



LUPUS EUROPE

LIVING WITH LUPUS IN 2020

COUNTRY LEVEL DATA

Croatia



Living with lupus in 2020 - Country level data

DATA FOR: **Croatia**

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

COUNTRY: Croatia

DEMOGRAPHICS:

	<u>Croatia</u>	<u>EUROPE</u>	<u>Age</u>	<u>Croatia</u>	<u>EUROPE</u>
Total number of responses	122	4375	Up to 25	10.7%	6.4%
			26 to 35	19.7%	17.9%
<u>Gender</u>	<u>Croatia</u>	<u>EUROPE</u>	36 to 45	33.6%	27.4%
Man	1.6%	3.7%	46 to 55	18.9%	26.6%
Woman	97.5%	95.6%	56 to 65	13.1%	14.8%
Other / prefer not to answer	0.8%	0.7%	above 65	1.6%	5.1%
Total	100.0%	100.0%	NA	2.5%	1.8%
			Grand Total	100.0%	100.0%

DIAGNOSIS

<u>Diagnosis</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>Time to Diagnosis</u>	<u>Croatia</u>	<u>EUROPE</u>
SLE	90.2%	94.4%	Within the year	22.0%	26.5%
Child onset SLE	9.8%	5.6%	1 year	23.9%	21.1%
Grand Total	100.0%	100.0%	2 years	11.9%	11.5%
			3 years	11.0%	5.7%
<u>Prior Diagnosis received before "Lupus"</u>	<u>Croatia</u>	<u>EUROPE</u>	4 years	2.8%	4.6%
None	49.2%	53.7%	5 years	6.4%	4.4%
UCTD/MCTD	4.9%	6.7%	6 years	2.8%	2.9%
Sjogren	4.9%	4.7%	7 years	5.5%	2.7%
APS	0.8%	2.4%	8 years	2.8%	2.4%
Other Autoimmune or Rheumatic	20.5%	13.8%	9 years	2.8%	2.3%
Fibromyalgia	4.9%	5.8%	10 to 20 years	7.3%	10.4%
Psychologic or mental disorder	7.4%	8.9%	More than 20 years	0.9%	5.5%
Other prior diagnosis	20.5%	16.5%	Grand Total	100.0%	100.0%
n=	120	4,275	n=	109	4,154



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IMPACT ON STUDIES & CAREER

<u>Education level</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>Employment level</u>	<u>Croatia</u>	<u>EUROPE</u>
Basic	3.4%	3.7%	Employed full time	56.5%	34.6%
Secondary	55.2%	53.9%	Employed part time	5.2%	16.5%
Academic	41.4%	42.5%	Self-employed full time	1.7%	3.0%
n=	116	4,150	Self-employed part time	0.9%	2.4%
			Looking for employment	6.1%	5.1%
<u>Economic profile</u>	<u>Croatia</u>	<u>EUROPE</u>	Stopped work for medical reason	6.1%	14.7%
No difficulties paying all bills	36.9%	46.9%	Retired	13.0%	11.6%
Occasional difficulties paying all bills.	23.0%	26.8%	Student	5.2%	4.0%
Often difficulties paying all bills	12.3%	10.4%	No paid employment / Full time home	3.5%	4.7%
Always difficulty paying all bills	13.9%	7.1%	Other / prefer not to answer	1.7%	3.5%
Did not respond	13.9%	8.9%			
n=	122	4375	n=	115	4247
<u>IMPACT ON STUDIES</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>IMPACT ON CAREER</u>	<u>Croatia</u>	<u>EUROPE</u>
Chose more relevant studies	5.9%	3.1%	No impact	45.1%	32.5%
could not do what they wanted	7.6%	11.1%	Changed career/ job	7.1%	13.5%
needed special support and received it	1.7%	4.6%	moved to Flexible hours	3.5%	8.1%
needed support but did NOT receive it	0.8%	2.9%	Reduced Work Schedule	4.4%	18.5%
Overall negative effect	11.8%	13.5%	Stopped work, gets social allowances	4.4%	18.5%
Overall positive effect	1.7%	1.4%	Missed promotion opportunities	15.9%	9.5%
No impact	74.8%	69.8%	Employment was terminated	18.6%	8.4%
n=	119	4240	Other negative impact	12.4%	20.8%
			Other positive impact	2.7%	1.8%
			Overall had negative impact	49.6%	57.9%
			n=	113	4024



