

Appendix 1 - Service user survey

Survey title: Your Experience of Lupus Care in Wales

Survey background

Thank you very much for your interest in this survey.

We want to hear from people with Lupus in Wales. We are interested in your experience of the care you receive from NHS Wales for your Lupus and how it could be improved. The more people living in Wales with Lupus that respond to this survey, the more we can work together to provide the best possible care.

In this survey, we will ask you about your experience of getting a diagnosis of Lupus and how it is managed, and your views on the care you have received for your condition.

The survey will take about 15 minutes to complete. Please answer all questions.

Your responses will be anonymous. However, if you would like to take part in an interview to provide more detailed feedback on your experience at a later date, you can provide your name and contact details at the end of the survey. The survey is being carried out by CEDAR, and only the research team at CEDAR will be able to see your personal details if you choose to provide them.

The feedback we gather will tell us more about people's experience of Lupus care and will help us understand how we could improve the NHS services provided in Wales. Results from this project will be fed back in a report to Welsh Government, however all responses will be reported anonymously even if you choose to tell us your name, and no-one will be able to identify you in the report. The report will be made publicly available on CEDAR's website.

More information about the survey can be found in the Participant Information Sheet which can be found here: <https://cedar.nhs.wales/our-work/evaluation/lupus-service-provision-in-wales/>

If you have any questions, or need any help completing the survey, please contact Michael Beddard, a Senior Researcher at CEDAR, using the email address below. You can also request the survey in a different format if required.

Contact email address: michael.beddard@wales.nhs.uk

Thank you for taking the time to complete this survey.

Survey Questions

1. How did you hear about this survey? Please tick the appropriate box.

- I received a letter in the post
- I received a text message from the NHS
- I received an email from LUPUS UK
- I saw it advertised on the LUPUS UK website
- Word of mouth
- Other (please state)

Your diagnosis

2. Approximately what age were you when you **first started having symptoms** of Lupus?
3. Approximately what age were you when **you were diagnosed** with Lupus?
4. Who first diagnosed you with Lupus? Please tick the appropriate box.

- General Practitioner (GP)
- Rheumatologist
- I don't know / I can't remember
- Other (please state)

Your Lupus management

5. We are aware that people often move and receive care from different organisations. We want to understand your experience of care in NHS Wales whilst learning from your experiences elsewhere. Please indicate where and what type of care you have received for your Lupus by placing a tick in the appropriate box in the table overleaf.

5.	I currently receive care from	I used to receive care from	I have never received care from
NHS Wales			
NHS England			
Private healthcare (online)			
Private healthcare (in Wales)			
Private healthcare (in England)			

6. Which of the following healthcare professionals have you seen for your Lupus **through NHS Wales**? Please tick all that apply.

- General Practitioner (GP)
- Rheumatology Specialist Nurse
- Rheumatologist
- Lupus Specialist Clinic
- Nephrologist
- Dermatologist
- Neurologist
- Cardiologist
- Immunologist
- Haematologist
- Physiotherapist
- Psychologist/Counsellor
- A&E/Casualty Doctor
- None of the above
- I don't know / I can't remember
- I have never received care from NHS Wales for Lupus
- Other (please state)

7. How long do/did you have to travel, on average, to receive **NHS care** for your Lupus?

- Less than 30 minutes
- 30 minutes to 1 hour
- Between 1 and 2 hours
- Between 2 and 3 hours
- More than 3 hours
- Not applicable
- Other (please state)

8. How long would you be willing to travel to receive **NHS care** for your Lupus in Wales?

- Less than 30 minutes
- 30 minutes to 1 hour
- Between 1 and 2 hours
- Between 2 and 3 hours
- More than 3 hours

9. How long do/did you travel, on average, to receive **private healthcare** for your Lupus?

- My private healthcare is online
- Less than 30 minutes
- 30 minutes to 1 hour
- Between 1 and 2 hours

- Between 2 and 3 hours
- More than 3 hours
- Not applicable [please skip to question 11]

10. Why did you access private healthcare, either instead of or in addition to, care from NHS Wales?

11. Please tell us what medications, if any, you have been prescribed to manage your Lupus since being diagnosed. Please select all that apply.

