Canolfan ar gyfer Gwerthuso, Asesu Dyfeisiau ac Ymchwil Gofal Iechyd
CEDAR
Centre for Healthcare Evaluation, Device Assessment and Research

NHS Wales Lupus Service Evaluation

Final report

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LUPUS UK

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Executive summary

Background

Lupus, or Systemic Lupus Erythematosus (SLE), is a complex autoimmune condition that often impacts multiple organs, requiring coordinated care from various medical specialists. The disease's unpredictable nature and diverse clinical manifestations pose significant challenges for both patients and healthcare providers, with many patients experiencing long delays in receiving a diagnosis. It can severely affect a person's quality of life and lead to long-term health complications, including physical and psychological impacts.

Aims and objectives

CEDAR, an independent NHS research group, was commissioned by the Welsh Government to evaluate the experience of services for people with lupus from the perspectives of people with lupus (service-users) and clinicians (service-providers) across NHS Wales. Working in partnership with the Welsh Musculoskeletal (MSK) Strategic Clinical Network, the primary objectives of this evaluation were to gather insights from patient and clinician experiences to identify strengths and areas needing improvement, and explore opportunities to enhance the delivery of lupus care in Wales.

Methods

This evaluation employed a mixed-methods approach, combining quantitative and qualitative data collection to provide a comprehensive analysis of the experience of care provision for people with lupus in Wales. Data were gathered from a survey that was distributed via two methods; one distributed to people with lupus by clinicians, and the other distributed via social media. A total of 288 participants responded to the survey. To supplement the survey data, in-depth qualitative insights were gathered through 15 online semi-structured interviews and four online focus groups of 15 participants in total. A national online survey of clinicians was also conducted, targeting staff working in rheumatology services across Wales, which received 17 responses.

Findings

The service-user survey included people with lupus from all Health Boards and Council areas in Wales. The results revealed variability in satisfaction with lupus care. While some patient participants reported positive experiences, particularly regarding the receipt of medications and support from their rheumatology consultant, a substantial proportion expressed dissatisfaction with aspects of their care. Key concerns included difficulty accessing urgent care during flare-ups, inadequate emotional wellbeing and mental health support, and a lack of

coordinated care between healthcare providers. Many also reported that non-specialist healthcare providers such as general practitioners and emergency departments, lacked awareness and understanding of lupus, which they felt affected the overall quality of care received.

Major themes

Navigating the healthcare system: Many patients reported difficulties in obtaining timely diagnoses, with some experiencing misdiagnoses. Delays in diagnosis were reported to have led to negative health consequences. A number of patient participants experienced a lack of coordination between specialists and fragmented care, making it difficult to navigate their treatment pathways effectively. Many reported having to advocate for particular tests or treatments for their condition. However, many reported having received excellent care from knowledgeable, supportive health care professionals. Participants reported that they would appreciate more clarity around the ongoing monitoring of their condition and more frequent monitoring appointments.

Challenges in being heard: Many participants reported feeling like they were not listened to during previous interactions with healthcare professionals. This was considered to have contributed to feelings of isolation and frustration as they struggled to advocate for their needs and receive appropriate care. Patient participants emphasised the importance of feeling listened to and supported throughout their care journey.

Lived experience of lupus: The unpredictable and often debilitating nature of lupus significantly impacted participants' daily lives, including their ability to work and mental health. Many participants reported that they had not been offered support to manage the psychological impact of lupus symptoms.

Clinician perspective

Of the 17 responses received from clinicians (clinical participants) providing care to people with lupus in NHS Wales, there were 12 consultant rheumatologists, two consultant paediatric rheumatologists, two rheumatology clinical nurse specialists, and a rheumatology registrar. The survey included representation from at least one clinician from each Welsh Health Board. Clinicians highlighted challenges related to limited service capacity, shortages of specialist staff, and the difficulties of managing people with complex presentations of lupus. They also acknowledged the need for better access to multidisciplinary care and more emotional support for people with lupus. Clinicians reported some strengths of the service; including their collaboration with other specialists and the availability of advanced treatments, such as biologics. They reported a need for improved collaboration between specialists, and dedicated clinics to improve the co-

ordination of care, and ensure timely interventions for people with complex presentations.

Opportunities for improvement

From survey responses, interviews, and focus groups, several opportunities to improve care for people with lupus in NHS Wales were identified. These include enabling regular monitoring and clear follow-up plans, increasing access to specialist healthcare professionals, and improving treatment navigation and signposting for newly diagnosed patients. Expanding access to mental health and emotional wellbeing support, facilitating quicker access to urgent care, and providing a dedicated phoneline for support and advice were also suggested. Additionally, enhancing healthcare provider training on lupus and increasing access to holistic multidisciplinary treatment through specialist centres or clinics were identified as key opportunities.

Conclusion

The evaluation highlighted a clear need for more responsive and coordinated services for people with lupus in NHS Wales. Key areas for improvement include enhancing access to specialist care, monitoring of people with lupus, providing timely interventions during flare-ups, and addressing the mental health and emotional wellbeing needs of people living with lupus. Both patient participants and clinicians expressed the desire for more personalised, accessible, and holistic care pathways. Despite the challenges, positive aspects such as specialist care, access to medication, and interdisciplinary collaboration were recognised as strengths that can be built upon. The findings from this evaluation aim to support the Welsh Government, NHS Wales and the NHS Wales Executive via the Musculoskeletal (MSK) Strategic Clinical Network and the Rheumatology Clinical Implementation Network, in understanding what works well within NHS Wales lupus services, and identifying opportunities to enhance service provision to better meet the needs of people with lupus in Wales.

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Abbreviations

Abbreviation	Definition
A&E	Accident and Emergency
BILAG (BR)	British Isles Lupus Assessment Group (Biologics Register)
BMI	Body Mass Index
BSR	British Society for Rheumatology
CEDAR	Centre for Healthcare Evaluation, Device Assessment and Research
CTD	Connective Tissue Disease
DEXA	Dual Energy X-ray Absorptiometry
DMARD	Disease-Modifying Anti-Rheumatic Drug
ePROM	Electronic Patient-Reported Outcome Measures
FTWW	Fair Treatment for the Women of Wales
HCP	Healthcare Professional
MDT	Multi-Disciplinary Team
MSK	Musculoskeletal
N/A	Not Applicable
NHS	National Health Service
NSAID	Non-Steroidal Anti-Inflammatory Drug
PROM	Patient Reported Outcome Measure
QoL	Quality of Life
SD	Standard Deviation
SLE	Systemic Lupus Erythematosus
SLEDAI	Systemic Lupus Erythematosus Disease Activity Index
UHB	University Health Board

About CEDAR

CEDAR is an NHS-academic research and evaluation centre which is part of Cardiff and Vale University Local Health Board and Cardiff University. As a healthcare technology research centre, CEDAR focuses on research and evaluation involving medical devices and diagnostics. We work with the NHS, academic institutions, commercial sector, publicly funded organisations, and charities. Our areas of expertise include systematic reviewing, health economics, clinical trial facilitation, qualitative research, analysis of routinely-collected and linked health data, and medical device regulations.

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- Dr Ceril Rhys-Dillon, Consultant Rheumatologist & Clinical Lead for Rheumatology Clinical Implementation Network in Wales
- Dalila Tremarias, Patient Representative
- Paul Howard, Ex-Chief Executive Officer, Lupus UK
- Laura Jones, Major Health Conditions Policy Officer, Welsh Government
- Gareth Hewitt, Head of Clinical Conditions and Pathways Team, Welsh Government

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This work has been commissioned and funded by Welsh Government, working in partnership with the MSK Strategic Clinical Network and the NHS Wales Executive. The authors declare no conflicts of interest.

Approvals

This evaluation was registered as a service evaluation project on the Audit Management and Tracking system at Cardiff and Vale UHB (Audit code: Rheumatology/SE/2023-24/01)

Appendices

A number of appendices accompanying this report, which are referenced throughout and available separately on the CEDAR website: https://cedar.nhs.wales/our-work/evaluation/lupus-service-provision-in-wales/lupus-evaluation-report-appendices/

Lupus Service Evaluation

1. Background

Introduction to Systemic Lupus Erythematosus (SLE)

Lupus or Systemic Lupus Erythematosus (SLE), is a chronic autoimmune disease characterised by diverse clinical manifestations often involving multiple organs (Fair Treatment for the Women of Wales, 2021). The manifestations of lupus can vary from mild to life-threatening and may come and go throughout a person's lifetime. One of the most common symptoms, affecting up to 90% of people with lupus, is fatigue, along with weight loss, fevers, arthritis, Raynaud's syndrome, hair loss, depression and skin changes including a distinctive 'butterfly 'rash across the cheeks and nose (Lupus UK, 2017). The condition can have a significant impact on various aspects of an individual's quality of life including employment and relationships, and can also reduce life expectancy, with people with lupus in the UK living, on average, 25 years less than unaffected individuals (Pearce et al., 2021).

