



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Belgium



Living with lupus in 2020 - Country level data

DATA FOR: **Belgium**

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

COUNTRY: Belgium

DEMOGRAPHICS:

	<u>Belgium</u>	<u>EUROPE</u>	<u>Age</u>	<u>Belgium</u>	<u>EUROPE</u>
Total number of responses	207	4375	Up to 25	3.9%	6.4%
			26 to 35	15.9%	17.9%
<u>Gender</u>	<u>Belgium</u>	<u>EUROPE</u>	36 to 45	23.7%	27.4%
Man	2.9%	3.7%	46 to 55	23.7%	26.6%
Woman	95.2%	95.6%	56 to 65	20.8%	14.8%
Other / prefer not to answer	1.9%	0.7%	above 65	10.1%	5.1%
Total	100.0%	100.0%	NA	1.9%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Belgium</u>	<u>EUROPE</u>
SLE	93.2%	94.4%	Within the year	28.6%	26.5%
Child onset SLE	6.8%	5.6%	1 year	16.1%	21.1%
Grand Total	100.0%	100.0%	2 years	13.6%	11.5%
			3 years	3.5%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Belgium</u>	<u>EUROPE</u>	4 years	5.5%	4.6%
None	48.3%	53.7%	5 years	5.5%	4.4%
UCTD/MCTD	3.4%	6.7%	6 years	2.0%	2.9%
Sjogren	10.1%	4.7%	7 years	1.0%	2.7%
APS	1.0%	2.4%	8 years	3.0%	2.4%
Other Autoimmune or Rheumatic	14.0%	13.8%	9 years	3.0%	2.3%
Fibromyalgia	8.7%	5.8%	10 to 20 years	12.1%	10.4%
Psychologic or mental disorder	10.6%	8.9%	More than 20 years	6.0%	5.5%
Other prior diagnosis	19.3%	16.5%	Grand Total	100.0%	100.0%
n=	202	4,275	n=	199	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Belgium</u>	<u>EUROPE</u>
Basic	2.1%	3.7%	Employed full time	19.9%	34.6%
Secondary	49.5%	53.9%	Employed part time	19.9%	16.5%
Academic	48.4%	42.5%	Self-employed full time	2.0%	3.0%
n=	188	4,150	Self-employed part time	3.0%	2.4%
			Looking for employment	2.5%	5.1%
<u>Economic profile</u>	<u>Belgium</u>	<u>EUROPE</u>	Stopped work for medical reason	26.9%	14.7%
No difficulties paying all bills	50.7%	46.9%	Retired	14.9%	11.6%
Occasional difficulties paying all bills.	28.5%	26.8%	Student	1.5%	4.0%
Often difficulties paying all bills	10.1%	10.4%	No paid employment / Full time home	4.0%	4.7%
Always difficulty paying all bills	3.9%	7.1%	Other / prefer not to answer	5.5%	3.5%
Did not respond	6.8%	8.9%	n=	201	4247
n=	207	4375			
<u>IMPACT ON STUDIES</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Belgium</u>	<u>EUROPE</u>
Chose more relevant studies	2.5%	3.1%	No impact	23.5%	32.5%
could not do what they wanted	7.9%	11.1%	Changed career/ job	7.0%	13.5%
needed special support and received it	5.9%	4.6%	moved to Flexible hours	6.0%	8.1%
needed support but did NOT receive it	0.0%	2.9%	Reduced Work Schedule	27.5%	18.5%
Overall negative effect	13.8%	13.5%	Stopped work, gets social allowances	31.5%	18.5%
Overall positive effect	0.0%	1.4%	Missed promotion opportunities	8.5%	9.5%
No impact	75.9%	69.8%	Employment was terminated	7.5%	8.4%
n=	203	4240	Other negative impact	17.0%	20.8%
			Other positive impact	1.5%	1.8%
			Overall had negative impact	73.0%	57.9%
			n=	200	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Belgium</u>	<u>EUROPE</u>
Child/young with family	3.5%	4.5%	None	28.4%	32.8%
Single	15.9%	17.4%	One child	24.0%	23.8%
Married / with partner	67.7%	66.9%	2 or more children	44.1%	38.9%
Divorced	10.4%	9.2%	Child/young living with family	3.4%	4.5%
Widowed	2.5%	2.0%			
n=	201	4206	n=	204	4288
<u>Would have liked more children</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Belgium</u>	<u>EUROPE</u>
A. Yes	28.3%	37.6%	A. One miscarriage	18.9%	18.4%
B. No	48.1%	37.7%	B. Some miscarriages	8.6%	8.5%
C. don't know / prefer not to answer	23.5%	24.7%	C. Many miscarriages	2.7%	2.9%
n (women only) =	187	3,645	D. No miscarriage	69.7%	70.2%
			n (women only) =	185	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Belgium</u>	<u>EUROPE</u>
No Problem at all 1	8.9%	16.2%	Less active due to lupus	78.2%	72.6%
2	30.7%	32.3%	Equally active	12.9%	15.6%
3	36.1%	34.3%	More active due to lupus	2.0%	3.6%
4	20.8%	15.4%	I don't know	6.9%	8.1%
Fully Unable 5	3.5%	1.8%			
n=	202	4226	n=	202	4212
<u>Impact on Sexual/emotional life</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Belgium</u>	<u>EUROPE</u>
Negative impact	39.6%	38.2%	It created tensions	34.1%	33.2%
Mixed Positive and negative	35.6%	36.2%	It is difficult for me	76.3%	68.4%
No significant impact	24.3%	23.9%	It is difficult for my partner	38.5%	26.7%
Positive impact	0.5%	1.6%	I am concerned for my couple	14.8%	13.2%
n=	202	4,204	Our relationship ended	14.1%	16.6%
			n=	135	2875



