

Appendix 1

English version of the survey

Living with Lupus in 2020 [ENGLISH]
In 2010 Lupus Europe conducted a big survey on how it is to live with lupus in Europe. A lot has happened since then and we would now like to conduct a similar survey to measure the differences and get a picture of the needs of lupus patients in Europe in 2020. Please help us gather this information. Our 32 questions survey has been designed so that it can be completed in no more than 10 minutes.
Thank you for helping us grow our knowledge of the Lupus Disease.
Q1 - In which country do you currently live?
Q2 – Are you a A) Man B) Woman C) Other / Prefer not to answer
Q3 – What ethnic origin best fits your situation? A. African/African American/Caribbean B. Asian/Pacific Islander/Indian C. Caucasian/White D. Hispanic/Latino. E. Middle Easterner/North African F. Mixed/multiple ethnic groups G. Prefer not to say H. Other (specify)
Q4 - What is your age?
Q5 - Which diagnosis of lupus do you currently have? A. Systemic lupus erythematosus (SLE) B. Cutaneous, Discoid or Chilblain lupus erythematosus C. Drug-induced lupus erythematosus D. Childhood systemic lupus erythematosus (SLE was diagnosed before 18 years of age) E. Lupus-like disease (Lupus is not yet officially diagnosed) F. I do not have lupus
Q6 - Which parts of your body are affected by lupus? A. Skin B. Heart C. Bloodstream D. Lungs E. CNS (Central Nervous System) F. Muscles G. Joints H. Kidney I. Anti-Phospholipid Syndrome (APS) J. Other
Q7 - Do you feel your lupus has been under control over the last 3 months? A. Yes B. No
Q8 – In which year were you diagnosed with lupus?
Q9 – In which year did you start having symptoms of lupus?
Q10 - Before you were diagnosed with lupus, did any specialist diagnose your symptoms as another

<p>condition?</p> <p>A. No</p> <p>B. Yes – UCTD or MCTD</p> <p>C. Yes, Sjogren</p> <p>D. Yes, APS (Anti-Phospholipid syndrome)</p> <p>E. Yes – Another Autoimmune / rheumatic disease</p> <p>F. Yes – Fibromyalgia</p> <p>G. Yes – A psychologic or mental disorder</p> <p>H. Yes – Other (specify)</p>
<p>Q10 B – Have you been given any diagnosis?</p> <p>A. No</p> <p>B. Yes – UCTD or MCTD</p> <p>C. Yes – Possibly lupus, but we need to confirm</p> <p>D. Yes, Sjogren</p> <p>E. Yes, APS (Anti-Phospholipid syndrome)</p> <p>F. Yes – Another Autoimmune / rheumatic disease</p> <p>G. Yes – Fibromyalgia</p> <p>H. Yes – A psychologic or mental disorder</p> <p>I. Yes – Other (specify)</p>
<p>Q11 - Please state your present civil status</p> <p>A. Child/young adult living with family'</p> <p>B. Single</p> <p>C. Married / living with partner</p> <p>D. Divorced</p> <p>E. Widowed</p> <p>F. Other / Prefer not to answer</p>
<p>Q12 - Do you have children?</p> <p>A. No</p> <p>B. Yes, I have 1</p> <p>C. Yes, I have 2 or more</p>
<p>Q12B - Have you experienced miscarriage(s)?</p> <p>A. Yes, One</p> <p>B. Yes, some</p> <p>C. Yes, many</p> <p>D. No</p> <p>E. Prefer not to answer</p>
<p>Q12 C - If 0 or 1 - Would you have had (more) children if you did not have lupus</p> <p>A. Yes</p> <p>B. No</p> <p>C. I don't know / prefer not to answer</p>
<p>Q13 – On January 1, 2020 were you:</p> <p>A. Employed full time</p> <p>B. Employed part time</p> <p>C. Self-employed full time</p> <p>D. Self-employed part time</p> <p>E. Looking for employment</p> <p>F. Stopped working for medical reason</p> <p>G. Retired</p> <p>H. Student</p> <p>I. Not in paid employment / Full time at home</p> <p>J. Other / prefer not to answer</p>