Epidemiology of lupus

An estimated 3,100 people in Wales have lupus (Fair Treatment for the Women of Wales, 2021). Lupus is reported to be six times more common in women than men, with a peak age of incidence from 50-59 years. A higher prevalence of lupus is evident in people from Black and Asian ethnic groups (Rees et al., 2016). The prevalence of lupus in the UK has increased fivefold between 1990-2000. This may reflect increased detection of the condition and/or improved survival outcomes (Ellis et al., 2024). The global prevalence in women is estimated to be 78.73 (28.61-196.33) per 100,000 persons, totalling 3.04 million people globally, while in men the estimates are 9.26 (3.36 to 22.97) per 100 000 persons and 0.36 million people, respectively (Tian et al., 2023).

Pathophysiology and causes

Lupus is primarily triggered by hyperactive B cells producing autoantibodies and creating immune complexes, which then induce inflammatory reactions (Maidhof et al., 2012). Although the cause is not clear, genetic, environmental and hormonal factors are thought to play a role. Therefore, the disease remains poorly understood and is often very unpredictable, with no definitive tests available to diagnose lupus, creating a diagnostic challenge for both patients and physicians. Earlier diagnosis has been associated with better prognosis, however, studies

have reported an average of 6-7 years for people to receive a diagnosis, and around half of people with lupus have reported that they were initially misdiagnosed (Morgan, 2014; Sloan, 2020). This can impact both physical and mental health, with many developing often irreversible damage to their health during this time. Organs impacted may include the kidney (affecting up to 60% of people with lupus), the heart (with a reported 7- to 10-fold increased risk of developing cardiovascular disease) as well as the lungs, skin and brain (Fosam et al., 2020). This delay in diagnosis can also cause psychological damage and insecurity in those who have who were dismissed or disbelieved (Sloan et al., 2021).

Treatment for lupus

The treatments provided for lupus vary depending on type and severity of the disease. Lifestyle management is recommended for all those with lupus and includes sun protection, a healthy diet, appropriate immunisations, and smoking cessation. However, depending on symptoms, treatments such as NSAIDs (e.g., ibuprofen, naproxen), corticosteroids (e.g., creams for skin rashes and injections for flare-ups), immunosuppressants/disease -modifying anti-rheumatic drugs (DMARDs) and antimalarials (the most common being hydroxychloroquine, used to reduce inflammation) may be used. Additionally, there are biological therapies which can be used when DMARDs are not effective, or if the lupus is very active. They work by targeting immune pathways associated with inflammation such as Rituximab and Belimumab, which reduce B cell survival. There are also numerous treatments used for the secondary health problems associated with lupus such as osteoporosis, high cholesterol and antiphospholipid syndrome. Many of these medications require regular blood tests to monitor blood counts, kidney and liver function.

Services for Lupus

People with lupus generally engage in treatment from a variety of healthcare professionals due to the complexity of the condition and treatment. The provision of care through multi-disciplinary healthcare teams or specific clinics is suggested to support holistic care for people with lupus. Lupus UK has created a list of criteria for specialist clinics to be awarded and named as a 'Centre of Excellence' by the charity. Ten Centres of Excellence exist in the UK, none currently in Wales (Lupus UK, 2024a). Lupus UK also funds specialist lupus nurses across England, Northern Ireland, and Scotland. In Wales, there is currently one specialist lupus nurse based in North Wales (Lupus UK, 2024b). A qualitative study explored the experiences of people who had received support from the lupus clinical nurse specialist in North Wales. The study reported that people were very positive about

their experience of receiving care from this specialist role, appreciating their expert knowledge of the condition, empathy and accessibility during flares of disease activity (Culshaw and Roychowdhury, 2020).

Insights from previous audits

In 2018, the British Society for Rheumatology published the first UK guidelines for managing systemic lupus erythematosus in adults (Gordon, 2018). A UK-wide baseline audit conducted shortly after identified gaps between the guideline standards and clinical practice, aiming to support quality improvement (Pearce et al., 2021). The audit included 51 units across the UK, covering 1021 clinic visits by 1003 patients, and revealed low compliance (<60%) with standards for disease activity assessment, drug toxicity reduction, and protection against comorbidities. Dedicated lupus clinics showed better compliance with urine protein quantification, while specialised centres performed better in blood pressure recording and British Isles Lupus assessment Group (BILAG) Biologics Register Recruitment. The audit underscored the need for improved disease control and reduction in corticosteroid toxicity. However, only one Welsh unit participated, and specific data on patients and clinic visits from Wales was not provided. Furthermore, the audit focused on patients attending rheumatology outpatient clinics, which may not represent the wider lupus population. Our evaluation addresses this gap by focusing specifically on the Welsh population, using a survey distributed via clinicians to people seen in clinics, and more widely on social media, to provide a more comprehensive and representative understanding of lupus care in Wales.

Following the UK-wide audit in 2018, a Wales-specific audit, aligned with the BSR guidelines was conducted in 2021, involving data from 62 clinical encounters of patients with SLE across five rheumatology centres in Wales (Wright et al., 2023). The audit highlighted several positive developments, including increased use of disease activity assessments, improved documentation of lipid profiles, greater emphasis on vaccination discussions and UV protection advice, and better recording of smoking status compared to previous audits. These areas reflect advancements in patient education and preventative care. However, the audit also identified areas needing further improvement, particularly in compliance with urine protein quantification, blood pressure monitoring, and prednisolone management. Monitoring for eye disease in patients on hydroxychloroquine and discussions of pregnancy and contraception also showed room for improvement. The results have been reproduced in table 1 below. The findings suggest that the shift to virtual consultations during the audit period impacted some clinical measures, but provide a valuable foundation for guiding future improvements in SLE care in Wales (Wright et al., 2023).

Table 1. Comparison of compliance with guidelines standards across the BSR UK Audit (2018), All-Wales Audit (2019), and All-Wales Audit (2021) (adapted from Wright et al., 2023).

Guideline Item	BSR UK Audit 2018	All-Wales Audit 2019	All-Wales Audit 2021
Assessment of disease activity using BILAG/SLEDAI	21.3%	23.3%	41.9%
Appropriate urine protein quantification	82.6%	85.3%	45.0%
If inactive disease, on ≤ 7.5mg prednisolone	84.0%	95.8%	50.0%
Documentation of monitoring for eye disease for patients on chloroquine/hydroxychloroquine within the last 12 months	52.8%	74.7%	70.8%
BP measurement documented	91.9%	88.8%	41.9%
eGFR measurement	93.9%	94.8%	93.6%
Lipid profile	39.0%	57.8%	64.5%
Vaccinations discussed	32.7%	40.8%	75.0%
UV protection discussed	30.3%	43.5%	58.1%
Smoking status recorded	61.8%	77.6%	85.0%
Pregnancy issues discussed	48.3%	67.6%	65.0%
Contraception discussed	43.8%	47.1%	50.0%

Recent surveys exploring the healthcare experiences of people with lupus in the UK have highlighted several recommendations for improving care. These include enhancing healthcare professionals' knowledge of lupus, fostering active listening skills, adopting a holistic approach to care, and providing greater support for wellbeing and quality of life (Sloan, 2020). Additionally, UK evidence points to significant challenges faced by people with lupus in accessing medical support during the COVID-19 pandemic (Sloan, 2020). However, Welsh participants represented less than 10% of these survey populations. This evaluation sought to address this evidence gap by investigating the experiences of people with lupus and the clinicians providing their care within NHS Wales.