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IMPACT ON SOCIAL / FAMILY

<u>Civil status</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>Have children</u>	<u>Croatia</u>	<u>EUROPE</u>
Child/young with family	11.8%	4.5%	None	27.5%	32.8%
Single	12.6%	17.4%	One child	22.5%	23.8%
Married / with partner	64.7%	66.9%	2 or more children	38.3%	38.9%
Divorced	7.6%	9.2%	Child/young living with family	11.7%	4.5%
Widowed	3.4%	2.0%			
n=	119	4206	n=	120	4288
<u>Would have liked more children</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>Faced Miscarriages</u>	<u>Croatia</u>	<u>EUROPE</u>
A. Yes	47.1%	37.6%	A. One miscarriage	18.8%	18.4%
B. No	31.4%	37.7%	B. Some miscarriages	10.9%	8.5%
C. don't know / prefer not to answer	21.6%	24.7%	C. Many miscarriages	0.0%	2.9%
n (women only) =	102	3,645	D. No miscarriage	70.3%	70.2%
			n (women only) =	101	3,756
<u>Difficulty to cope with Daily activities</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>More or less active than others same age</u>	<u>Croatia</u>	<u>EUROPE</u>
No Problem at all 1	16.0%	16.2%	Less active due to lupus	65.5%	72.6%
2	40.3%	32.3%	Equally active	12.6%	15.6%
3	36.1%	34.3%	More active due to lupus	10.9%	3.6%
4	6.7%	15.4%	I don't know	10.9%	8.1%
Fully Unable 5	0.8%	1.8%			
n=	119	4226	n=	119	4212
<u>Impact on Sexual/emotional life</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>Negative Impact on couple</u>	<u>Croatia</u>	<u>EUROPE</u>
Negative impact	28.8%	38.2%	It created tensions	26.3%	33.2%
Mixed Positive and negative	45.8%	36.2%	It is difficult for me	51.3%	68.4%
No significant impact	22.9%	23.9%	It is difficult for my partner	11.8%	26.7%
Positive impact	2.5%	1.6%	I am concerned for my couple	3.9%	13.2%
n=	118	4,204	Our relationship ended	19.7%	16.6%
			n=	76	2875



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DISEASE ACTIVITY							
<u>Lupus was under control past 3 months</u>		<u>Croatia</u>	<u>EUROPE</u>	<u>Number of symptoms (list of 23)</u>		<u>Croatia</u>	<u>EUROPE</u>
Yes		80%	72%	1		2.5%	1.6%
No		20%	28%	2		0.0%	2.1%
	n=	122	4347	3		5.0%	4.4%
				4		6.7%	5.9%
				5		8.4%	6.1%
				6		11.8%	8.5%
				7		9.2%	9.3%
<u>Average nr of symptoms (list of 23)</u>		<u>Croatia</u>	<u>EUROPE</u>	8		12.6%	10.4%
	n=	8.3	8.8	9		7.6%	10.1%
		119	4197	10		8.4%	9.3%
				11		5.0%	8.3%
				12		9.2%	7.0%
<u>Median number of symptoms</u>		<u>Croatia</u>	<u>EUROPE</u>	13		7.6%	5.8%
	n=	8	9	14		1.7%	4.4%
		119	4197	15		1.7%	2.7%
				16		0.8%	2.1%
				17		0.8%	1.1%
				18		0.0%	0.4%
				19		0.8%	0.3%
				20		0.0%	0.0%
				n=		119	4197



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Symptoms or Features experienced / Most bothersome