<p>Q14 - Please state your highest level of education (TBD)</p> <p>A. Primary</p> <p>B. GCSE/</p> <p>C. High school / A level / International Baccalaureate/ Vocational</p> <p>D. Bachelor/ Lower academic degree</p> <p>E. Masters degree/Higher academic degree</p> <p>F. Prefer not to answer</p>
<p>Q15 - Have your studies been impacted by lupus?</p> <p>A. YES – I decided to study in a field more relevant to lupus (medical, social, ...)</p> <p>B. YES - I could not do what I wanted to do</p> <p>C. YES - I needed special arrangements / support, and I received it</p> <p>D. YES - I needed special arrangements / support, and I did NOT receive it</p> <p>E. E: YES, they were impacted in a negative way</p> <p>F. F: YES, they were impacted in a positive way</p> <p>G. No</p>
<p>Q16 - (Non-students) - Did your lupus affect your career? (tick all that applies)</p> <p>A. No, not in a significant way</p> <p>B. Yes, I decided to change career / job</p> <p>C. Yes, I moved to flexible hours.</p> <p>D. Yes, I changed to a reduced work schedule</p> <p>E. Yes, I had to stop working due to my lupus and I am now on social or disability allowance.</p> <p>F. Yes, I missed promotion opportunities</p> <p>G. Yes, my employment was terminated</p> <p>H. Yes, other negative effects</p> <p>I. Yes, other positive effects</p>
<p>Q17 – How easy (economically) is your end of month?</p> <p>A. I have no difficulties paying all my bills.</p> <p>B. I occasionally have difficulties paying all my bills.</p> <p>C. I often have difficulties paying all my bills</p> <p>D. I always have difficulty paying all my bills</p>
<p>Q18 – How do you assess your mobility, i.e. your ability to walk around?</p> <p>no problem at all → Unable to walk 5</p>
<p>Q19 – How do you assess your ability to perform self-care tasks like washing or dressing yourself?</p> <p>no problem at all → Unable to wash or dress myself</p>
<p>Q20 – How do you assess your ability to perform normal daily activities, like studying, working, housework, leisure or participation to family life</p> <p>no problem at all → Unable to perform those</p>
<p>Q21 - Compared to people of the same age, are you</p> <p>A. Less active due to lupus</p> <p>B. Equally active</p> <p>C. More active due to lupus</p> <p>D. I don't know</p> <p>E. Prefer not to answer</p>
<p>Q22 – How do you assess your level of discomfort or pain?</p> <p>no pain/discomfort → extreme pain/discomfort</p>
<p>Q23 – Do you feel Anxious or depressed?</p> <p>Not at all → Yes, extremely</p>
<p>Q24 - Has lupus had an impact on your emotional and sexual life?</p> <p>A. Yes – it had a positive impact</p> <p>B. Yes – it had a negative impact</p> <p>C. Mixed – there have been positive and negative points</p>

D. No – My lupus did not have a significant impact on this
<p>Q24 B – Tick all that applies:</p> <ul style="list-style-type: none"> A. It created tensions amongst us B. It is difficult for me C. It is difficult for my partner D. I am concerned about our relationship E. My relationship ended
<p>Q25 - Which of the following symptoms or features do you regularly experience?</p> <ul style="list-style-type: none"> A. Rash B. Sun sensitivity C. Mouth ulcers D. Dryness in the mouth or eyes E. Dryness of the skin F. Hair loss G. Pain & swelling in joints H. Jacoud (hand deformation) or tendons and ligaments damage I. Muscle Pain and Weakness J. Headaches or migraine K. Fatigue and weakness L. Flu-like symptoms/Fevers M. Shortness of breath N. Depression or Anxiety O. Haematologic problems incl. anemia P. Poor circulation or Raynauds Q. Kidney problems R. Chest pain S. High Blood pressure T. Stroke, mini-stroke, Blood clots U. Osteoporosis V. Other (specify)
<p>Q26 - If you could have ONE symptom or feature go away which one would it be?</p> <p>- SAME list as above</p> <p>- the symptom you listed under "Other"</p>
<p>Q27 - If you could have ONE other symptom or feature go away which one would it be?</p> <p>- SAME list as above</p> <p>- the symptom you listed under "Other"</p>
<p>Q28 - If you could have a Third symptom or feature go away which one would it be?</p> <p>- SAME list as above</p> <p>- the symptom you listed under "Other"</p>
Q 29 - 'What is the most important thing that helps you manage your condition? (max 10 words)