2. Purpose of the evaluation

Aim

Working in partnership with the MSK Strategic Clinical Network, Welsh Government have commissioned CEDAR to conduct an independent evaluation of the experience of people accessing and delivering services for people with lupus in Wales. The findings from this evaluation aim to support the Welsh Government, NHS Wales and the NHS Wales Executive via the Musculoskeletal (MSK) Strategic Clinical Network and the Rheumatology Clinical Implementation Network, in understanding what works well within NHS Wales lupus services, and identifying

opportunities to enhance service provision to better meet the needs of people with lupus

Objectives

The evaluation objectives were to:

1. **Explore in-depth the perspectives of people with lupus (service users) using a mixed-methods approach**

   Gain an in-depth understanding of the experiences of people with lupus who interact with NHS services, their treatment pathways, satisfaction levels, and identification of positive aspects of care.

2. **Gather clinician insights on lupus care in Wales**

   Gather insights from clinicians on the strengths and challenges in lupus care across Wales, and identify opportunities for improving care delivery within the NHS.

3. **Identify actionable opportunities for service improvement**

   Highlight key areas for improvement in the lupus service within NHS Wales, from both the perspectives of individuals with lupus and clinicians.

4. **Publish a publicly available bilingual report**

   Write-up project and publish a publicly available version in both English and Welsh.

3. Methods

To achieve the evaluation objectives, a pragmatic, mixed-methods approach was adopted. The key data collection methods were:

- Service user survey
- Semi structured online interviews with service-users
- Semi structured online focus groups with service-users
- Clinician (service provider) survey

A project steering group, consisting of two lead clinicians, and a representative from Welsh Government provided guidance throughout the evaluation. Their input ensured that the evaluation aims were met, and that all relevant issues were addressed. This included supporting the design of the surveys and interview materials such as the topic guide, although the final decisions on the content were made by the CEDAR research team. Lupus UK were also involved in the design of

the survey and interview materials to ensure that the perspectives of people with lupus were included.

A study flowchart outlining the steps in the study is available in figure 1 below.

Study flowchart

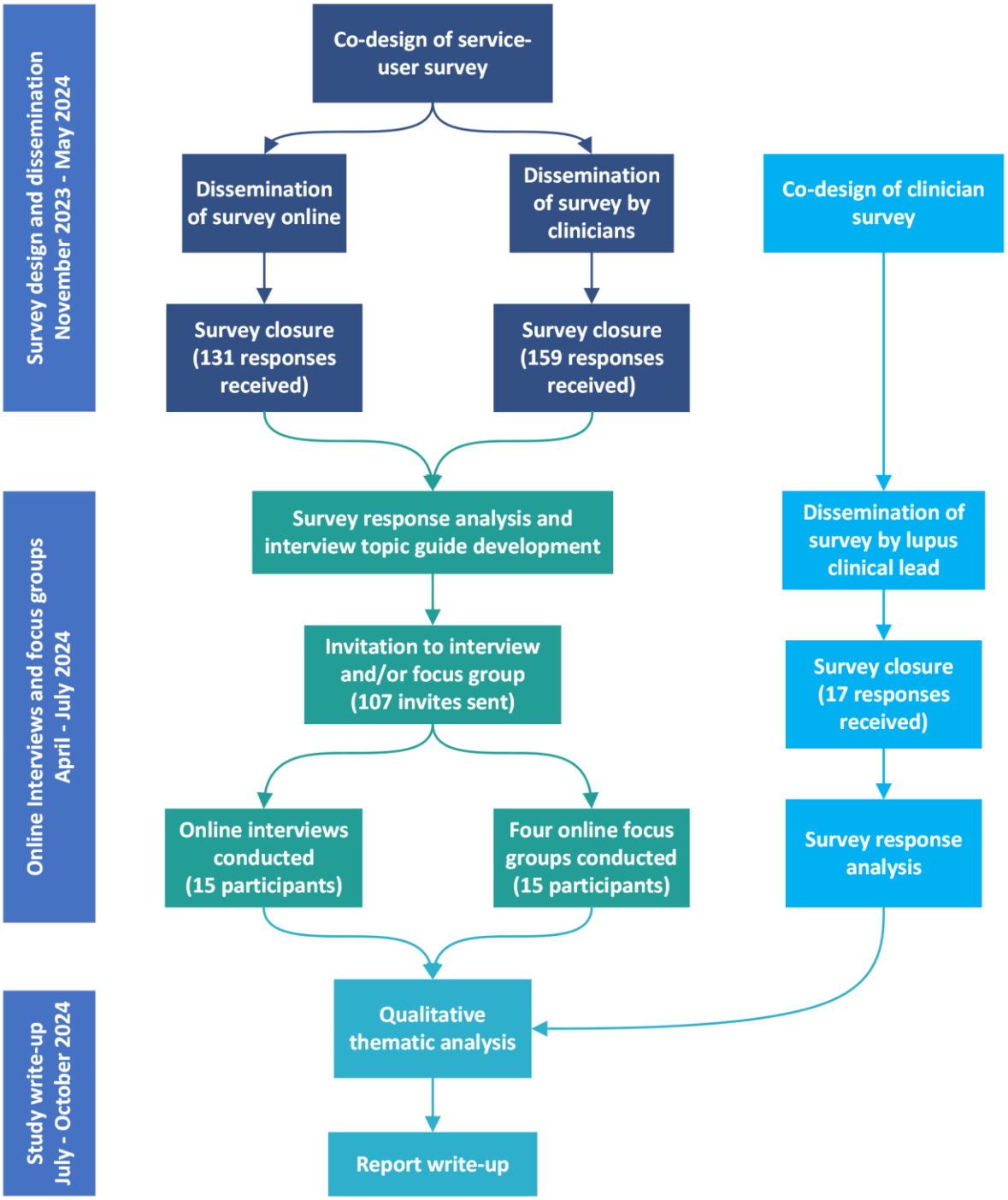

Figure 1. Study flowchart detailing the stages of the lupus evaluation

Service user survey

In early 2024, CEDAR co-designed a bilingual (Welsh and English) survey with the project steering group, clinical leads in Wales, and Lupus UK. This involved initial discussions among the steering group to identify potential themes of interest, with these drafted into questions by CEDAR staff for review and comment by the steering group. The draft questions were shared with Lupus UK for discussion in a focus group, comprising of volunteers with lupus and facilitated by a member of Lupus UK. This was observed by a clinician, and CEDAR staff member from the steering group who were able to clarify any issues and had an opportunity to ask questions. Co-production of the questionnaire was important to ensure that all themes relevant to people with lupus were included, and that the wording of questions was clear and accessible. The survey is available in Appendix 1. The survey collected demographic information and explored:

- Peoples experience of lupus diagnosis and management
- Satisfaction with lupus care in NHS Wales
- Impact of lupus on daily life and employment
- Suggestions for improvement of lupus services in NHS Wales

In order to try and reach a broad sample of people with lupus in Wales, two versions of an identical online survey were created. At the conclusion of the survey, participants were asked whether they were interested in participating in an interview or focus group.

The survey was disseminated via two distinct methods and are referred to as the 'Clinician-distributed' and 'Social media-distributed' surveys throughout the report. Both versions of the survey were available to complete on Microsoft Teams and were open for four months, from January 2024-May 2024. Service-users were also able to request a survey to be sent to them by post.

Clinician-distributed survey

Clinical leads within Welsh health boards were asked to identify people clinically coded as having lupus. Each identified service-user was sent a link or website address for the survey by post or SMS text message, depending on the preferences of each health board. The number of individuals coded as having lupus within each health board was not shared with the authors, and therefore it was not possible to calculate a response rate. Additionally, not all health boards were able to contact every individual with a lupus diagnosis within their health board.

Social-media distributed survey

Alongside the clinician-distributed survey, and to address the potential limitations of solely relying on clinical databases, such as missed diagnoses or those with lupus who may not be actively engaged with hospital services, the survey was also disseminated online through social media channels by CEDAR, Lupus UK, Cymru Versus Arthritis, and a patient representative. Lupus UK also sent letters by post to advertise the survey, with a QR code to access the survey online. The letter is available in Appendix 2.

This recruitment strategy aimed to support the capture of data related to experiences of individuals who might not be coded in hospital records, including those who have not had a lupus diagnosis or treatment in NHS Wales, or those diagnosed in primary care settings. By employing direct invitations to people diagnosed with lupus, supported by an open online distribution, we aimed to include views from a wide range of people with lupus, regardless of their level of engagement with the healthcare system.