Patient reported Symptoms or features	Croatia		Patient reported Symptoms or features	EUROPE	
	Regularly experience	Top 3 most bothersome		Regularly experience	Top 3 most bothersome
A. Rash	29%	7%	A. Rash	40%	9%
B. Sun sensitivity	76%	27%	B. Sun sensitivity	69%	23%
C. Mouth ulcers	29%	2%	C. Mouth ulcers	35%	3%
D. Dryness in the mouth or eyes	47%	11%	D. Dryness in the mouth or eyes	55%	9%
E. Dryness of the skin	62%	5%	E. Dryness of the skin	57%	4%
F. Hair loss	40%	9%	F. Hair loss	53%	14%
G. Pain / swelling in joints	70%	45%	G. Pain / swelling in joints	77%	49%
H. Jaccoud (hand deformation) or tendons a	9%	3%	H. Jaccoud (hand deformation) or tendor	14%	4%
I. Muscle Pain/Weakness	63%	33%	I. Muscle Pain/Weakness	68%	33%
J. Headaches or migraine	45%	20%	J. Headaches or migraine	51%	17%
K. Fatigue and weakness	87%	55%	K. Fatigue and weakness	85%	55%
L. Flu-like symptoms/Fevers	21%	1%	L. Flu-like symptoms/Fevers	28%	4%
M. Shortness of breath	33%	6%	M. Shortness of breath	32%	6%
N. Depression or Anxiety	37%	18%	N. Depression or Anxiety	44%	17%
O. Haematologic problems incl. anemia	38%	7%	O. Haematologic problems incl. anemia	27%	4%
P. Poor circulation or Raynauds	41%	8%	P. Poor circulation or Raynauds	45%	8%
Q. Kidney problems	17%	14%	Q. Kidney problems	20%	11%
R. Chest pain	35%	8%	R. Chest pain	24%	4%
S. High Blood pressure	23%	4%	S. High Blood pressure	23%	4%
T. Stroke, mini-stroke, Blood clots	6%	3%	T. Stroke, mini-stroke, Blood clots	9%	4%
U. Osteoporosis	23%	3%	U. Osteoporosis	19%	5%
n=	122	115	n=	4375	4084



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MEDICATION

	<u>Croatia</u>	<u>EUROPE</u>		<u>Croatia</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=	117	4099	n=	117	4099
<u>Number of medications (list of 16)</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>% using given medication type:</u>	<u>Croatia</u>	<u>EUROPE</u>
1	7.7%	5.4%	Non Steroids Anti-Inflammatory	35.0%	32.9%
2	5.1%	9.0%	Antimalarials	63.2%	75.0%
3	6.8%	12.5%	Oral Steroids	70.9%	52.4%
4	20.5%	14.1%	Immunosuppressants	29.9%	39.8%
5	9.4%	14.8%	Biologics	2.6%	10.9%
6	18.8%	13.9%	Painkillers	42.7%	50.1%
7	13.7%	11.8%	Antidepressant	10.3%	17.0%
8	6.0%	9.0%	Anxiolytic	6.0%	11.7%
9	9.4%	5.1%	Anticoagulants	13.7%	16.6%
10	0.9%	2.5%	Thyroid medication	28.2%	14.8%
11	0.9%	1.1%	Blood circulation and heart	27.4%	23.3%
12	0.9%	0.4%	Stomach protection	54.7%	47.0%
13	0.0%	0.2%	Statins	0.9%	5.9%
n=	117	4099	Calcium	42.7%	29.7%
			Vitamin D	76.9%	68.4%
			Vitamins (excl.D) / mineral complements	31.6%	25.4%



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

<u>I have appropriate access to</u>	<u>Croatia</u>	<u>EUROPE</u>	<u>HrQoL dimensions</u>	<u>Croatia</u>	<u>EUROPE</u>
Average scores (1 Fully disagree - 5 fully agree)			AVERAGE SCORES (1=FULLY ABLE, 5= FULLY UNABLE)		
Experienced lupus doctors	3.62	3.81	Mobility	2.09	2.22
Multidisciplinary team	3.20	3.28	Self care	1.54	1.71
Specialised nurses that know lupus	2.98	2.92	Daily Activities	2.36	2.54
Prescribed medication	3.95	4.08	Pain or discomfort	3.09	3.14
Affordable treatments	3.56	3.77	Anxiety or depression	2.96	2.96
Social support and benefits	2.15	2.78	Average	2.41	2.51
Physiotherapy, Rehab, Occupational Thera	2.54	2.77			
Professional psychological support	2.42	2.68			
	n min	80		n min	118
	n max	106		n max	119
		3126			4196
		3842			4240
<u>Worry about lupus progressing?</u>	<u>Croatia</u>	<u>EUROPE</u>			
Very Low (1-2)	3.4%	3.6%			
Low (3-4)	6.0%	9.3%			
Mid (5-6)	19.8%	24.5%			
High (7-8)	39.7%	41.0%			
Very high (9-10)	31.0%	21.6%			
	n=	116			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>Croatia</u>			<u>EUROPE</u>		
	<u>lupus under control</u>	<u>not under control</u>		<u>lupus under control</u>	<u>not under control</u>	
Mobility	74%	67%	Mobility	73%	59%	
Self care	88%	79%	Self care	86%	73%	
Daily Activities	67%	63%	Daily Activities	66%	51%	
Pain or discomfort	48%	45%	Pain or discomfort	51%	35%	
Anxiety or depression	53%	44%	Anxiety or depression	54%	44%	
Average	66%	59%	Average	66%	52%	
	n min	94	24	n min	3011	1179
	n max	95	24	n max	3042	1194