<p>Q 30 - Which of those do you use:</p> <p>A. Non Steroids Anti-Inflammatory (such as Aspirin, Ibuprofen, Diclofenac, Noraminopyrine, Celecoxib, ...)</p> <p>B. Antimalarials (such as Hydroxychloroquine, Plaquenil, Quensyl, Nivaquine, Quinine, ...)</p> <p>C. Oral Steroids (such as Prednisolone, Prednisone, Cortisone, ...) (not creams containing steroids)</p> <p>D. Immunosuppressants (such as Azathioprine, Methotrexate, Mycophenolate, Cyclosporin)</p> <p>E. Biologics (such as Benlysta, Belimumab, Rituximab, ...mab or ...mib)</p> <p>F. Painkillers (such as Paracetamol, Tramadol, Cocodamol, Cannabis, morphine)</p> <p>G. Antidepressant (such as Sertraline, Citalopram, Escitalopram, Duloxetine, Fluoxetine, Quetiapine, Paroxetine, Trazodone, Velafaxine, ...)</p> <p>H. Anxiolytic (such as Alprazolam, Zolpidem, Diazepam, Lorazepam, Bromazepam, Zopiclone, ...)</p> <p>I. Anticoagulants (such as Warfarin, Clopidogrel, Acenocoumarol, Phenprocoumon, Rivoroxaban, Apixaban, Enoxaparin, ...)</p> <p>J. Thyroid medication (such as Levothyroxine, ...)</p> <p>K. Blood circulation and heart (like Bisoprolol, Amlodipine, Ramipril, Candesartan, or any other ... olol, ...dipine, ...pril, ... sartan)</p> <p>L. Stomach protection (such as Omeprazole, pantoprazole, Ranitidine, ...)</p> <p>M. Statins</p> <p>N. Calcium</p> <p>O. Vitamin D</p> <p>P. Vitamin (other than Vitamin D) or Mineral complements</p> <p>Q. Prefer not to answer</p>
<p>Q31- What quantity of steroids do you take:</p> <p>A. Up to 5mg/day</p> <p>B. 5 to 15mg/day</p> <p>C. More than 15mg/day</p> <p>D. Injections in past 3 months</p>
<p>Q32 – From a personal point of view, do you agree or disagree with the following statements:</p> <ul style="list-style-type: none"> • I have appropriate access to experienced lupus doctors • I have appropriate access to a multidisciplinary team (doctors from different specialities, nurses and other medical staff working together) • I have appropriate access to specialised nurses that know lupus • I have appropriate access to the prescribed medication • I have access to affordable treatments • I have appropriate access to social support and benefits • I have appropriate access to Physiotherapy, Rehabilitation or Occupational Therapy • I have appropriate access to professional psychological support <p>For each statement:</p> <p>A. Strongly agree</p> <p>B. Agree</p> <p>C. Neither agree nor disagree</p> <p>D. Disagree</p> <p>E. Strongly Disagree</p> <p>F. Not applicable</p>
<p>Q33 - With regards to the mid to long term future, how worried are you about your lupus progressing? Not worried at all → Extremely worried</p>
<p>We thank you very much for your time and cooperation.</p>
<p>We would love to keep you informed about the results of this survey, or to stay in touch with you, but want to make sure that your answers to this survey can in no way be traced to you. So, if you would like to receive news from us, simply give us your email here and select what you would</p>

like us to use it for. It will be stored in a safe place, completely separate from your survey answers.
For more information about Lupus Europe: www.lupus-europe.org