- Non-steroidal anti-inflammatory drugs (NSAIDs) e.g. ibuprofen or naproxen
- Steroid cream and / or tablets
- Steroid injections
- Antimalarials. e.g. hydroxychloroquine, chloroquine or mepacrine
- Disease-modifying anti-rheumatic drugs (DMARDs) e.g. azathioprine /cyclosporin /cyclophosphamide /methotrexate /mycophenolate.
- Biological therapies e.g. rituximab or belimumab.
- None
- I don't know / I can't remember
- Other (please state)

12. Is there anything else (non-medicine) that you do to help manage your Lupus symptoms?

- Yes
- No [please skip to question 14]

13. If yes, please tell us what else you do to manage your Lupus symptoms.

14. Do you have access to a 24-hour helpline for Lupus through NHS Wales?

- Yes, and I use it
- Yes, but I do not use it
- No, but I used to have access [please skip to question 16]
- No, I have never had access [please skip to question 16]
- I don't know / I can't remember [please skip to question 16]

15. If yes, how satisfied are you with this helpline?

- Very dissatisfied
- Somewhat dissatisfied
- Neither satisfied nor dissatisfied
- Somewhat satisfied
- Very Satisfied

16. Do you have an emergency treatment plan in place through NHS Wales?

- Yes
- No, but I used to
- No, I have never had an emergency treatment plan
- I don't know / I can't remember

17. How stable do you think your Lupus symptoms are? Please select one option.

- I have very few / no symptoms
- My symptoms are usually stable but I have occasional flare ups
- I have flare ups regularly but they are mild
- I have flare ups regularly of moderate severity
- I have severe flare ups
- I do not think my Lupus is stable at all
- Prefer not to say

Your views on the medical support provided for your Lupus

18. Please rate your experience of the following aspects of your Lupus care **in NHS Wales** by putting a tick in the appropriate box for each aspect of care.

	Very poor	Poor	Fair	Good	Excellent	Not applicable
Getting a diagnosis of lupus						
Getting medicines for your Lupus						
Getting supportive treatments to manage your Lupus						
Accessing support when you need it (e.g. during a flare up)						
Support for the emotional impact of Lupus						
Support from your lead consultant (e.g. rheumatologist, dermatologist or nephrologist)						
Support from your GP						
Advice and information received to						

	Very poor	Poor	Fair	Good	Excellent	Not applicable
manage your Lupus						
Overall current medical support for your Lupus						

19. Please tell us **what went well** in relation to your Lupus **diagnosis** through NHS Wales.

20. Please tell us **what could have been better** about your Lupus **diagnosis** through NHS Wales.

21. Please tell us **what has gone well** in relation to your Lupus **management** through NHS Wales.

22. Please tell us **what could have been better** in relation to your Lupus **management** through NHS Wales.

23. Do you feel that your Lupus diagnosis has affected the care you receive when you have symptoms that are not related to your Lupus?

Yes

No [please skip to question 24]

I don't know / I can't remember [please skip to question 24]

24. Please explain how your Lupus diagnosis has affected the care you receive when you have symptoms that are not related to your Lupus.

25. Please tell us how you think we could improve the NHS services provided for people with Lupus in Wales.

About you

Please answer the following questions so we know a little bit more about you. This will help us make sure we have had feedback from a range of different people and will help us understand more about the information that we get.

We're asking for demographic information in order to make sure participants are an accurate representation of the population of Wales.

All the data we collect is treated in accordance with the Data Protection Act 2018 and UK General Data Protection Regulation (GDPR).

[continues overleaf]

26. What area of Wales do you live in? Please select one option.

- Blaenau Gwent
- Bridgend
- Caerphilly
- Cardiff
- Carmarthenshire
- Ceredigion
- Conwy
- Denbighshire
- Flintshire
- Gwynedd
- Isle of Anglesey
- Merthyr Tydfil

- Monmouthshire
- Neath Port Talbot
- Newport
- Pembrokeshire
- Powys
- Rhondda Cynon Taf
- Swansea
- Torfaen
- Vale of Glamorgan
- Wrexham
- I live outside of Wales

