

Lupus Survey HCQ
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Supplement

Methods

The survey included 19 questions (supplementary Table 1) and was designed and conducted using the open-source software LimeSurvey (Limesurvey GmbH./LimeSurvey Version 3.22.8+200309: An Open Source survey tool /LimeSurvey GmbH, Hamburg, Germany. URL <http://www.limesurvey.org>). The survey was open for online participation from April 27 to May 8, 2020. Ethics approval was obtained (Protocol number 35/4/20). The link to the survey was distributed via the German Lupus self-help organization (Lupus Erythematodes Selbsthilfegemeinschaft e.V.) communication channels. Data were exported and analyzed with GraphPad Prism version 8 (Version 8.4.0 for macOS, GraphPad Software, La Jolla California USA, www.graphpad.com).

Table S1. Survey questions (translated version from German).

No	Question	Answer options
1	Do you suffer from systemic lupus erythematosus (SLE)?	Yes – question 2 No – end of survey
2	What is your gender?	Male Female Diverse
3	How old are you?	18-30 years 31-40 years 41-50 years 51-60 years 61-70 years >70 years
4	Do you suffer from one or more of the following organ manifestations of SLE? Please tick all that apply.	Joints (arthritis) Skin (cutaneous lupus) Kidney/renal (lupus nephritis) Lung/pulmonary Heart (Myocarditis, endocarditis) Fluid collections (serositis) Central nervous system (neuropsychiatric lupus) Blood count abnormalities

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		(hematological) Other (please specify)
5	Do you take hydroxychloroquine or chloroquine as part of your SLE treatment regime?	Yes – question 6 No – end of survey
6	What is your daily dose of hydroxychloroquine or chloroquine?	200 mg 400 mg 200/400 mg alternating Other (please specify)
7	How long have you been taking hydroxychloroquine/chloroquine? Please tick.	< 1 year 1-5 years 6-10 years > 10 years
8	Do you sometimes forget to take your hydroxychloroquine/chloroquine medication? If so, how often (on a weekly average)?	0, I never forget to take this medication 1-2 days per week 3 days per week More than 3 days per week
9	Do you take any other medication for the management of SLE? If so, please tick all that apply.	Prednisone (or other glucocorticoids/steroids) Methotrexate (MTX) Azathioprine Mycophenolate Cyclosporine Tacrolimus Belimumab (Benlysta) Cyclophosphamide Other (please specify)
10	Do you consider hydroxychloroquine/chloroquine essential for your SLE treatment?	Yes No
11	Have you experienced any side effects or adverse reactions of this medication? If so, please specify.	Yes No
12	Have you experienced problems securing your hydroxychloroquine/chloroquine medication due to the Covid-19 pandemic?	No, I have not experienced any problems Yes, I have received a different product Yes, I had to source it via a different pharmacy Yes, I was unable to get my medication through a pharmacy at all Yes, I only received my medication after my doctor intervened Other, please specify
13	Are you concerned or afraid of being unable to secure your hydroxychloroquine/chloroquine medication in the coming weeks/months due to supply chain disruptions?	Yes No

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14	Have you reduced your hydroxychloroquine/chloroquine dose or skipped doses in order to bridge possible supply shortages?	Yes No
15	Do you consider yourself protected from an infection with SARS-CoV2/Covid-19 due to hydroxychloroquine/chloroquine therapy?	Yes No
16	Are you concerned about an increased vulnerability to Covid-19 due to the medications you take for SLE?	Yes No
17	Have you been infected with SARS-CoV2/suffered from Covid-19 disease?	Yes – question 17 No – Question 18
18	If so, how severe was the Covid-19 disease course?	Mild, I was able to recover at home Moderate to severe, I required admission to hospital
19	Please share any other thoughts you may have concerning this topic in the comments section below.	