Semi-structured Interviews

A total of 35 people who expressed an interest in an interview were contacted by email, with participation available in English or Welsh language mediums. Invitations included a service-user information sheet explaining what the interview would entail, and a consent form (Appendix 3). Participants were offered the opportunity to ask any questions beforehand by email or telephone. Each participant invited initially was followed up once with a reminder email if no response was received.

Included in the group invited to participate were two participants who had requested participation in the medium of Welsh. However, no responses were subsequently received from these individuals following the invitation or reminder. Consequently, no interviews were conducted in Welsh.

Three interviewers experienced in qualitative interviewing techniques, conducted a total of 15 online semi-structured interviews between 03/04/2024 – 15/07/2024. Interviews were guided using an interview topic guide developed from the survey findings (Appendix 4). The interview topic guide was developed by CEDAR and reviewed by Lupus UK and clinical leads to ensure they met the evaluation objectives and included all key issues. Participants were asked questions related to:

- Their experience of obtaining a diagnosis
- Impact of lupus on daily life
- Lupus care and management
- Self-management and support
- Suggestions for improvements to the service

Semi-structured Focus groups

A total of 72 people who had expressed an interested in taking part in a focus group were contacted by email and invited to take part. Similarly to the interviews, invitations included a service-user information sheet and consent form to read prior to joining the focus group. Four online focus groups with a total of 15 participants, took place between 18/06/2024 – 17/07/2024. Focus groups were organised using participant's rating of their lupus care (Q18: 'Overall current medical support for your lupus'). This resulted in two focus groups with participants who responded 'Excellent', 'Good' or 'Fair'. Another two took place with people who had responded 'Poor' or 'Very poor'. The purpose of this strategy was to encourage discussion, while not mixing people with widely differing experiences in case this caused distress or frustration.

The focus groups were guided by a topic guide based on the interview findings to explore service users' priorities in greater depth, focusing on several key aspects of their lupus care experience (Appendix 5). The aim was to gain a deeper insight into the information needed at diagnosis, ways to personalise and coordinate lupus care, optimum services for managing flare-ups, recommended information sources, and the adequacy of mental health and emotional wellbeing support.

All interviews and focus groups were recorded with the consent of participants. Recordings were transcribed in house using an intelligent verbatim format, supported by the Teams transcription function. Transcripts were password protected and recordings accessible only to the researchers involved in the evaluation.

National Staff Survey

A separate survey was sent to clinicians working in rheumatology services across Wales to gather their perspectives on the care provided. This included challenges in care provision, areas where services perform effectively, and any opportunities for improving the management of lupus within NHS Wales. The survey was co-developed with the project steering group, and a lupus clinical lead. The survey was open for one month throughout July 2024 and is available in Appendix 6.

Analysis

Quantitative analysis

Survey responses were reviewed to explore whether there were potentially multiple responses from any individual, where they may have responded to both the social media and clinician requests to complete the survey. Key characteristics including name, email address, age of symptom onset, age at diagnosis and health board were initially considered, with a full review of responses where there were potential duplicates identified.

Closed-ended survey responses for both the service-user and clinician surveys were analysed using descriptive statistics.

Qualitative analysis

Open-ended free-text survey responses were analysed by two researchers using inductive thematic analysis.

For the interviews and focus groups with individuals with lupus, a constant comparative approach was adopted to iteratively identify their care priorities Interviews and focus groups were recorded, transcribed by two researchers, and de-identified for analysis.

The transcripts from the interviews and focus groups were thematically analysed to identify patterns and insights. Through this process, key themes and subthemes were extracted, which provide a deeper understanding of the participants' experiences, perspectives and opportunities for improvement within the service. The themes are detailed in section 5.

Salient quotes from surveys and interviews/focus groups were extracted by two researchers to illustrate each theme throughout the report. All interview/focus group findings have been anonymised, with no participant names or identifiable details included in the report. Each participant is identified using a 'participant' number – i.e. P123.

4. Survey Results

Service user surveys

A total of 290 responses were received across both survey distribution channels: 159 from the clinician-distributed survey and 131 from the social media-distributed survey. Two participants were identified to have responded to both the social media and clinician administered invitations to participate, providing similar responses and identical names and email addresses. No other potential duplicates were identified. The duplicate responses were included in the qualitative review as some feedback differed, but removed from the quantitative analysis, leaving a total of 288 individual participant responses.

Survey demographics

Table 2 below provides a detailed breakdown of each question. Results are combined, but also separated by survey version

Table 2. Demographic characteristics of survey participants

Category		Clinician (n=157)		Social media (n=131)		Combined (n=288)	
Sex N, %	Male	7	4.5%	7	5.3%	14	4.9%
	Female	150	95.5%	122	93.1%	272	94.4%
	Prefer not to say	0	0.0%	2	1.5%	2	0.7%
Age mean, SD		53.9	15.1	51.1	13.4	52.6	14.4
Age at symptom onset mean, SD		32.2	15.2	31.1	13.6	31.7	14.5
Age at diagnosis mean, SD		38.4	14.8	38.1	14.1	38.3	14.5
Area of Wales	Blaenau Gwent	0	0.0%	5	3.8%	5	1.7%
	Bridgend	2	1.3%	3	2.3%	5	1.7%
	Caerphilly	4	2.5%	1	0.8%	5	1.7%
	Cardiff	38	24.2%	18	13.7%	56	19.4%
	Carmarthenshire	15	9.6%	13	9.9%	28	9.7%
	Ceredigion	3	1.9%	0	0.0%	3	1.0%
	Conwy	7	4.5%	5	3.8%	12	4.2%
	Denbighshire	6	3.8%	4	3.1%	10	3.5%
	Flintshire	3	1.9%	3	2.3%	6	2.1%
	Gwynedd	9	5.7%	5	3.8%	14	4.9%
	Isle of Anglesey	3	1.9%	0	0.0%	3	1.0%
	Merthyr Tydfil	12	7.6%	2	1.5%	14	4.9%
	Monmouthshire	1	0.6%	2	1.5%	3	1.0%
	Neath Port Talbot	0	0.0%	4	3.1%	4	1.4%
	Newport	1	0.6%	8	6.1%	9	3.1%
	Pembrokeshire	5	3.2%	23	17.6%	28	9.7%
	Powys	2	1.3%	11	8.4%	13	4.5%
	Rhondda Cynon Taf	30	19.1%	7	5.3%	37	12.8%
	Swansea	1	0.6%	10	7.6%	11	3.8%
	Torfaen	1	0.6%	2	1.5%	3	1.0%
	Vale of Glamorgan	11	7.0%	2	1.5%	13	4.5%
	Wrexham	2	1.3%	2	1.5%	4	1.4%
	Outside of Wales	1	0.6%	1	0.8%	2	0.7%
Health Board	Aneurin Bevan University Health Board	5	3.2%	20	15.3%	25	8.7%
	Betsi Cadwaladr University Health Board[1]	30	19.1%	19	14.5%	49	17.0%
	Cardiff and Vale University Health Board	52	33.1%	19	14.5%	71	24.7%
	Cwm Taf Morgannwg University Health Board	42	26.8%	15	11.5%	57	19.8%
	Hywel Dda Health Board	21	13.4%	34	26.0%	55	19.1%
	I don't receive Lupus care via NHS Wales	3	1.9%	7	5.3%	10	3.5%
	Swansea Bay University Health Board	3	1.9%	15	11.5%	18	6.3%