27. What Health Board provides your Lupus care, or most of your Lupus care?
Please select one option.

- Aneurin Bevan University Health Board
- Betsi Cadwaladr University Health Board
- Cardiff and Vale University Health Board
- Cwm Taf Morgannwg University Health Board
- Hywel Dda Health Board
- Powys Teaching Health Board
- Swansea Bay University Health Board
- I don't receive Lupus care via NHS Wales
- Other (please state below)

28. What best describes your gender?

- Male
- Female
- Non-Binary
- Prefer not to say
- Prefer to self-describe (please state below)

29. Is the gender you identify with the same as your sex registered at birth?

- Yes
- No
- Prefer not to say

30. Which of the following best describes your sexual orientation?

- Heterosexual/ Straight
- Bi/Bisexual
- Gay/Lesbian
- Prefer not to say
- Other (please state below)

31. Please tell us your age (in years).

32. Please tell us your ethnic group (Please select one)

<p><u>White</u></p> <p><input type="checkbox"/> Welsh, English, Scottish, Northern Irish or British</p> <p><input type="checkbox"/> Irish</p> <p><input type="checkbox"/> Gypsy or Irish Traveller</p> <p><input type="checkbox"/> Roma</p> <p><input type="checkbox"/> Any other White background</p> <p><u>Asian or Asian British</u></p> <p><input type="checkbox"/> Indian</p> <p><input type="checkbox"/> Pakistani</p> <p><input type="checkbox"/> Bangladeshi</p> <p><input type="checkbox"/> Chinese</p> <p><input type="checkbox"/> Any other Asian background</p> <p><u>Black, Black British, Caribbean or African</u></p> <p><input type="checkbox"/> Caribbean</p> <p><input type="checkbox"/> African</p> <p><input type="checkbox"/> Any other Black, Black British, or Caribbean background</p>	<p><u>Mixed or multiple ethnic groups</u></p> <p><input type="checkbox"/> White and Black Caribbean</p> <p><input type="checkbox"/> White and Black African</p> <p><input type="checkbox"/> White and Asian</p> <p><input type="checkbox"/> Any other Mixed or multiple ethnic background</p> <p><u>Other ethnic group</u></p> <p><input type="checkbox"/> Arab</p> <p><input type="checkbox"/> Any other ethnic group</p> <p><input type="checkbox"/> Prefer not to say</p>
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33. Which of these describe your employment status at time of your Lupus diagnosis? (Please select all that apply)

<p><input type="checkbox"/> Full-time employed or self-employed</p> <p><input type="checkbox"/> Part-time employed or self-employed</p> <p><input type="checkbox"/> Unemployed / seeking work</p> <p><input type="checkbox"/> Looking after home or family</p> <p><input type="checkbox"/> Student</p> <p><input type="checkbox"/> Retired</p> <p><input type="checkbox"/> Long-term sick</p> <p><input type="checkbox"/> Disabled</p> <p><input type="checkbox"/> Prefer not to say</p> <p><input type="checkbox"/> Other (please state below)</p>

34. Has your employment status changed as a result of your Lupus diagnosis?

<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No [skip to question 35]</p> <p><input type="checkbox"/> I don't know / I can't remember [skip to question 35]</p>
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35. If your employment status has changed as a result of your diagnosis, please tell us how it has changed.

Further involvement and accessing support

So that we can get more detailed information, we would like to ask some people to take part in one-to-one interviews, or focus groups (group interviews).

These would all be done remotely (i.e. by telephone or video) and would allow us to learn more about the experiences of people like you. Interviews and focus groups can take place in English or in Welsh, and will take place early in 2024.

36. Would you be interested in taking part in an interview or focus group? *If you choose 'yes', we will contact you at a later date to arrange the interview or focus group. If you choose 'no', you do not need to answer questions 36-40.*

Yes

No

37. Would you prefer to take part in an interview or focus group?

I am interested in taking part in an interview

I am interested in taking part in a focus group

Either an interview or focus group

38. Please provide your full name.

39. Please provide your email address and/or phone number.

40. Preferred method of contact.

Email

Phone

I don't mind

41. Preferred language for interview/focus group.

English

Welsh

Either English or Welsh

Thank you for completing this survey, we appreciate your help and support.

Please return your completed survey to us by popping it into the freepost envelope provided and posting it. You don't need to attach a stamp.

Please use the space below to add additional comments or provide more detailed responses to any of the survey questions. Please indicate which question(s) you are referring to.