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DISEASE ACTIVITY							
<u>Lupus was under control past 3 months</u>		<u>Belgium</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>		<u>Belgium</u>	<u>EUROPE</u>
Yes		74%	72%	1		1.0%	1.6%
No		26%	28%	2		0.5%	2.1%
	n=	206	4347	3		3.5%	4.4%
				4		4.5%	5.9%
				5		6.0%	6.1%
				6		6.0%	8.5%
				7		13.4%	9.3%
<u>Average nr of symptoms (list of 23)</u>		<u>Belgium</u>	<u>EUROPE</u>	8		10.0%	10.4%
	n=	9.0	8.8	9		14.9%	10.1%
		201	4197	10		11.4%	9.3%
				11		8.5%	8.3%
				12		7.0%	7.0%
<u>Median number of symptoms</u>		<u>Belgium</u>	<u>EUROPE</u>	13		3.0%	5.8%
	n=	9	9	14		3.0%	4.4%
		201	4197	15		4.0%	2.7%
				16		1.0%	2.1%
				17		1.0%	1.1%
				18		1.0%	0.4%
				19		0.5%	0.3%
				20		0.0%	0.0%
				n=		201	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Belgium		Patient reported Symptoms or features	EUROPE	
	Regularly experience	Top 3 most bothersome		Regularly experience	Top 3 most bothersome
A. Rash	40%	6%	A. Rash	40%	9%
B. Sun sensitivity	76%	22%	B. Sun sensitivity	69%	23%
C. Mouth ulcers	28%	2%	C. Mouth ulcers	35%	3%
D. Dryness in the mouth or eyes	61%	12%	D. Dryness in the mouth or eyes	55%	9%
E. Dryness of the skin	63%	2%	E. Dryness of the skin	57%	4%
F. Hair loss	50%	9%	F. Hair loss	53%	14%
G. Pain / swelling in joints	80%	52%	G. Pain / swelling in joints	77%	49%
H. Jaccoud (hand deformation) or tendons a	17%	4%	H. Jaccoud (hand deformation) or tendor	14%	4%
I. Muscle Pain/Weakness	78%	37%	I. Muscle Pain/Weakness	68%	33%
J. Headaches or migraine	54%	13%	J. Headaches or migraine	51%	17%
K. Fatigue and weakness	89%	59%	K. Fatigue and weakness	85%	55%
L. Flu-like symptoms/Fevers	32%	4%	L. Flu-like symptoms/Fevers	28%	4%
M. Shortness of breath	37%	7%	M. Shortness of breath	32%	6%
N. Depression or Anxiety	37%	12%	N. Depression or Anxiety	44%	17%
O. Haematologic problems incl. anemia	24%	2%	O. Haematologic problems incl. anemia	27%	4%
P. Poor circulation or Raynauds	39%	4%	P. Poor circulation or Raynauds	45%	8%
Q. Kidney problems	16%	8%	Q. Kidney problems	20%	11%
R. Chest pain	26%	6%	R. Chest pain	24%	4%
S. High Blood pressure	20%	3%	S. High Blood pressure	23%	4%
T. Stroke, mini-stroke, Blood clots	10%	6%	T. Stroke, mini-stroke, Blood clots	9%	4%
U. Osteoporosis	17%	3%	U. Osteoporosis	19%	5%
n=	207	189	n=	4375	4084