Category		Clinician (n=157)		Social media (n=131)		Combined (n=288)	
	Powys Teaching Health Board	0	0.0%	2	1.5%	2	0.7%
	Other	1	0.6%	0	0.0%	1	0.3%
Ethnicity	White (Welsh, English, Scottish, Northern Irish, British, Irish or Any other White background)	136	86.6%	128	97.7%	264	91.7%
	Asian or Asian British (Chinese, Indian or Any other Asian Background)	9	5.7%	0	0.0%	9	3.1%
	Mixed or multiple ethnic groups	7	4.5%	0	0.0%	7	2.4%
	Black, Black British, Caribbean or African	4	2.5%	0	0.0%	4	1.4%
	Prefer not to say	1	0.6%	3	2.3%	4	1.4%
Sexual Orientation	Heterosexual/straight	149	94.9%	124	94.7%	273	94.8%
	Lesbian/Gay/Bisexual/Pansexual	6	3.8%	3	2.3%	9	3.1%
	Prefer not to say	2	1.3%	4	3.1%	6	2.1%
Employment status at time of diagnosis	Disabled	20	12.7%	12	9.2%	32	11.1%
	Full-time employed/self-employed	53	33.8%	53	40.5%	106	36.8%
	Long-term sick	10	6.4%	13	9.9%	23	8.0%
	Looking after home or family	12	7.6%	6	4.6%	18	6.3%
	Part-time employed/self-employed	27	17.2%	36	27.5%	63	21.9%
	Prefer not to say	3	1.9%	1	0.8%	4	1.4%
	Retired	27	17.2%	16	12.2%	43	14.9%
	Student	9	5.7%	4	3.1%	13	4.5%
	Unemployed/seeking work	2	1.3%	1	0.8%	3	1.0%
	Other	3	1.9%	2	1.5%	5	1.7%
Employment change as a result of diagnosis	Yes	72	45.9%	82	62.6%	154	53.5%
	No	77	49.0%	47	35.9%	124	43.1%
	Prefer not to say	6	3.8%	1	0.8%	7	2.4%
	Don't know/can't remember	2	1.3%	1	0.8%	3	1.0%
How did you hear about this survey?	Letter in the post	132	84.1%	0	0.0%	132	45.8%
	LUPUS-UK e-mail/website	3	1.9%	78	59.5%	81	28.1%
	Text message from NHS	19	12.1%	0	0.0%	19	6.6%
	Word-of-mouth	1	0.6%	10	7.6%	11	3.8%

Category		Clinician (n=157)		Social media (n=131)		Combined (n=288)	
	Other	2	1.3%	2	1.5%	4	1.4%
	Lupus support groups	0	0.0%	4	3.1%	4	1.4%
	Social media (Facebook, X, Instagram, WhatsApp)	0	0.0%	37	28.2%	37	12.8%

N: Number; SD: Standard Deviation

As anticipated, a notable difference was observed in how participants heard about the survey. Among those who responded to the clinician-distributed survey, 84.1% (n=132) learned about it through a letter in the post. In contrast, participants who responded to the social-media distributed survey primarily learned about it through the Lupus UK website or email (59.5%, n=78) or social media platforms (28.2%, n=37).

Participant demographics summary

Overall, responses were predominantly from female participants, with 94.4% (n=272) identifying as female, and 4.9% (n=14) as male. The average age of participants was 53.6 years (SD = 14.4), with symptoms typically first occurring around the age of 32 years (SD = 14.5). Figure 2 shows the ages of survey participants at the time of survey completion, for both survey versions.

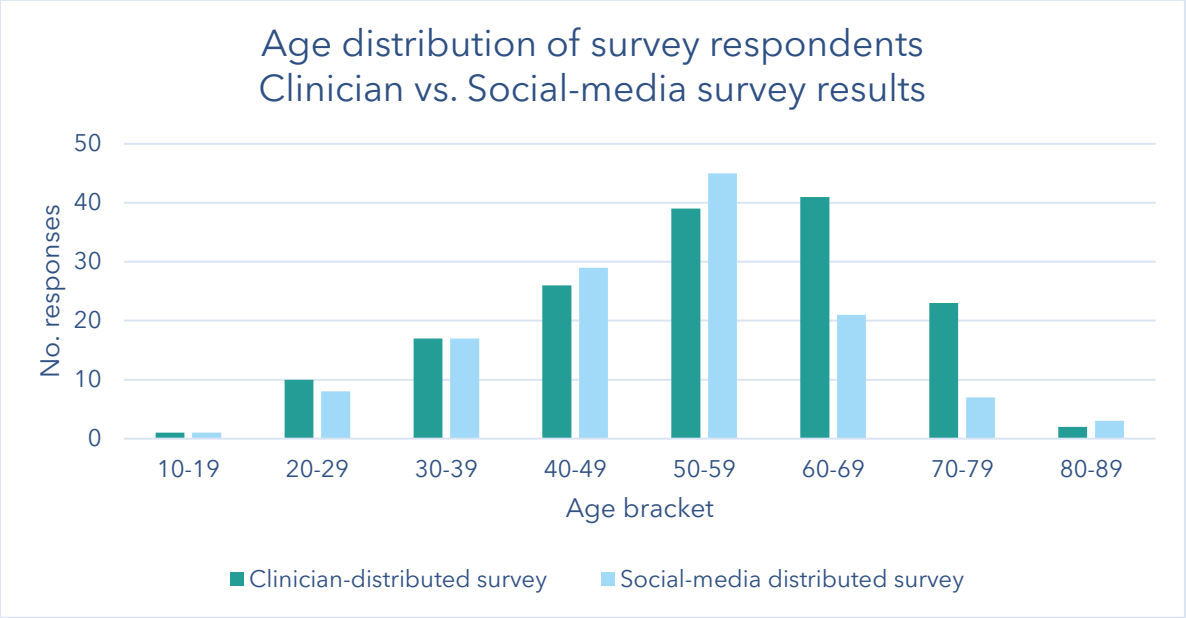

Figure 2. Age distribution of survey participants

Those in the social-media distributed survey, overall, experienced symptoms at a later age. Figure 3 shows the service-user age at first symptoms, highlighting the difference between both survey versions.

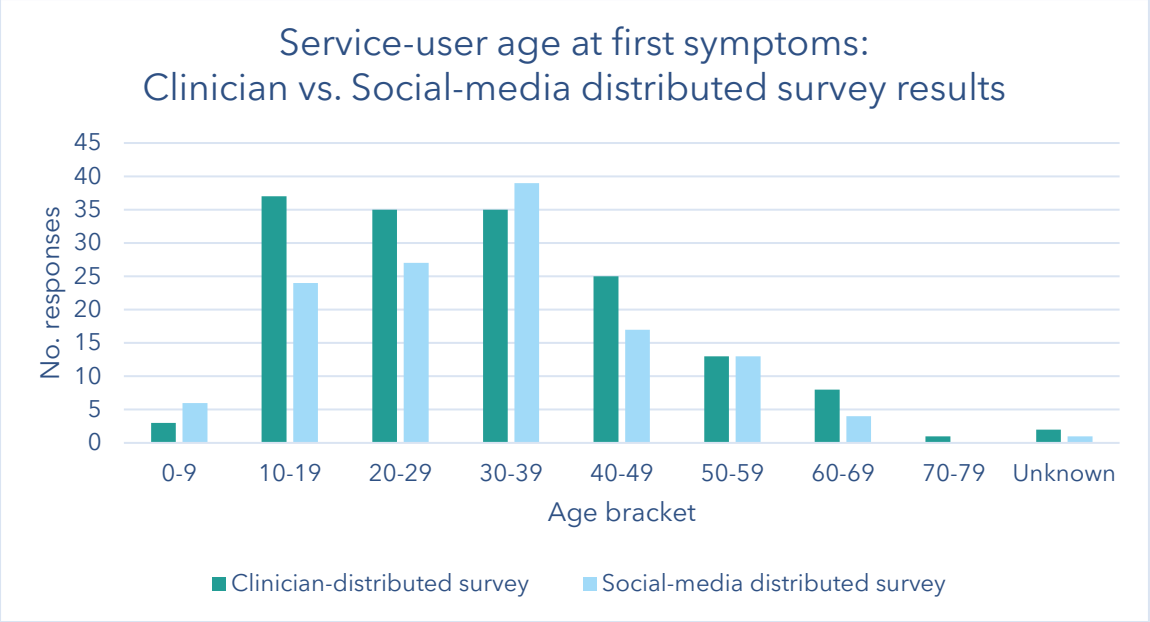

Figure 3. Comparison of age at first symptoms of lupus: Clinical-distributed vs social-media distributed survey

Participants were mostly diagnosed several years later, on average at around age 38 years (SD = 14.5). In the social-media distributed survey, a higher proportion reported being diagnosed at a later age, mostly between the ages of 30-39, versus those in the clinician-distributed survey who mostly fell into the 20-29 age range for diagnosis. Figure 4 shows the age at diagnosis for both survey versions.

