

Appendix 6 - National Staff Survey

Survey Background

We are undertaking a national evaluation of lupus services in NHS Wales. As part of this, we would like to hear from healthcare professionals who provide care for people with lupus in Wales.

This survey asks questions about your role, the health and care services that your Health Board provides for people with lupus, and your views on this care. The survey will take approximately 10 minutes to complete and will close at 7pm on Friday 19th July. We recommend completing the survey on a computer or tablet rather than a mobile phone.

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-academic research and evaluation centre which is part of Cardiff and Vale University Health Board (UHB) and Cardiff University.

Only researchers from CEDAR will be able to see your survey responses. All information provided will be anonymised and analysed with other survey responses. Findings will be included in a report for Welsh Government. This report will be made available publicly on CEDAR's website later in 2024:

<https://cedar.nhs.wales/>

If you have any questions, require any help completing this survey, or require the survey in an alternative format, please get in touch with the project lead, Michael Beddard at CEDAR via email: Michael.Beddard@wales.nhs.uk

1. Please state your role and speciality.
2. Which Health Board(s) do you work in? Please select all that apply.

- 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

3. How many years have you been practising as a healthcare professional? *Please give your answer as a whole number (e.g. 18).*

4. Approximately how many service-users with lupus do you routinely see in a year?

5. Is the answer you gave to question 4 taken from a database, or based on an estimate?

- Estimate
- Database (Please state which database)
- Other

6. How often do you see service-users with lupus?

- Daily
- Weekly
- Monthly
- Yearly
- Other

7. How satisfied are you with the care you are able to provide to service-users with lupus?

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

8. Please provide further details on why you gave the answer you did to the previous question.

9. Does your Health Board(s) offer dedicated lupus clinics?

- Yes
- No
- Unsure

10. If your Health Board has a dedicated lupus clinic, would you change anything about them?

11. Do you think all Health Boards in NHS Wales should offer dedicated lupus clinics?

12. Please explain your answer to the previous question.

13. What, in your opinion, should a dedicated lupus clinic involve? Select all those that apply.

- A dedicated session for service-users for lupus/CTD only
- Consultant supervising care having a specialist interest in CTD
- Access to blood pressure, urine and body mass index (BMI) testing at each clinic
- Lupus specialist nurse input
- Access to BILAG Biologics Register (BILAG BR) studies i.e. be a BILAG registered site. (BILAG BR is a UK-wide study looking at the safety and effectiveness of biologic and biosimilar treatment for systemic lupus erythematosus (SLE))
- SLEDAI or BILAG disease activity measuring as standard
- Access to biologics
- None of the above
- Unsure
- Other

14. Do you think service-users with lupus who require biologic clinics should be seen in a dedicated lupus clinic?

- Yes
- No
- Unsure

15. Please explain your answer to the previous question.

16. If a service-user needed biologic therapy for lupus, what are the most important factors to consider?

Please rank the following factors between 1 and 4, with 1 being the most important factor.

1. Administer at local unit
2. Administer at site chosen by service-user
3. Administer at a site with dedicated lupus clinic
4. Administer at BILAG registered site to enable inclusion in BILAG-BR & relevant research studies

17. What are your views on the standard of care provided to service users for the following aspects of lupus care in the Health Board(s) you currently work in?

- Getting a diagnosis of lupus
- Getting medicines for lupus
- Getting supportive treatments to manage lupus
- Accessing support when a service-user needs it (e.g. during a flare up)
- Support for the emotional impact of lupus
- Support for service-users from a lead consultant (e.g. rheumatologist, dermatologist or nephrologist)
- Support for service-users from a GP

- Advice and information received to manage lupus
- Overall current medical support for lupus

- 18.** Is there anything that makes it difficult for you to provide care for service-users with lupus?
- 19.** Is there anything that makes it easier for you to provide care for service-users with lupus in Wales?
- 20.** Is there anything you think your Health Board(s), or NHS Wales, is doing particularly well in terms of providing care for service-users with lupus?
- 21.** Is there anything you think your Health Board(s), or NHS Wales, could be doing better for service-users with lupus?
- 22.** Which, if any, of the below do you think would help improve care for service-users with lupus in Wales? Select all those that apply.
- 23.** What, if anything, do you do to evaluate the quality of care provided to service-users with lupus?
- 24.** Do you think using a service-user-reported outcome measure (PROM) would be useful to understand the quality of life of service-users with lupus in Wales?
- 25.** Do you have any additional comments, concerns or suggestions about lupus care in Wales that you like to make us aware of?