Appendix 2**Country of residence**

Q1 - country where live	4375 (100)
France	680 (15.54)
United Kingdom	667 (15.25)
Italia	556 (12.71)
Germany	301 (6.88)
Spain	284 (6.49)
Belgium	207 (4.73)
Portugal	195 (4.46)
Finland	187 (4.27)
Bulgaria	168 (3.84)
Norway	135 (3.09)
Croatia	122 (2.79)
Poland	120 (2.74)
Denmark	110 (2.51)
The Netherlands	99 (2.26)
Switzerland	87 (1.99)
Lithuania	73 (1.67)
Czech Republic	57 (1.3)
Greece	55 (1.26)
Slovakia	52 (1.19)
Ireland	39 (0.89)
Bosnia	34 (0.78)
Sweden	29 (0.66)
Romania	25 (0.57)
Cyprus	24 (0.55)
Serbia	19 (0.43)
Austria	13 (0.3)
Estonia	13 (0.3)
Slovenia	8 (0.18)
Iceland	3 (0.07)
Luxemburg	3 (0.07)
Macedonia	3 (0.07)
Montenegro	3 (0.07)
Hungary	2 (0.05)
Albania	1 (0.02)
Malta	1 (0.02)

Appendix 3

Most common & bothersome symptoms of SLE

Symptoms/features of SLE	Regularly experience it		Top 3 Most bothersome		
	Number of respondents	%	Number of respondents	% of all respondents	% of respondents with the symptom
Fatigue and weakness	3578	85.3	2311	55.1	64.6
Pain & swelling in joints	3227	76.9	2076	49.5	64.3
Sun sensitivity	2875	68.5	969	23.1	33.7
Muscle Pain and Weakness	2853	68.0	1400	33.4	49.1
Dryness of the skin	2386	56.9	150	3.6	6.3
Dryness in the mouth or eyes	2289	54.5	392	9.3	17.1
Hair loss	2226	53.0	569	13.6	25.6
Headaches or migraine	2144	51.1	701	16.7	32.7
Poor circulation or Raynaud's	1894	45.1	321	7.6	16.9
Depression or Anxiety	1831	43.6	724	17.3	39.5
Rash	1673	39.9	393	9.4	23.5
Mouth ulcers	1488	35.5	141	3.4	9.5
Shortness of breath	1328	31.6	242	5.8	18.2
Flu-like symptoms/Fevers	1171	27.9	149	3.6	12.7
Haematologic problems incl. anemia	1133	27.0	161	3.8	14.2
Chest pain	1028	24.5	159	3.8	15.5
High Blood pressure	966	23.0	174	4.1	18.0
Kidney problems	842	20.1	463	11.0	55.0
Osteoporosis	817	19.5	198	4.7	24.2
Jaccoud / tendons / ligaments damage	582	13.9	170	4.1	29.2
Stroke, mini-stroke, Blood clots	385	9.2	175	4.2	45.5

Appendix 4

Differences in care, according to countries

Country	Data availability	Experienced doctor	Multidisciplinary teams	Specialized nurse	Biologics
Belgium	191	74.9%	53.5%	33.8%	3.6%
Bulgaria	154	74.0%	50.0%	41.8%	15.4%
Croatia	106	57.5%	42.4%	33.0%	2.6%
Denmark	103	71.8%	54.5%	60.4%	11.3%
Finland	169	48.5%	34.8%	47.2%	10.7%
France	599	77.6%	53.7%	25.7%	8.0%
Germany	267	69.7%	52.0%	27.7%	14.4%
Italy	448	63.6%	41.7%	29.3%	13.6%
Norway	119	40.3%	32.5%	30.9%	9.2%
Poland	101	59.4%	23.9%	11.5%	3.5%
Portugal	172	77.9%	53.8%	31.3%	9.5%
Spain	241	73.4%	59.6%	28.3%	15.3%
United Kingdom	622	67.0%	47.6%	46.1%	11.0%

Country	Prescribed medication	Affordable treatment	Social support & benefits	Physiotherapy	Psychologic support
Belgium	91.1%	70.6%	34.2%	50.0%	29.4%
Bulgaria	25.7%	26.2%	37.0%	28.6%	21.5%
Croatia	82.4%	58.4%	11.3%	21.0%	21.7%
Denmark	88.2%	72.3%	40.9%	53.8%	26.7%
Finland	85.2%	51.9%	22.2%	33.1%	34.1%
France	86.6%	84.6%	21.2%	15.2%	19.9%
Germany	88.3%	60.4%	37.6%	47.0%	34.4%
Italy	77.3%	67.0%	26.5%	21.0%	21.1%
Norway	77.0%	43.2%	32.3%	33.6%	20.6%
Poland	55.8%	38.7%	11.1%	14.0%	18.9%
Portugal	93.9%	67.7%	32.2%	21.0%	27.6%
Spain	95.0%	83.5%	24.5%	15.6%	30.5%
United Kingdom	83.0%	71.8%	33.4%	31.2%	20.7%