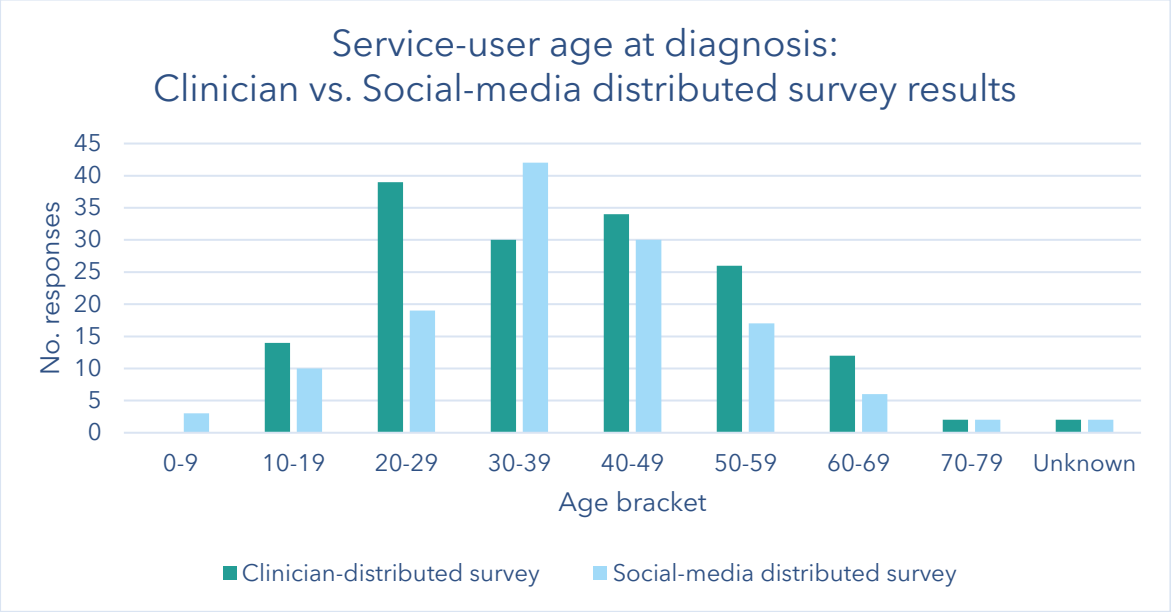

Figure 4. Comparison of age at diagnosis of lupus: Clinical-distributed vs Social-media distributed survey.

Most participants were of white ethnicity (91.7%), with smaller proportions identifying as Asian or Asian British (3.1%), and mixed or multiple ethnic groups (2.4%). There was a higher representation of minority ethnic groups in the clinician-distributed survey compared to the social media-distributed survey.

In terms of sexual orientation, 94.8% of participants identified as heterosexual/straight, with a smaller proportion (3.1%) identifying as lesbian, gay, bisexual, or pansexual.

Geographical distribution

There was representation from each of the seven Welsh Health Boards. The highest proportion (24.7%, n=71) received care through Cardiff and Vale University Health Board (UHB), followed by Cwm Taf Morgannwg UHB (19.8%, n=57), and Hywel Dda Health Board (19.1%, n=55). There was also a small number (3.5%, n=10) who did not receive lupus care via NHS Wales. Figure 5 shows the survey participants by health board for both survey versions.

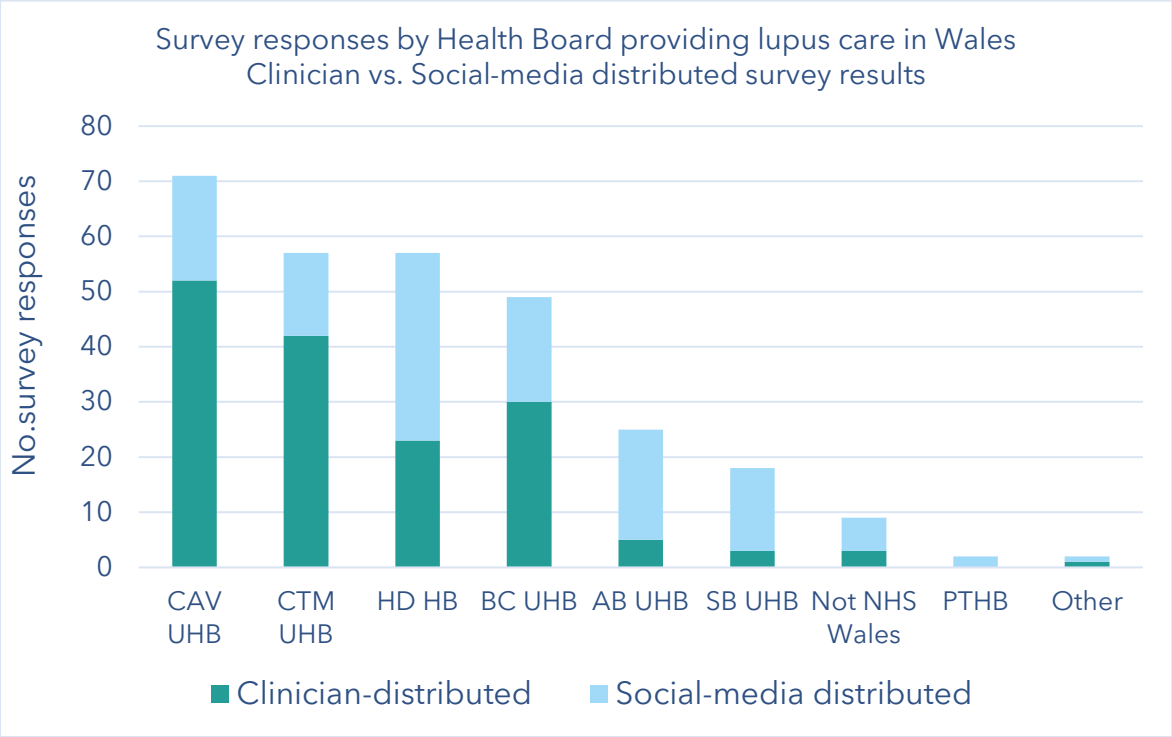

Figure 5. Distribution of survey participants for both surveys across each of the seven Welsh Health Boards.

Participants were fairly distributed across various regions of Wales, with most living in Cardiff (19.4%, n=56), and Carmarthenshire (9.7%, n=28). Pembrokeshire showed a higher response rate in the social-media distributed survey, contributing to 17.6% of responses from this group, while Cardiff had a higher response rate from the clinician-distributed survey (24.2%). Overall, Cardiff represented the largest proportion of participants. Figure 6 shows the area of residence of all survey participants combined.

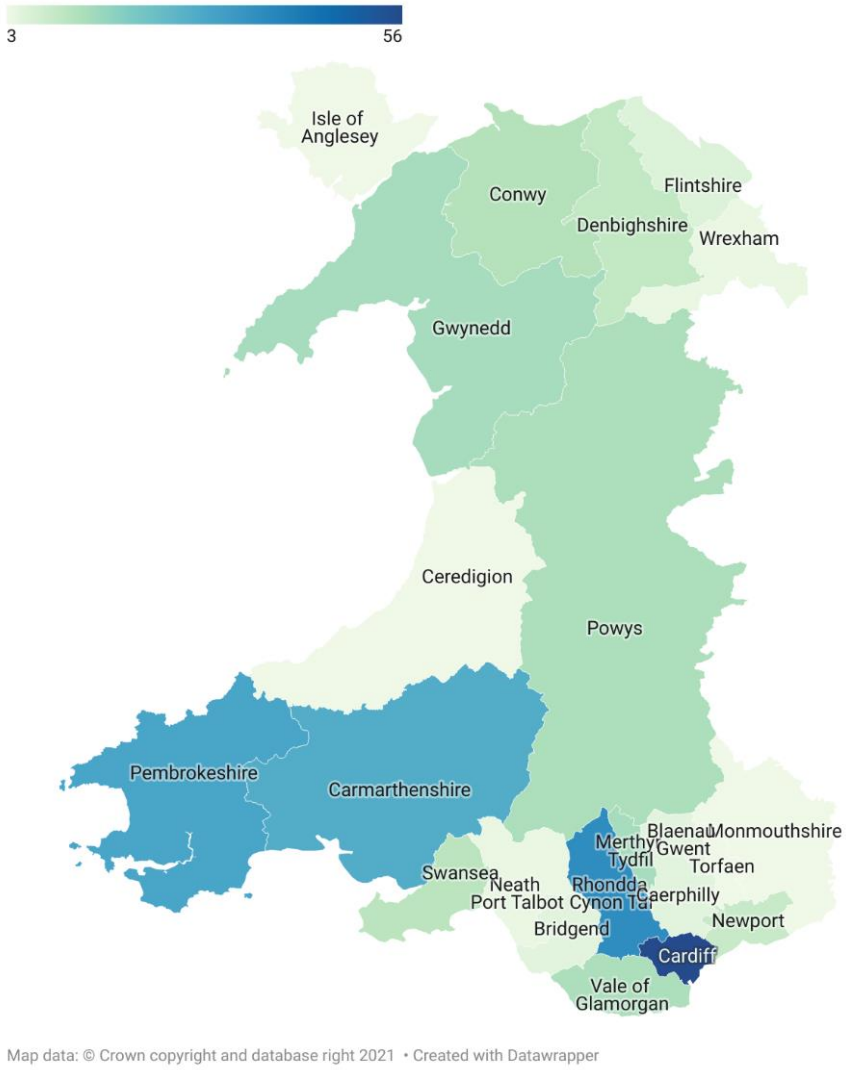

Figure 6. Area of residence of all survey participants combined.