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MEDICATION

	<u>Belgium</u>	<u>EUROPE</u>		<u>Belgium</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	5.4	5.2	<u>Median number of medication (from list of 16)</u>	5	5
n=	196	4099	n=	196	4099
<u>Number of medications (list of 16)</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Belgium</u>	<u>EUROPE</u>
1	3.1%	5.4%	Non Steroids Anti-Inflammatory	40.3%	32.9%
2	8.7%	9.0%	Antimalarials	72.4%	75.0%
3	12.8%	12.5%	Oral Steroids	43.4%	52.4%
4	14.3%	14.1%	Immunosuppressants	31.6%	39.8%
5	14.8%	14.8%	Biologics	3.6%	10.9%
6	11.7%	13.9%	Painkillers	57.1%	50.1%
7	12.2%	11.8%	Antidepressant	18.9%	17.0%
8	14.8%	9.0%	Anxiolytic	19.4%	11.7%
9	5.1%	5.1%	Anticoagulants	11.7%	16.6%
10	1.5%	2.5%	Thyroid medication	21.9%	14.8%
11	1.0%	1.1%	Blood circulation and heart	21.9%	23.3%
12	0.0%	0.4%	Stomach protection	45.4%	47.0%
13	0.0%	0.2%	Statins	7.1%	5.9%
n=	196	4099	Calcium	37.2%	29.7%
			Vitamin D	72.4%	68.4%
			Vitamins (excl.D) / mineral complements	32.7%	25.4%



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

<u>I have appropriate access to</u>	<u>Belgium</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Belgium</u>	<u>EUROPE</u>	
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)			
Experienced lupus doctors	4.03	3.81	Mobility	2.26	2.22	
Multidisciplinary team	3.39	3.28	Self care	1.71	1.71	
Specialised nurses that know lupus	2.89	2.92	Daily Activities	2.79	2.54	
Prescribed medication	4.29	4.08	Pain or discomfort	3.19	3.14	
Affordable treatments	3.75	3.77	Anxiety or depression	2.57	2.96	
Social support and benefits	2.78	2.78	Average	2.50	2.51	
Physiotherapy, Rehab, Occupational Thera	3.14	2.77				
Professional psychological support	2.72	2.68				
	n min	143	3126	n min	200	4196
	n max	191	3842	n max	202	4240
<u>Worry about lupus progressing?</u>	<u>Belgium</u>	<u>EUROPE</u>				
Very Low (1-2)	4.5%	3.6%				
Low (3-4)	8.6%	9.3%				
Mid (5-6)	26.8%	24.5%				
High (7-8)	49.0%	41.0%				
Very high (9-10)	11.1%	21.6%				
	n=	198	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>Belgium</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%	57%	Mobility	73%	59%	
Self care	86%	70%	Self care	86%	73%	
Daily Activities	59%	44%	Daily Activities	66%	51%	
Pain or discomfort	51%	29%	Pain or discomfort	51%	35%	
Anxiety or depression	64%	53%	Anxiety or depression	54%	44%	
Average	66%	51%	Average	66%	52%	
	n min	149	51	n min	3011	1179
	n max	151	51	n max	3042	1194

	<u>Belgium</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	74.2%	90.2%	Less active due to lupus	68.6%	83.0%	
Equally active	16.6%	2.0%	Equally active	18.8%	7.6%	
More active due to lupus	2.6%	0.0%	More active due to lupus	4.0%	2.7%	
I don't know	6.6%	7.8%	I don't know	8.7%	6.7%	
	n=	151	51	n=	3018	1189

	<u>Belgium</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	35.1%	52.9%	Negative impact	34.0%	49.0%	
Mixed + and -	35.1%	37.3%	Mixed + and -	36.4%	35.7%	
No significant impact	29.1%	9.8%	No significant impact	27.8%	14.1%	
Positive impact	0.7%	0.0%	Positive impact	1.8%	1.2%	
	n=	151	51	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>Belgium</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	74%	62%	Mobility	75%	62%
Self care	85%	77%	Self care	86%	76%
Daily Activities	63%	48%	Daily Activities	67%	53%
Pain or discomfort	49%	40%	Pain or discomfort	52%	39%
Anxiety or depression	63%	60%	Anxiety or depression	52%	49%
Average	67%	58%	Average	66%	56%
	Difference	-9%		Difference	-10%
	of which - explained by age (*)	-1%		of which - explained by age	-3%
	n min	87		n min	1926
	n max	88		n max	1951
	average age:	47.2			41.2
		63			1239
		64			1249
		51.0			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



