

# Evaluation of Lupus Care in NHS Wales

## Participant Information Sheet

We'd like to invite you to take part in an interview with an NHS researcher to hear your views on lupus care in NHS Wales.

Before you decide whether or not to take part, please read the following information to understand what the interview is for and what it would involve for you. There will be an opportunity to ask questions if anything is not clear or if you would like any more information before you decide.

### What is the purpose of this project?

This project aims to find out what people with lupus who live in Wales think of the lupus care provided by NHS Wales. To do this, we are asking people across Wales about their experiences of lupus care and how it can be improved. This can help us understand what works well and what could be improved.

This project has been funded by Welsh Government and is supported by clinical leads in Wales. The work is being carried out by CEDAR, an independent NHS Research Group. The findings from this work will be written up in a report for Welsh Government and will be available publicly.

### What would taking part involve?

If you choose to take part, you will be invited to an informal interview with an NHS researcher at a time that is convenient to you. The interview can be an online video call using Microsoft Teams, or a telephone call. We expect that the interview will take about an hour. You will have an opportunity to ask any questions you may have, and we will ask for your consent before the interview begins. During the interview, we will ask you a number of questions about your experience of the care you have received from NHS Wales for your lupus. You will not have to do anything to prepare for the interview.

The interview will be carried out by a researcher who works at CEDAR which is part of the NHS in Cardiff & Vale University Health Board. With your permission, we will record the

interview so that we can type up your answers afterwards. This makes sure we do not miss anything you say. The researcher may also take some additional notes during the interview.

**No one from your care team will be involved in the interview and they will not see your answers to the questions or hear the interview.** Anything we discuss will be anonymous, but we may use anonymised quotes in reports and feedback we provide.

#### Do I have to take part?

No, it is up to you whether or not you take part. You can change your mind at any time without giving a reason. Whether you choose to take part or not, or if you change your mind about taking part, it will not affect the care that you receive. If you decide to take part, you will be asked to verbally complete a consent form (see page 4) prior to the start of the interview.

#### What will happen if I change my mind?

We would like to emphasise that your participation in this interview is completely voluntary. If you decide to take part you are free to change your mind at any time without giving a reason. Please get in touch with us using the contact details at the end of this form if you no longer wish to take part. We will destroy any information we hold about you. If you change your mind after your interview has taken place, we will destroy your personal contact details and the recording of the interview. However, the anonymised interview data will still be used in our reports.

If you do not wish to participate, or if you later wish to withdraw from the project, it will not affect the standard of care you receive or your legal rights as a patient.

#### How will we use information about you?

We will need to use information about you for this project. This information will include your name and contact details, and the demographic information that you provided in the survey. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. All information you provide will be confidential (i.e. we won't use your name or any information that could identify you).

Once we have finished the project, all personal information and any recordings will be destroyed. The handling and storage of personal information will be covered by strict NHS data protection standards. If you decide to take part, we will keep the information you provide, including your name and contact details, and the recording of the interview

until the end of the project. After that, all of the identifiable information will be destroyed and only the anonymous feedback will be kept.

We will aim to use the information we get from the interviews to write a report which anyone can read. We will write our report in a way that no-one can work out who took part in the project.

The report will be published later in 2024 on CEDAR's website: <https://cedar.nhs.wales/>

What do I need to do next?

Your help would be greatly appreciated, but it is not compulsory. It is up to you whether or not you take part and you can change your mind at any time.

If you would like to take part, please respond to the email invitation you received. We will then arrange a convenient time for the interview to take place.

If you have any questions before you decide, please contact us either by email or telephone:

Email: [Michael.Beddard@wales.nhs.uk](mailto:Michael.Beddard@wales.nhs.uk) or [Kathleen.Withers@wales.nhs.uk](mailto:Kathleen.Withers@wales.nhs.uk)

Phone: 029 218 44771

Thank you for taking the time to read this information sheet.

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## Consent Form

Please ensure that you have read and understood the information contained in the Participant Information Sheet and ask any questions you may have before you verbally consent to the statements below at the start of the interview.

1. I have read and understood the information in the Participant Information Sheet, which I have been given to read before being asked to sign this form.
2. I have been given the opportunity to ask questions, and have had these answered satisfactorily.
3. I understand that my participation is voluntary, and that I am free to withdraw at any time without giving a reason and it will not affect the care I receive.
4. I understand that if I withdraw from the study, the anonymised information I provide in the interview will be retained for analysis.
5. I agree that anonymised information and quotes from the interviews may be used in future publications.