



Information Sheet: Views and experiences of LUPUS UK forum members

The HealthUnlocked LUPUS UK forum is a place where patients with lupus and other related conditions talk freely and openly about their condition. It also includes people who have an uncertain diagnosis or feel they may have lupus and are searching for answers. We have seen that many of the conversations are on similar themes and show that people are often having similar experiences, both positive and negative.

Putting your experiences together and publishing them in an academic journal that will be read by doctors, researchers, academics and patients will enable better understanding of patient views and experiences.

We are going to analyse the forum using scientific research methods where we take posts and responses and put them into categories (for example, positive/ negative experiences with doctors, misdiagnosis, living with lupus etc) and then onto a database that helps us find common themes (for example 'inequality') For the next month, LUPUS UK and the research team will also be posting some questions onto the forum that any member can choose to respond to or not in common with other postings. This study is all about the forum members experiences so we very much value any input and discussions on your views, your ideas for common themes for this study and any ideas for future research.

What are the possible risks of taking part?

We do not foresee any risks to your health from participating in this study. Should you find any posts asking questions about the disease and any diagnostic difficulties too distressing, you can request the contact details of any support services from LUPUS UK.

What are the possible benefits from taking part?

We anticipate the information from analysing this forum will help inform clinicians, researchers and patients about the combined experiences and views of patients potentially leading to greater understanding, support and improvements. Your opinions will be combined to give lupus and related connective disease patients a voice that will be heard on a wider and more influential scale than the forum.

The use of quotes

- We will look at your views and what you have said about your experiences together with others and look for common patterns. We will ask to use direct quotes from some people in the write up of the study if they explain common views and give consent to be quoted.
- If we wish to use one of your direct quotes, Paul Howard, moderator of the forum, will request this through the HealthUnlocked private messaging, with the quote we would like to use. It is entirely up to you to decide if we can use your quote and it will not affect your medical care or forum participation if you refuse. We will not use a direct quote without that individual's written permission through the messaging service.

- If consent is granted, direct quotes will be labelled with your gender, decade of age and country. No names (either real or forum pseudonyms) will be included and we will ensure that identities (both real life and forum) are protected by allocating an identification number.
- For example '*I felt very depressed that my GP wouldn't listen to me or refer me for more help. He made me feel I was imagining it*' (Female, 30s, Scotland) or '*My rheumy is great, he always listens to me*' (Male, 50s, Australia)
- We will publish commonly used words (such as '*dismissed*') and may use combined, similar quotes from several people. We won't ask consent for these as they will not be able to be identified as from any individual.

How confidential is this study?

- The published results will not include any information that could identify individuals by their real-world identity.
- We will be following the new data protection regulations, GDPR, May 2018.
- Cambridge University is the sponsor for this study. We will not be collecting or holding any personally identifiable information from you for this study.

Who is organising and funding the study?

The study is being conducted by the Behavioural science group at the University of Cambridge, LUPUS UK and a group of LUPUS UK forum members.

What do I do if I do not want my posts or responses to be included in looking for common experiences?

- Although the posts are publically accessible, if you do not want us to use any of your posts or responses in the general analysis, then you may request this by emailing the researcher on the email below or messaging the researcher or forum moderators through the forum. We will then not include any of your experiences to find common themes in the analyses.
- Please make this request within one month of this information sheet being posted on the forum as once data has been combined to include in the write up we may not be able to remove it.

If you would like further information, please feel free to contact Melanie Sloan (lead researcher) on mas229@medschl.cam.ac.uk or 07975799052 or Paul Howard (forum moderator and LUPUS UK CEO) through forum messaging.

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