Appendix 5

SLE burden on studies, career and daily life

Burden of disease	n (%)
Impact on studies [data available for 4240 respondents]	
Had to do more relevant studies	133 (3.1)
Could not do what I wanted	472 (11.1)
Special support - received	197 (4.6)
Special support - NOT received	123 (2.9)
Negative effect	574 (13.5)
Positive effect	61 (1.4)
No impact	2959 (69.8)
Impact on career [data available for 4024 respondents]	
No impact	1307 (32.5)
Had to change career / job	543 (13.5)
Flexible hours	325 (8.1)
Reduced Work Schedule	744 (18.5)
Stop/social allowance	743 (18.5)
Missed promotion opportunities	381 (9.5)
Terminated employment	337 (8.4)
Other negative impact	838 (20.8)
Other positive impact	71 (1.8)
Economic profile [data available for 3987 respondents]	
No difficulties paying all bills.	2052 (51.5)
Occasional difficulties paying all bills.	1172 (29.4)
Often difficulties paying all bills	454 (11.4)
Always difficulty paying all bills	309 (7.8)
Impact on daily activities, compared with others [data available for 4226 respondents]	
Less active due to lupus	3060 (72.4)
Equally active	658 (15.6)
More active due to lupus	152 (3.6)
I don't know	342 (8.1)
Prefer not to answer	14 (0.3)
Burden of discomfort/pain [data available for 4198 respondents]	
1 (not at all)	251 (6)
2	766 (18.2)
3	1603 (38.2)
4	1283 (30.6)
5 (Yes extremely)	295 (7)

Feeling anxious/depressed [data available for 4196 respondents]	
1 (not at all)	609 (14.5)
2	847 (20.2)
3	1299 (31)
4	965 (23)
5 (Yes extremely)	476 (11.3)
Impact on sexual/emotional life [data available for 4204 respondents]	
Positive impact	67 (1.6)
Negative impact	1608 (38.2)
Mixed impact	1523 (36.2)
No significant impact	1006 (23.9)
Worry for lupus progressing, median (IQR25-75), based on 4042 answers	7 (5-8)

Appendix 6

Benchmarking comparison of European countries with > 50 respondents

Countries	Nb	median time to diagnosis	% on oral steroids	% on anti malarials	% on IS	% on Biologics	% on AD or anxiolyt.	Median Burden
Belgium	207	2	44	73	32	4	29	12
Bulgaria	168	2	73	76	26	16	9	13
Croatia	122	2	71	63	30	3	13	12
Czech Republic	57	1	69	79	48	4	25	11
Denmark	110	2	42	76	58	11	17	12
Finland	187	2	50	71	28	11	15	12
France	680	1	43	78	31	8	26	12
Germany	301	2	58	72	54	14	15	12
Greece	55	2	46	80	46	15	28	13
Italia	556	1	57	68	40	13	20	12
Lithuania	73	1	65	74	32	21	19	12
The Netherlands	99	3	49	68	45	13	22	13
Norway	135	3	61	83	27	9	18	13
Poland	120	1	67	76	44	4	12	12
Portugal	195	1	70	74	42	9	44	13
Slovak republic	52	1	76	63	41	16	12	12
Spain	284	2	51	81	42	15	33	12
Switzerland	87	2	39	81	31	15	15	10
United Kingdom	667	3	40	77	53	11	31	14

Nb: number of patients with available data.

Median diagnosis delay for SLE.

Percentage of patients using oral glucocorticoids, antimalarials, immunosuppressive agents (IS), biologics, antidepressants (AD) or anxiolytics (anxiolyt).

Total burden score as the sum of individual burden items (the higher the score, the higher the burden).