Employment and impact of diagnosis

At the time of diagnosis, 36.8% (n=106) of participants were employed full-time or self-employed, while 21.9% (n=63) were employed part-time. A notable 53.5% (n=154) of participants reported that their employment status had changed as a result of their lupus diagnosis. This change was more prominent in the social media-distributed survey participants (62.6%, n=82), versus the clinician-distributed survey (45.9%, n=72). Figure 7 shows the employment status at the time of lupus diagnosis. Of note, 46.5% of participants reported that their lupus diagnosis had affected their care for non-lupus-related symptoms – a figure that was relatively consistent across both survey groups.

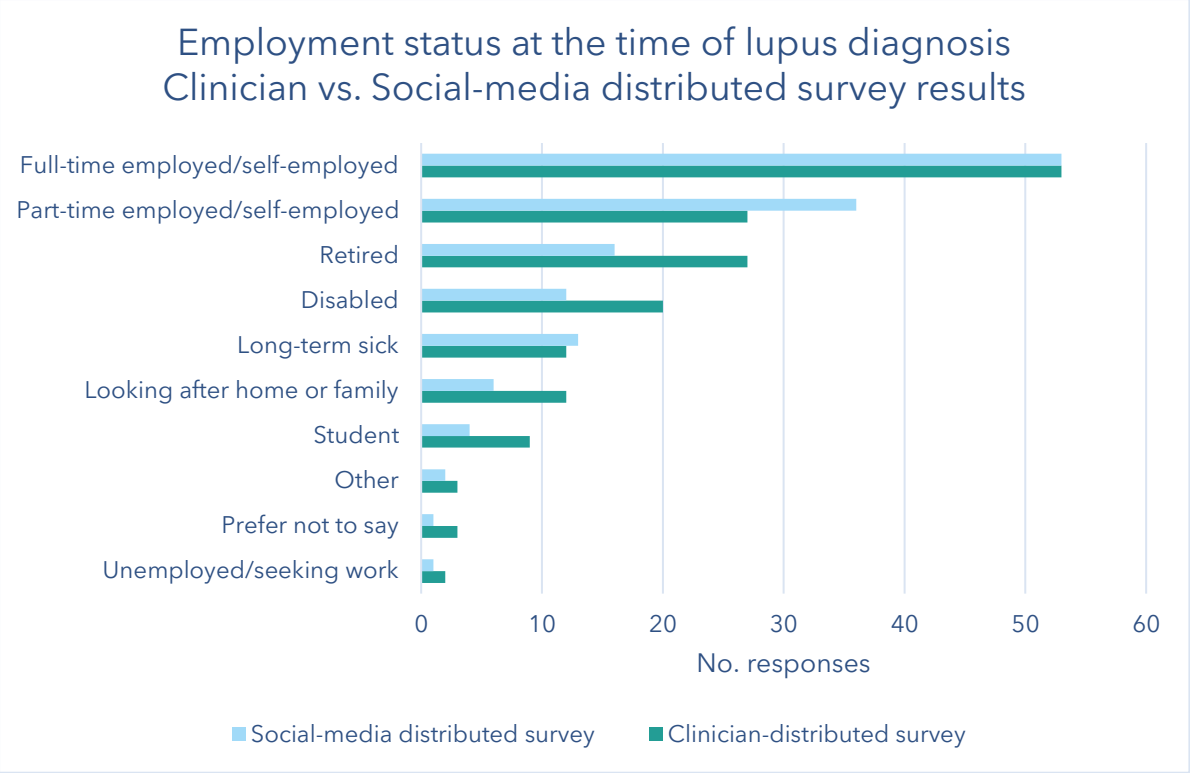

Figure 7. Employment status at the time of lupus diagnosis for all survey participants

Access to lupus services

Table 3 below provides a detailed breakdown of each question response. Results are combined, but also separated by survey version

Table 3. Service-user medication use, symptom stability, and healthcare provider involvement in lupus care.

Category		Clinician (n=157)		Social media (n=131)		Combined (n=288)	
Medication prescribed	Antimalarial	135	86.0%	114	87.0%	249	86.5%
	Biological therapies	19	12.1%	14	10.7%	33	11.5%
	DMARDs	93	59.2%	71	54.2%	164	56.9%
	NSAIDs	70	44.6%	63	48.1%	133	46.2%
	Steroid cream/tablet	95	60.5%	75	57.3%	170	59.0%
	Steroid injections	58	36.9%	48	36.6%	106	36.8%
	Other	8	5.1%	16	12.2%	24	8.3%
Symptom stability	My symptoms are usually stable but I have occasional flare ups	57	36.3%	47	35.9%	104	36.1%
	I have flare ups regularly of moderate severity	39	24.8%	38	29.0%	77	26.7%
	I do not think my Lupus is stable at all	16	10.2%	18	13.7%	34	11.8%
	I have flare ups regularly but they are mild	17	10.8%	12	9.2%	29	10.1%
	I have very few/no symptoms	16	10.2%	8	6.1%	24	8.3%

	I have severe flare ups	11	7.0%	8	6.1%	19	6.6%
	Prefer not to say	1	0.6%	0	0.0%	1	0.3%
Healthcare provider	Currently or has received lupus care from NHS Wales	157	100.0%	126	96.2%	283	98.3%
	Currently or has received private healthcare (in Wales, England or online) for lupus	28	17.8%	59	45.0%	87	30.2%
	Currently or has received lupus care from NHS England	28	17.8%	33	25.2%	61	21.2%
Diagnosing HCP	Rheumatologist	111	70.7%	82	62.6%	193	67.0%
	GP	19	12.1%	16	12.2%	35	12.2%
	Other	24	15.3%	30	22.9%	54	18.8%
	Don't know/missing	3	1.9%	3	2.3%	6	2.1%
HCPs involved in lupus care	Cardiologist	20	12.7%	22	16.8%	42	14.6%
	Casualty Doctor/A&E	29	18.5%	36	27.5%	65	22.6%
	Dermatologist	41	26.1%	31	23.7%	72	25.0%
	GP	106	67.5%	97	74.0%	203	70.5%
	Haematologist	13	8.3%	11	8.4%	24	8.3%
	Immunologist	6	3.8%	19	14.5%	25	8.7%
	Lupus specialist clinic	40	25.5%	27	20.6%	67	23.3%
	Nephrologist	19	12.1%	19	14.5%	38	13.2%
	Neurologist	10	6.4%	3	2.3%	13	4.5%
	Other	6	3.8%	11	8.4%	17	5.9%
	Physiotherapist	32	20.4%	40	30.5%	72	25.0%
	Psychologist/Counsellor	8	5.1%	12	9.2%	20	6.9%
	Rheumatologist	152	96.8%	122	93.1%	274	95.1%
	Rheumatology Specialist Nurse	79	50.3%	57	43.5%	136	47.2%
Average travel time	Less than 30 mins	80	51.0%	54	41.2%	134	46.5%
	30-60 mins	51	32.5%	44	33.6%	95	33.0%
	60-120 mins	19	12.1%	19	14.5%	38	13.2%
	120-180 mins	6	3.8%	5	3.8%	11	3.8%
	Over 180 mins	1	0.6%	2	1.5%	3	1.0%
	N/A or other	0	0.0%	7	5.3%	7	2.4%
Access to 24-hour helpline through NHS Wales	Yes	43	27.4%	26	19.8%	69	24.0%
	No	73	46.5%	92	70.2%	165	57.3%
	Don't know/can't remember	41	26.1%	13	9.9%	54	18.8%
Satisfaction with helpline	Very satisfied	15	34.9%	7	26.9%	22	31.9%
	Somewhat satisfied	8	18.6%	7	26.9%	15	21.7%
	Neither satisfied not dissatisfied	11	25.6%	5	19.2%	16	23.2%
	Somewhat dissatisfied	4	9.3%	3	11.5%	7	10.1%

