



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Bulgaria



Living with lupus in 2020 - Country level data

DATA FOR: **Bulgaria**

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

COUNTRY: Bulgaria

DEMOGRAPHICS:

	<u>Bulgaria</u>	<u>EUROPE</u>	<u>Age</u>	<u>Bulgaria</u>	<u>EUROPE</u>
Total number of responses	168	4375	Up to 25	4.8%	6.4%
			26 to 35	16.1%	17.9%
<u>Gender</u>	<u>Bulgaria</u>	<u>EUROPE</u>	36 to 45	35.7%	27.4%
Man	4.2%	3.7%	46 to 55	26.8%	26.6%
Woman	95.2%	95.6%	56 to 65	12.5%	14.8%
Other / prefer not to answer	0.6%	0.7%	above 65	1.2%	5.1%
Total	100.0%	100.0%	NA	3.0%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Bulgaria</u>	<u>EUROPE</u>
SLE	100.0%	94.4%	Within the year	25.5%	26.5%
Child onset SLE	0.0%	5.6%	1 year	14.3%	21.1%
Grand Total	100.0%	100.0%	2 years	14.3%	11.5%
			3 years	8.1%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Bulgaria</u>	<u>EUROPE</u>	4 years	5.6%	4.6%
None	53.6%	53.7%	5 years	5.6%	4.4%
UCTD/MCTD	7.1%	6.7%	6 years	2.5%	2.9%
Sjogren	4.2%	4.7%	7 years	3.7%	2.7%
APS	1.8%	2.4%	8 years	3.7%	2.4%
Other Autoimmune or Rheumatic	14.9%	13.8%	9 years	4.3%	2.3%
Fibromyalgia	1.2%	5.8%	10 to 20 years	10.6%	10.4%
Psychologic or mental disorder	4.8%	8.9%	More than 20 years	1.9%	5.5%
Other prior diagnosis	25.0%	16.5%	Grand Total	100.0%	100.0%
n=	166	4,275	n=	161	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Bulgaria</u>	<u>EUROPE</u>
Basic	3.1%	3.7%	Employed full time	59.0%	34.6%
Secondary	34.6%	53.9%	Employed part time	3.7%	16.5%
Academic	62.3%	42.5%	Self-employed full time	6.2%	3.0%
n=	162	4,150	Self-employed part time	1.2%	2.4%
			Looking for employment	4.3%	5.1%
<u>Economic profile</u>	<u>Bulgaria</u>	<u>EUROPE</u>	Stopped work for medical reason	6.8%	14.7%
No difficulties paying all bills	31.5%	46.9%	Retired	11.2%	11.6%
Occasional difficulties paying all bills.	28.6%	26.8%	Student	3.1%	4.0%
Often difficulties paying all bills	19.0%	10.4%	No paid employment / Full time home	1.9%	4.7%
Always difficulty paying all bills	17.3%	7.1%	Other / prefer not to answer	2.5%	3.5%
Did not respond	3.6%	8.9%			
n=	168	4375	n=	161	4247
<u>IMPACT ON STUDIES</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Bulgaria</u>	<u>EUROPE</u>
Chose more relevant studies	3.1%	3.1%	No impact	34.6%	32.5%
could not do what they wanted	10.0%	11.1%	Changed career/ job	14.5%	13.5%
needed special support and received it	2.5%	4.6%	moved to Flexible hours	8.2%	8.1%
needed support but did NOT receive it	1.3%	2.9%	Reduced Work Schedule	6.9%	18.5%
Overall negative effect	9.4%	13.5%	Stopped work, gets social allowances	13.2%	18.5%
Overall positive effect	3.1%	1.4%	Missed promotion opportunities	11.3%	9.5%
No impact	72.5%	69.8%	Employment was terminated	14.5%	8.4%
n=	160	4240	Other negative impact	19.5%	20.8%
			Other positive impact	1.9%	1.8%
			Overall had negative impact	52.2%	57.9%
			n=	159	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Bulgaria</u>	<u>EUROPE</u>
Child/young with family	3.7%	4.5%	None	17.5%	32.8%
Single	10.6%	17.4%	One child	42.8%	23.8%
Married / with partner	67.7%	66.9%	2 or more children	36.1%	38.9%
Divorced	14.3%	9.2%	Child/young living with family	3.6%	4.5%
Widowed	3.7%	2.0%			
n=	161	4206	n=	166	4288
<u>Would have liked more children</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Bulgaria</u>	<u>EUROPE</u>
A. Yes	78.5%	37.6%	A. One miscarriage	17.0%	18.4%
B. No	4.7%	37.7%	B. Some miscarriages	5.9%	8.5%
C. don't know / prefer not to answer	16.8%	24.7%	C. Many miscarriages	0.0%	2.9%
n (women only) =	149	3,645	D. No miscarriage	77.1%	70.2%
			n (women only) =	153	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Bulgaria</u>	<u>EUROPE</u>
No Problem at all 1	22.8%	16.2%	Less active due to lupus	71.9%	72.6%
2	38.3%	32.3%	Equally active	18.8%	15.6%
3	27.2%	34.3%	More active due to lupus	3.1%	3.6%
4	9.9%	15.4%	I don't know	6.3%	8.1%
Fully Unable 5	1.9%	1.8%			
n=	162	4226	n=	160	4212
<u>Impact on Sexual/emotional life</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Bulgaria</u>	<u>EUROPE</u>
Negative impact	45.6%	38.2%	It created tensions	43.3%	33.2%
Mixed Positive and negative	37.5%	36.2%	It is difficult for me	48.1%	68.4%
No significant impact	15.0%	23.9%	It is difficult for my partner	7.7%	26.7%
Positive impact	1.9%	1.6%	I am concerned for my couple	10.6%	13.2%
n=	160	4,204	Our relationship ended	10.6%	16.6%
			n=	104	2875



