%



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

<u>I have appropriate access to</u>	<u>Poland</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Poland</u>	<u>EUROPE</u>
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)		
Experienced lupus doctors	3.29	3.81	Mobility	2.14	2.22
Multidisciplinary team	2.47	3.28	Self care	1.64	1.71
Specialised nurses that know lupus	2.09	2.92	Daily Activities	2.25	2.54
Prescribed medication	3.25	4.08	Pain or discomfort	3.12	3.14
Affordable treatments	2.89	3.77	Anxiety or depression	3.28	2.96
Social support and benefits	2.26	2.78	Average	2.48	2.51
Physiotherapy, Rehab, Occupational Thera	2.27	2.77			
Professional psychological support	2.43	2.68			
	n min	86		n min	116
	n max	101		n max	118
		3126			4196
		3842			4240
<u>Worry about lupus progressing?</u>	<u>Poland</u>	<u>EUROPE</u>			
Very Low (1-2)	2.7%	3.6%			
Low (3-4)	11.7%	9.3%			
Mid (5-6)	14.4%	24.5%			
High (7-8)	36.0%	41.0%			
Very high (9-10)	35.1%	21.6%			
	n=	111			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>Poland</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%	60%	Mobility	73%	59%	
Self care	89%	73%	Self care	86%	73%	
Daily Activities	73%	59%	Daily Activities	66%	51%	
Pain or discomfort	52%	35%	Pain or discomfort	51%	35%	
Anxiety or depression	47%	33%	Anxiety or depression	54%	44%	
Average	67%	52%	Average	66%	52%	
	n min	83	33	n min	3011	1179
	n max	84	34	n max	3042	1194

	<u>Poland</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	67.9%	82.4%	Less active due to lupus	68.6%	83.0%	
Equally active	25.0%	8.8%	Equally active	18.8%	7.6%	
More active due to lupus	2.4%	2.9%	More active due to lupus	4.0%	2.7%	
I don't know	4.8%	5.9%	I don't know	8.7%	6.7%	
	n=	84	34	n=	3018	1189

	<u>Poland</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	33.3%	55.9%	Negative impact	34.0%	49.0%	
Mixed + and -	36.9%	35.3%	Mixed + and -	36.4%	35.7%	
No significant impact	29.8%	8.8%	No significant impact	27.8%	14.1%	
Positive impact	0.0%	0.0%	Positive impact	1.8%	1.2%	
	n=	84	34	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>Poland</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	90%	76%	Self care	86%	76%
Daily Activities	79%	50%	Daily Activities	67%	53%
Pain or discomfort	57%	32%	Pain or discomfort	52%	39%
Anxiety or depression	48%	32%	Anxiety or depression	52%	49%
Average	70%	50%	Average	66%	56%
	Difference	-20%		Difference	-10%
	of which - explained by age (*)	-1%		of which - explained by age	-3%
	n min	57		n min	1926
	n max	59		n max	1951
	average age:	36.2			41.2
		40.2			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



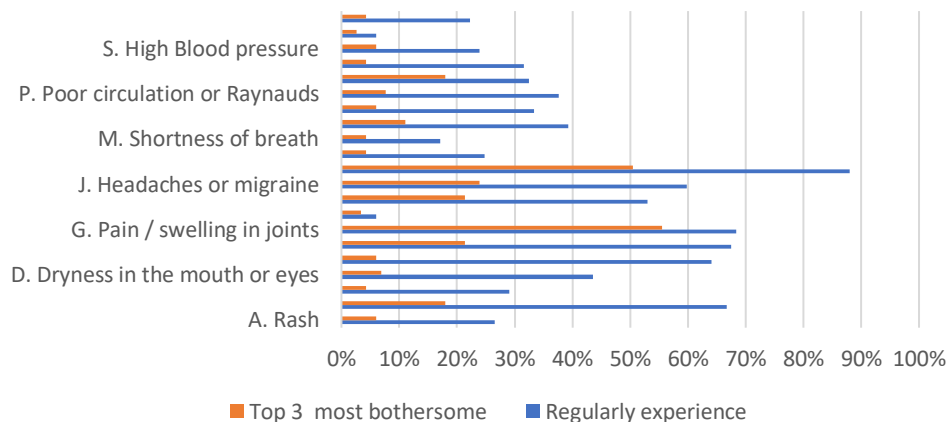
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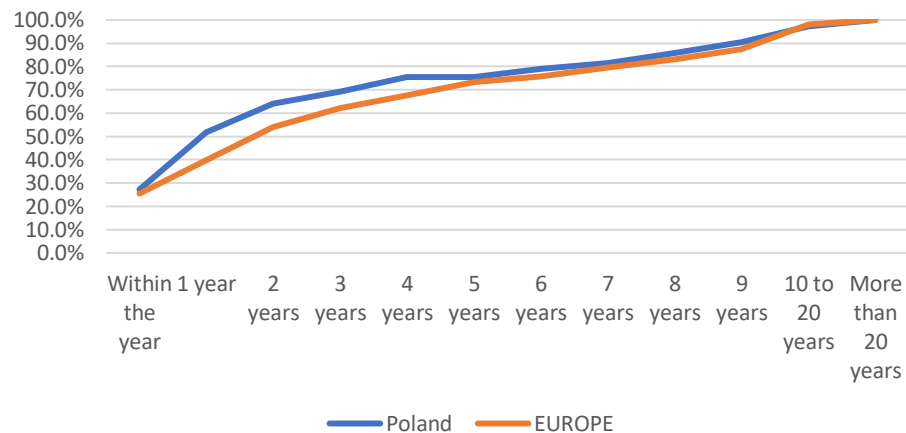
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

