

Participant Information Sheet: Rheumatology patients' experiences of support, medical care, and the effects of their diseases on physical and mental health

You are being invited to complete a questionnaire aimed at finding out symptoms, experiences and views of rheumatology patients. We want to explore what you, the patients, think are the effects of your disease, living with a difficult disease and your interactions with clinicians, on your life, wellbeing and health. This is to gain more information to work together to raise awareness and develop plans to improve the care and lives of people with these diseases.

The questions in this questionnaire have been decided by patients with input from researchers, charities, psychologists and a group of patient-centred clinicians, who are all keen to learn from you about patient views, needs and ideas.

Do I have to take part?

If you decide to take part, your participation is entirely voluntary and any decision of whether to participate or not will not affect your medical care. Your doctors will not know whether you have participated in this study. Your responses to the questionnaire can be completely anonymous if you choose. You can withdraw at any stage without giving a reason. For those happy to be contacted further and giving a first name and email, these will be anonymised to a participant number on receipt and no-one other than the data manager and lead researcher (if contacting for further information) will know any personal details.

What do I need to do to take part in this study?

You will need to complete the questionnaire please. This contains questions about your disease symptoms, medical relationships, physical and mental health support, and feelings. In order to be a part of this study you will need to meet the following criteria:

- Be aged 18 or over.
- Be diagnosed with an autoimmune rheumatological disease. This includes diseases such as: Rheumatoid Arthritis (RA) and other inflammatory arthritis, lupus, Sjögrens, undifferentiated (UCTD) or mixed (MCTD) connective tissue disease, systemic sclerosis, PMR, Inflammatory muscle diseases, and vasculitis.
- We welcome participants from all countries.

What are the possible risks of taking part?

We do not foresee any direct risks to your physical health from participating in this study. However, some people may find thinking about health difficulties and medical experiences distressing. If you find any of these questions upsetting or would like some support, please do contact your GP/Primary care doctor or your specialist clinicians.

If you live in the UK and need someone to talk to, you can get in touch with the Samaritans about anything that's troubling you, no matter how large or small the issue feels.

Whatever you're going through, call the Samaritans for free at any time, from any phone,

on: 116123.

If you are not from the UK, please contact your primary care physician for support or alternatively (UK and International) please do contact Melanie if you require signposting to support for mental health in your country. Please also contact Melanie if you have any remaining questions about the study or anything to add: mas229@medschl.cam.ac.uk

At the end of the questionnaire you will also be given these contact details of where to obtain support.

What are the possible benefits from taking part?

We anticipate the information from the questionnaires will help inform doctors and researchers about the impacts of your disease, and positive and negative medical experiences leading to greater understanding and support. Knowing your experiences and views will be heard and used to try and make a difference in the future can be very helpful in coming to terms with any distress caused by any negative experiences and can help others in learning from positive experiences. Being involved in helping with research into your own disease may be empowering and help to improve communication and medical support in the future.

Everyone who completes the questionnaire has the option to be entered into a prize draw to win £100 of Amazon vouchers.

How confidential are my responses and how will you use my personal data?

- All data will be stored securely.
- The published results will not include any information that could identify individuals.
- We will analyse your experiences together with others and look for common patterns. We will use direct quotes from some peoples' questionnaires in the write-up of the study. These will be labelled with a participant number and no names will be included.
- We will be following the General Data Protection Regulations, GDPR, May 2018.
- Cambridge University is the sponsor for this study. We will be using information from you in order to undertake this study and will act as data controller for this. This means that we are responsible for looking after your information and using it properly. Cambridge University will keep identifiable information about you for two years after the study and any follow-up study is completed, following which time any identifying material will be destroyed and the non-identifiable data will be archived for five years, then destroyed.
- Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. You may withdraw from the study at any stage. If you do not fully complete the survey, we will retain the data already completed and may use this data in the overall analysis. To safeguard your rights, we will use the minimum personally-identifiable information possible.
- Further information about how the University uses personal data can be found at: <http://www.information-compliance.admin.ac.uk/data-protection/research-participant-data>

Ethical review of the study.

This project has been reviewed by the Cambridge Psychology Research Ethics Committee.

Who is organising and funding the study?

The study is being led by the Behavioural Science Group at the University of Cambridge and funded by LUPUS UK.

Principal Investigator: Melanie Sloan, mas229@medschl.cam.ac.uk

If you wish to participate, please use the online link to complete the consent form and questionnaire. If you would like further information, please feel free to contact Melanie Sloan (researcher) on mas229@medschl.cam.ac.uk or 07975799052. Behavioural Science Group, Primary Care Unit, Department of Public Health & Primary Care, Institute of Public Health, University of Cambridge, Forvie site, Robinson Way, Cambridge, CB2 0SR. Should you have problems with the conduct of the study, please contact Professor Felix Naughton on F.naughton@uea.ac.uk.