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DISEASE ACTIVITY							
<u>Lupus was under control past 3 months</u>		<u>Bulgaria</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>		<u>Bulgaria</u>	<u>EUROPE</u>
Yes		69%	72%	1		1.2%	1.6%
No		31%	28%	2		1.2%	2.1%
	n=	167	4347	3		4.3%	4.4%
				4		10.4%	5.9%
				5		6.1%	6.1%
				6		8.6%	8.5%
				7		8.6%	9.3%
<u>Average nr of symptoms (list of 23)</u>		<u>Bulgaria</u>	<u>EUROPE</u>	8		12.9%	10.4%
	n=	8.5	8.8	9		9.2%	10.1%
		163	4197	10		8.0%	9.3%
				11		7.4%	8.3%
				12		4.9%	7.0%
<u>Median number of symptoms</u>		<u>Bulgaria</u>	<u>EUROPE</u>	13		6.7%	5.8%
	n=	8	9	14		5.5%	4.4%
		163	4197	15		3.1%	2.7%
				16		1.2%	2.1%
				17		0.6%	1.1%
				18		0.0%	0.4%
				19		0.0%	0.3%
				20		0.0%	0.0%
				n=		163	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Bulgaria	
	Regularly experience	Top 3 most bothersome
A. Rash	41%	17%
B. Sun sensitivity	63%	20%
C. Mouth ulcers	29%	6%
D. Dryness in the mouth or eyes	45%	7%
E. Dryness of the skin	60%	3%
F. Hair loss	63%	20%
G. Pain / swelling in joints	70%	52%
H. Jaccoud (hand deformation) or tendons a	7%	4%
I. Muscle Pain/Weakness	61%	30%
J. Headaches or migraine	46%	16%
K. Fatigue and weakness	80%	41%
L. Flu-like symptoms/Fevers	22%	2%
M. Shortness of breath	27%	12%
N. Depression or Anxiety	50%	16%
O. Haematologic problems incl. anemia	31%	4%
P. Poor circulation or Raynauds	44%	6%
Q. Kidney problems	27%	13%
R. Chest pain	20%	4%
S. High Blood pressure	34%	7%
T. Stroke, mini-stroke, Blood clots	4%	2%
U. Osteoporosis	25%	9%
n=	168	158

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>Bulgaria</u>	<u>EUROPE</u>		<u>Bulgaria</u>	<u>EUROPE</u>
<u>Average number of medication (from list of 16)</u>	4.7	5.2	<u>Median number of medication (from list of 16)</u>	4	5
n=	162	4099	n=	162	4099
<u>Number of medications (list of 16)</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Bulgaria</u>	<u>EUROPE</u>
1	6.8%	5.4%	Non Steroids Anti-Inflammatory	25.3%	32.9%
2	11.1%	9.0%	Antimalarials	75.9%	75.0%
3	16.0%	12.5%	Oral Steroids	73.5%	52.4%
4	17.9%	14.1%	Immunosuppressants	25.9%	39.8%
5	14.8%	14.8%	Biologics	15.4%	10.9%
6	13.0%	13.9%	Painkillers	24.7%	50.1%
7	8.0%	11.8%	Antidepressant	6.8%	17.0%
8	4.3%	9.0%	Anxiolytic	3.1%	11.7%
9	3.7%	5.1%	Anticoagulants	9.3%	16.6%
10	2.5%	2.5%	Thyroid medication	19.8%	14.8%
11	1.2%	1.1%	Blood circulation and heart	20.4%	23.3%
12	0.0%	0.4%	Stomach protection	48.8%	47.0%
13	0.6%	0.2%	Statins	1.9%	5.9%
n=	162	4099	Calcium	17.3%	29.7%
			Vitamin D	66.0%	68.4%
			Vitamins (excl.D) / mineral complements	37.0%	25.4%



