

Survey: Lupus Care in Wales

Participant Information Sheet

We are asking people across Wales about their experiences of Lupus care and how it can be improved. We would like to invite you to provide feedback as part of this work.

About us

This project has been funded by Welsh Government and is supported by clinical leads in Wales. The work will be carried out by CEDAR, an independent NHS Research Group.

What is the purpose of this?

Speaking to people who have experience of Lupus care in Wales can help us understand what works well and what we can do to make it better.

Why have I been asked?

We want to talk to a range of patients who have received care from teams across Wales. By talking to you we can find out which services are good and which services need to improve. It is important that we talk to a range of different people, and we would like to know about your experience and what was good or bad.

What will I have to do?

If you want to take part, you will complete an online survey about your experience of Lupus care in Wales. It will take approximately 15 minutes.

We would also like some people to take part in interviews or focus groups (group interviews) so we can learn more about your thoughts on Lupus care in Wales. The survey and interviews are available in Welsh and in English. The focus groups may be run in Welsh or

English depending on participation and preference. If you are interested in taking part in these interviews or focus groups, when you fill in the survey you can leave your name and contact details for us to get in touch; this means that we will know what your answers to the questions have been. Your survey response will be anonymous unless you provide your name and contact details in the survey itself.

What will happen to the information I give?

The information from your survey will be used with the feedback from others to help us understand more about peoples experience of Lupus care in Wales. This will help us to improve future services. Findings will be written up as a report for Welsh Government. This report will be made available publicly on CEDAR's website.

Will my taking part be confidential and will my personal details be secure?

All information which you provide will be confidential. The handling and storage of personal information will be covered by strict NHS data protection standards. We will aim to use the information we get from the surveys to write a report which will be publicly available for anyone can read. We will not use anyone's real names or personal information, so no one reading the report will be able to identify you.

What will happen if I change my mind?

We would like to emphasise that it is completely voluntary to take part. If you provide your contact details and agree to take part in an interview or focus group, but later change your mind, you are able to withdraw at any time. You can also choose to withdraw your survey responses after you submit; however, this will not be possible if you complete the survey anonymously. If you do not wish to participate, it will not affect the standard of care you receive or your legal rights as a patient.