DATA FOR: 0

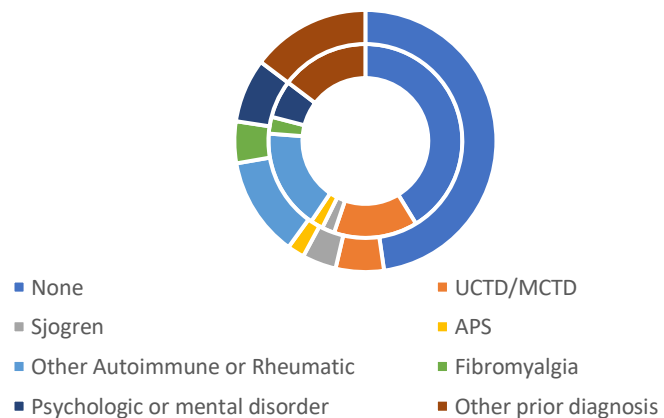
## Patient reported symptoms and features



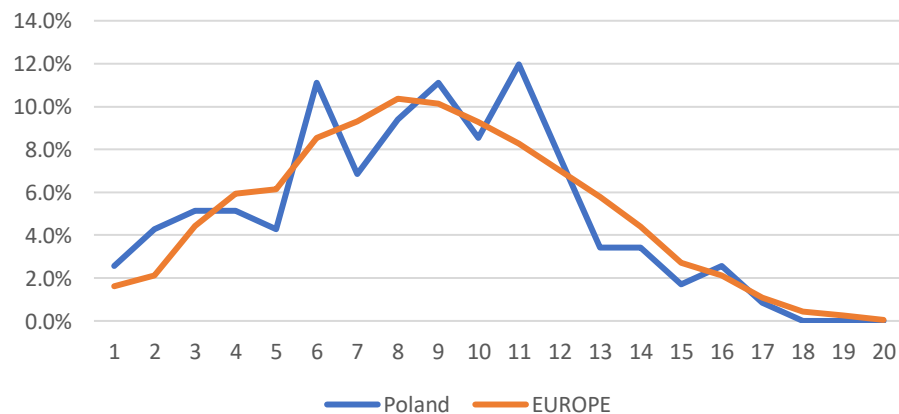
## Patient time to diagnosis



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



## Number of symptoms experienced





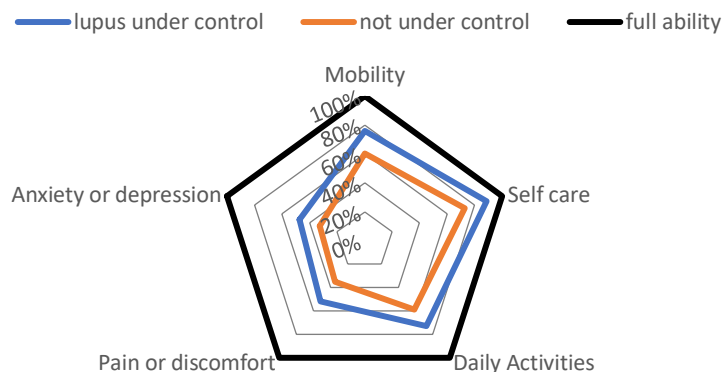
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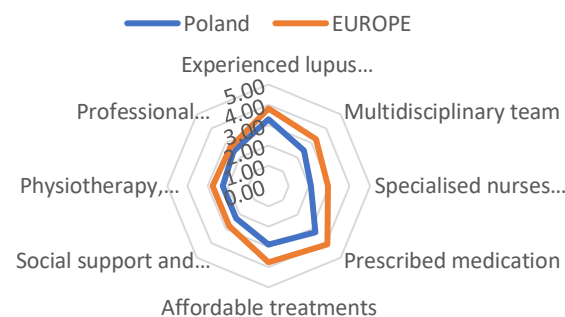
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DATA FOR: 0

### % 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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