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

<u>I have appropriate access to</u>	<u>Bulgaria</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Bulgaria</u>	<u>EUROPE</u>
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)		
Experienced lupus doctors	3.98	3.81	Mobility	2.34	2.22
Multidisciplinary team	3.39	3.28	Self care	1.69	1.71
Specialised nurses that know lupus	3.14	2.92	Daily Activities	2.30	2.54
Prescribed medication	2.55	4.08	Pain or discomfort	3.18	3.14
Affordable treatments	2.76	3.77	Anxiety or depression	3.27	2.96
Social support and benefits	2.98	2.78	Average	2.55	2.51
Physiotherapy, Rehab, Occupational Thera	2.73	2.77			
Professional psychological support	2.68	2.68			
n min	126	3126	n min	160	4196
n max	154	3842	n max	162	4240
<u>Worry about lupus progressing?</u>	<u>Bulgaria</u>	<u>EUROPE</u>			
Very Low (1-2)	3.9%	3.6%			
Low (3-4)	6.5%	9.3%			
Mid (5-6)	27.1%	24.5%			
High (7-8)	29.7%	41.0%			
Very high (9-10)	32.9%	21.6%			
n=	155	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>Bulgaria</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	71%	57%	Mobility	73%	59%	
Self care	87%	74%	Self care	86%	73%	
Daily Activities	72%	59%	Daily Activities	66%	51%	
Pain or discomfort	52%	32%	Pain or discomfort	51%	35%	
Anxiety or depression	47%	36%	Anxiety or depression	54%	44%	
Average	66%	51%	Average	66%	52%	
	n min	110	49	n min	3011	1179
	n max	112	50	n max	3042	1194

	<u>Bulgaria</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	70.0%	76.0%	Less active due to lupus	68.6%	83.0%	
Equally active	20.9%	14.0%	Equally active	18.8%	7.6%	
More active due to lupus	3.6%	2.0%	More active due to lupus	4.0%	2.7%	
I don't know	5.5%	8.0%	I don't know	8.7%	6.7%	
	n=	110	50	n=	3018	1189

	<u>Bulgaria</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	44.1%	49.0%	Negative impact	34.0%	49.0%	
Mixed + and -	36.0%	40.8%	Mixed + and -	36.4%	35.7%	
No significant impact	17.1%	10.2%	No significant impact	27.8%	14.1%	
Positive impact	2.7%	0.0%	Positive impact	1.8%	1.2%	
	n=	111	49	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>Bulgaria</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%	61%	Mobility	75%	62%
Self care	89%	76%	Self care	86%	76%
Daily Activities	72%	59%	Daily Activities	67%	53%
Pain or discomfort	51%	36%	Pain or discomfort	52%	39%
Anxiety or depression	42%	41%	Anxiety or depression	52%	49%
Average	65%	55%	Average	66%	56%
	Difference	-10%		Difference	-10%
	of which - explained by age (*)	-3%		of which - explained by age	-3%
	n min	61		n min	1926
	n max	62		n max	1951
	average age:	38.4			41.2
		51			1239
		51			1249
		46.3			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



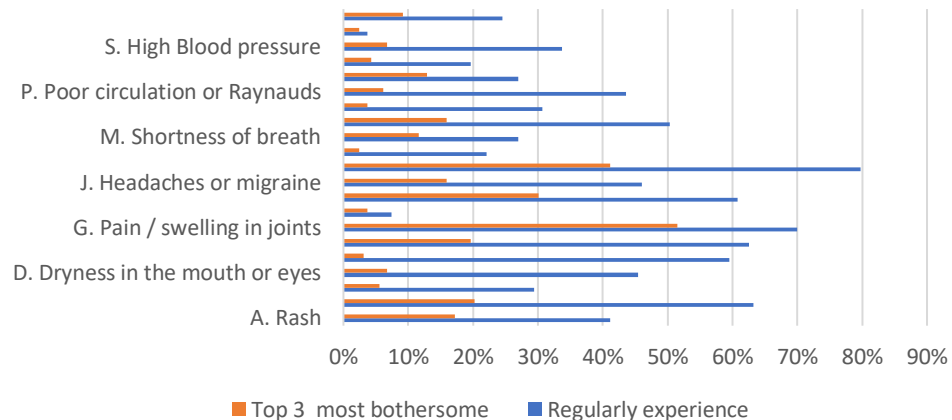
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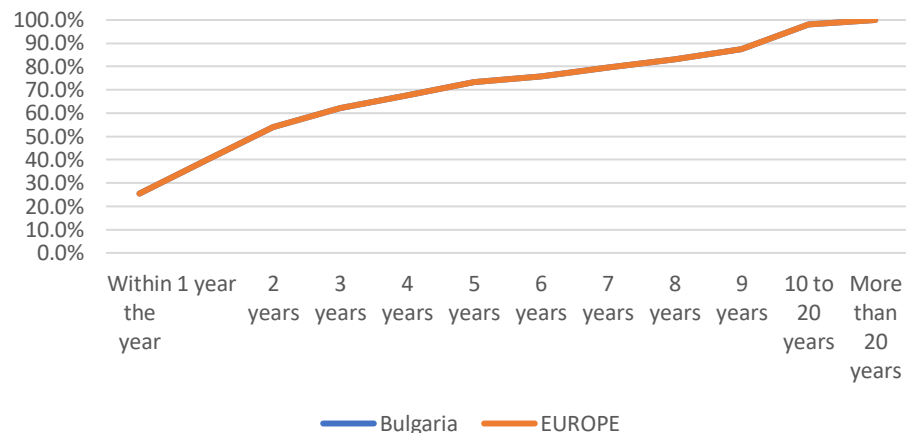
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