	<u>Croatia</u>			<u>EUROPE</u>		
	<u>lupus under control</u>	<u>not under control</u>		<u>lupus under control</u>	<u>not under 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	62.1%	79.2%	Less active due to lupus	68.6%	83.0%	
Equally active	15.8%	0.0%	Equally active	18.8%	7.6%	
More active due to lupus	11.6%	8.3%	More active due to lupus	4.0%	2.7%	
I don't know	10.5%	12.5%	I don't know	8.7%	6.7%	
	n=	95	24	n=	3018	1189

	<u>Croatia</u>			<u>EUROPE</u>		
	<u>lupus under control</u>	<u>not under control</u>		<u>lupus under control</u>	<u>not under control</u>	
<u>Impact on Sexual/emotional life</u>			<u>Impact on Sexual/emotional life</u>			
Negative impact	28.4%	30.4%	Negative impact	34.0%	49.0%	
Mixed + and -	43.2%	56.5%	Mixed + and -	36.4%	35.7%	
No significant impact	25.3%	13.0%	No significant impact	27.8%	14.1%	
Positive impact	3.2%	0.0%	Positive impact	1.8%	1.2%	
	n=	95	23	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>Croatia</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%	73%	Mobility	75%	62%
Self care	89%	86%	Self care	86%	76%
Daily Activities	67%	65%	Daily Activities	67%	53%
Pain or discomfort	55%	41%	Pain or discomfort	52%	39%
Anxiety or depression	54%	52%	Anxiety or depression	52%	49%
Average	68%	63%	Average	66%	56%
	Difference	-5%		Difference	-10%
	of which - explained by age (*)	-2%		of which - explained by age	-3%
	n min	50		n min	1926
	n max	50		n max	1951
	average age:	37.8			41.2
		42.9			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



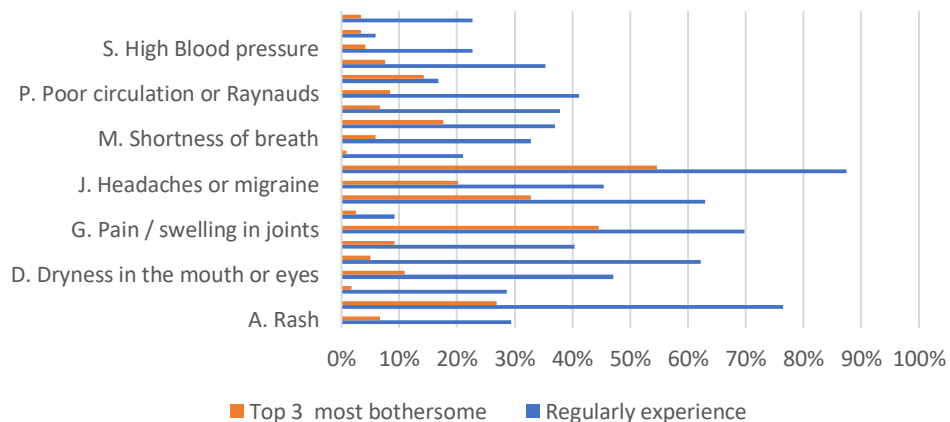
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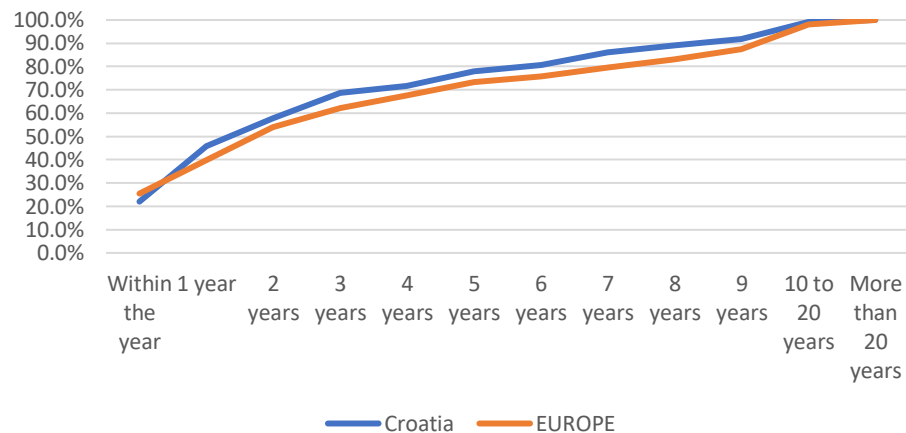
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