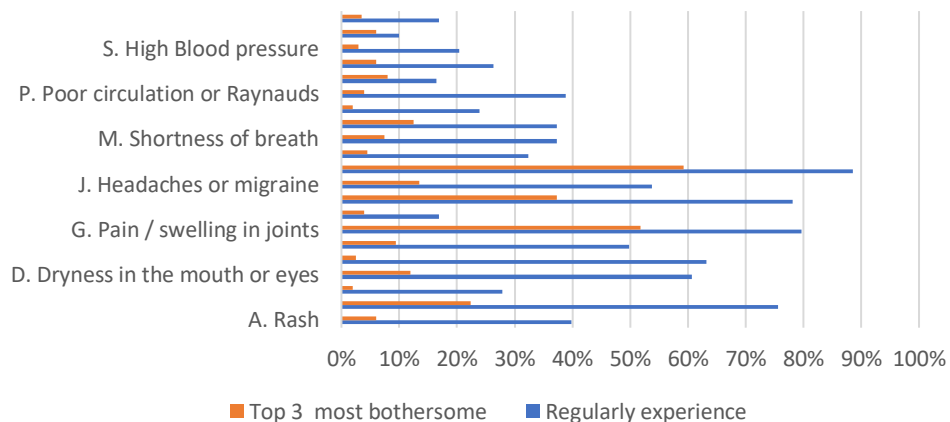
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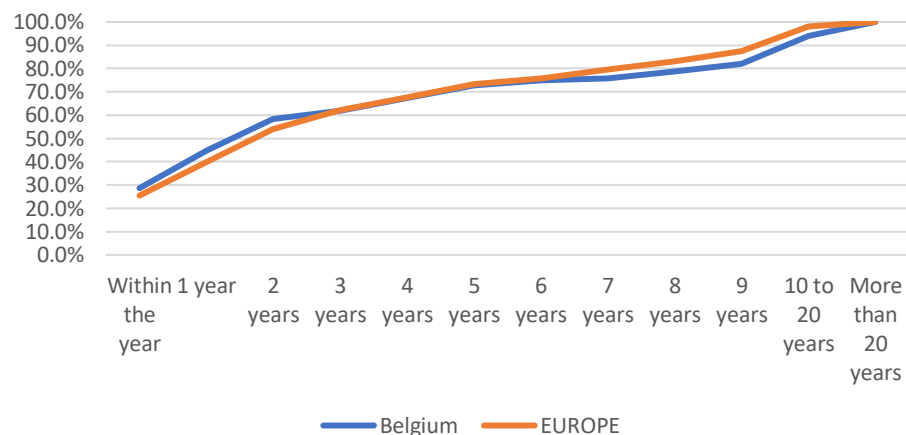
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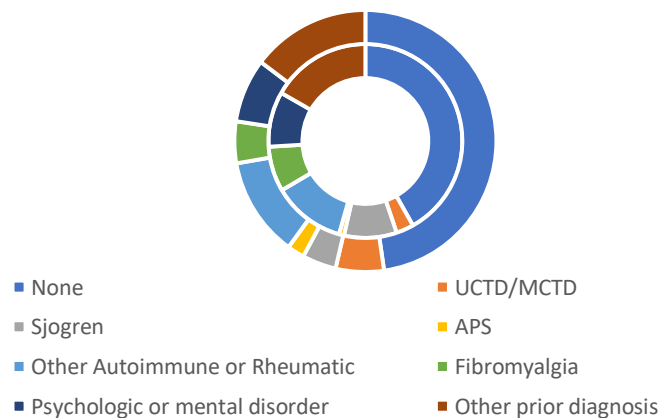
Patient reported symptoms and features



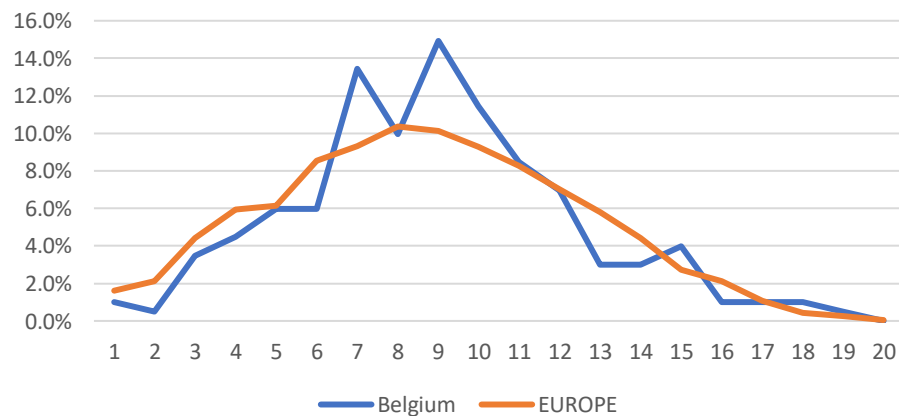
Patient time to diagnosis



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



Number of symptoms experienced



DATA FOR: Belgium