DATA FOR: 0

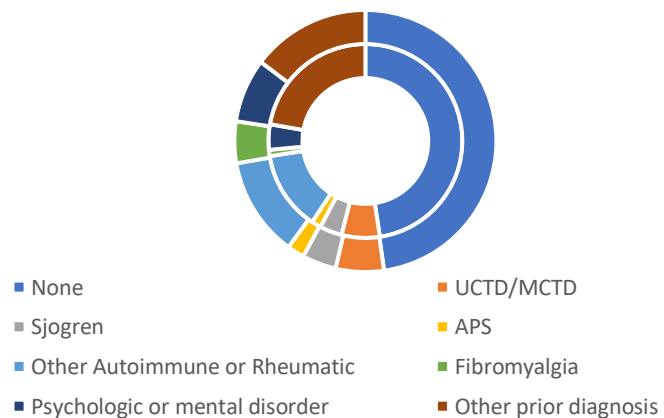
Patient reported symptoms and features



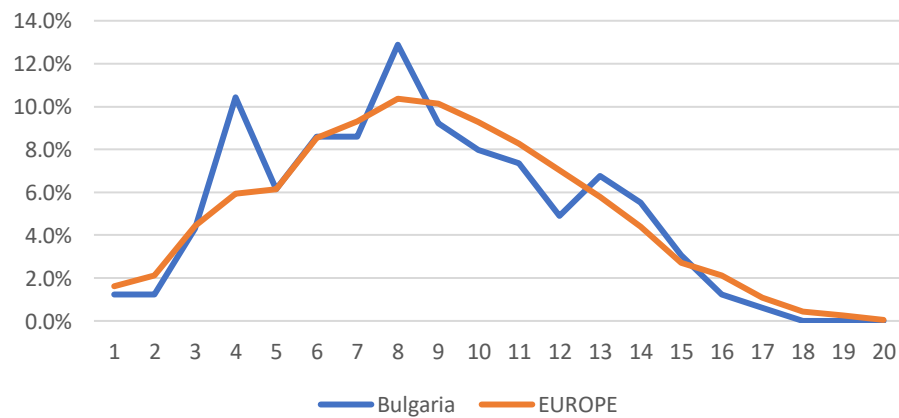
Patient time to diagnosis



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



Number of symptoms experienced





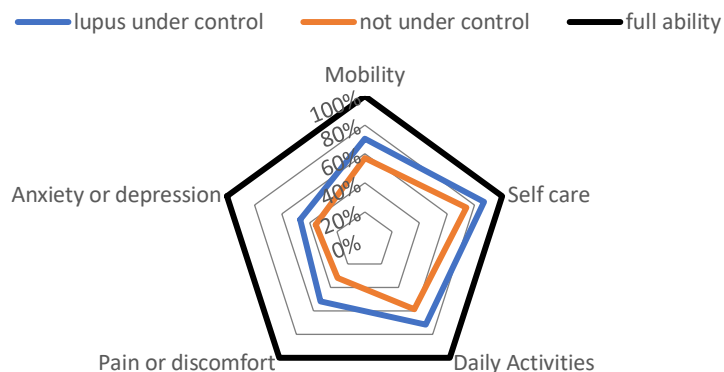
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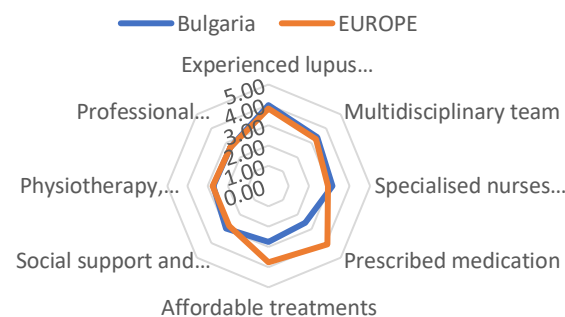
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

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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