DATA FOR: 0

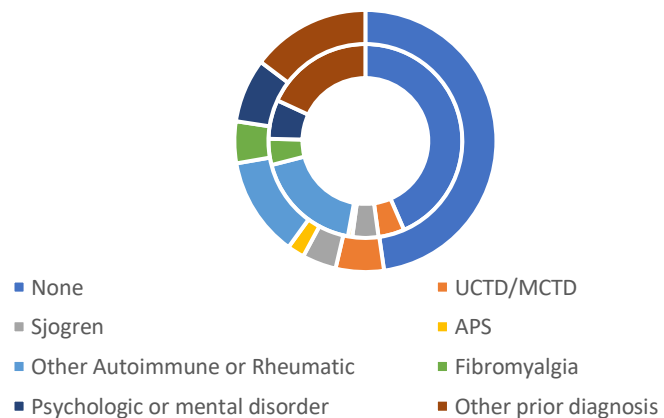
Patient reported symptoms and features



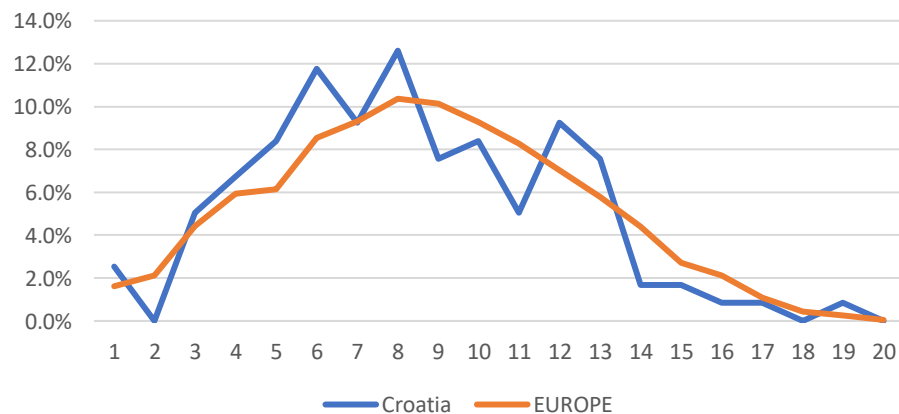
Patient time to diagnosis



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



Number of symptoms experienced





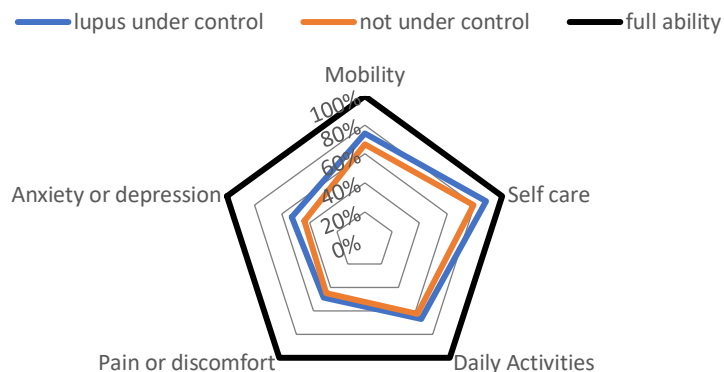
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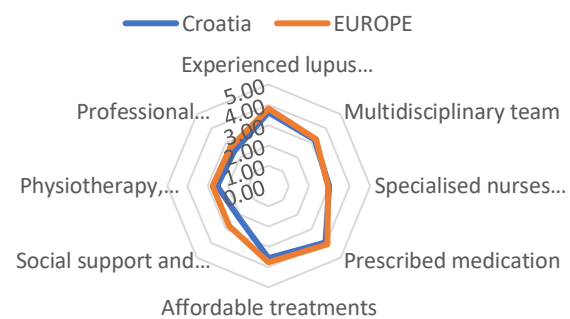
Publication: <http://dx.doi.org/10.1136/lupus-2020-000469>

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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