	Very dissatisfied	5	11.6%	4	15.4%	9	13.0%
Emergency treatment plan in place through NHS Wales	Yes	6	3.8%	4	3.1%	10	3.5%
	No	129	82.2%	122	93.1%	251	87.2%
	I don't know/can't remember	22	14.0%	5	3.8%	27	9.4%
Affected care for non-lupus symptoms	Yes	71	45.2%	63	48.1%	134	46.5%
	No	52	33.1%	44	33.6%	96	33.3%
	I don't know/can't remember	34	21.7%	24	18.3%	58	20.1%

Medication prescribed

The majority of participants (86.5%) reported being prescribed antimalarial medication, which is a common treatment for lupus. Additionally, 56.9% of participants were prescribed Disease-Modifying Anti-Rheumatic Drugs (DMARDs), and 59.0% were prescribed steroid creams or tablets. The use of biological therapies was reported by 11.5% of participants.

Symptom stability

While 36.1% of all participants indicated that their symptoms were usually stable but with occasional flare-ups, 26.7% reported experiencing regular, moderate flare-ups. A small group (11.8%) did not believe their lupus was stable at all. There was little difference in symptom stability between the two survey groups. Figure 8 shows the symptom stability in lupus for participants from both survey versions.

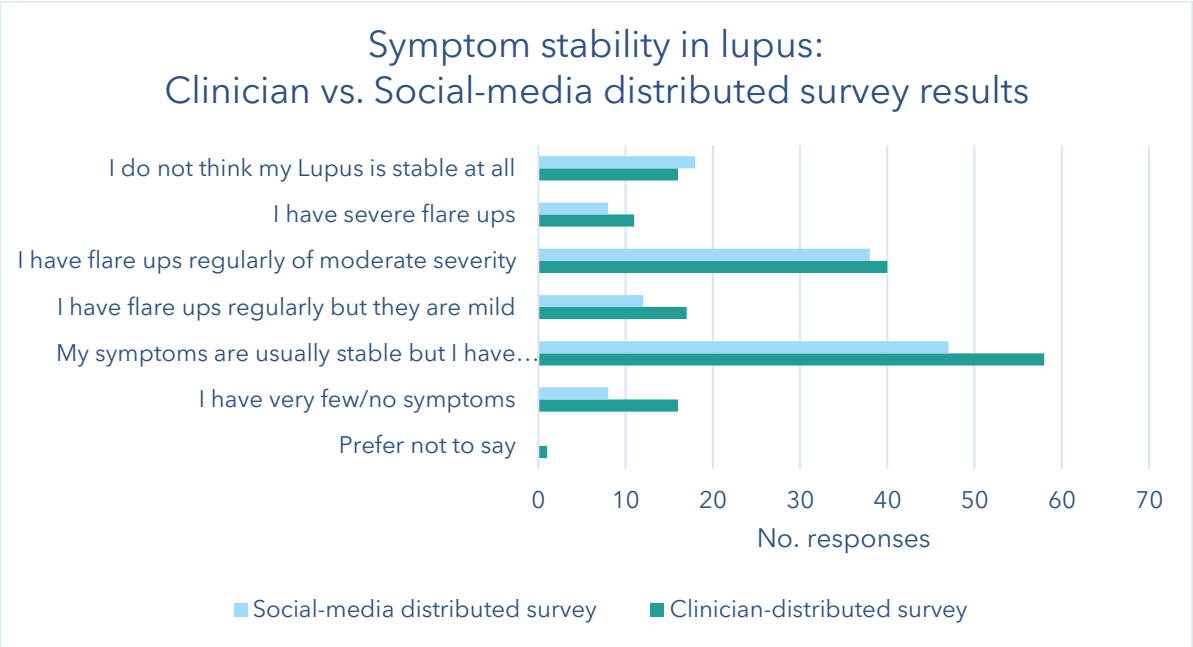

Figure 8: Stability of lupus symptoms

Healthcare providers

Almost all participants (98.3%) reported receiving lupus care through NHS Wales. However, a higher percentage of social media-distributed survey participants (45.0%) reported accessing private healthcare compared to those in the clinician-distributed group (17.8%).

The majority of participants (67.0%) were diagnosed by a rheumatologist. However, 18.8% of participants reported being diagnosed by other healthcare professionals. For clinicians involved in all lupus care beyond diagnosis, rheumatologists were the healthcare providers most commonly involved, with 95.1% of participants reporting rheumatologist involvement. GPs were also frequently involved, with 70.5% of participants noting GP care as part of their lupus management. Notable differences were seen in the involvement of certain specialists, such as immunologists, who were involved in the care of 14.5% of social media-distributed participants, compared to only 3.8% in the clinician-distributed group. Figure 9 shows the healthcare professionals involved in lupus care for both survey groups.

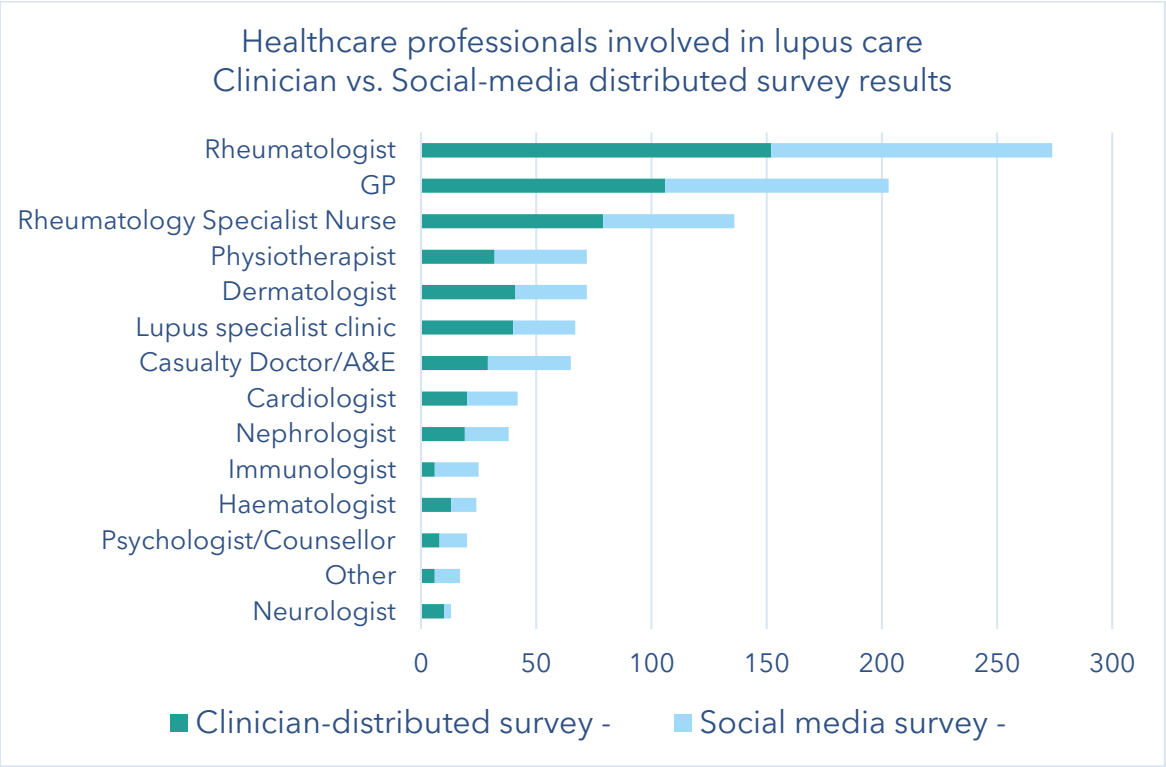

Figure 9. Healthcare professionals involved in lupus care in NHS Wales.

Access to healthcare services

Most participants (46.5%) reported traveling less than 30 minutes to access their lupus care, while 33.0% travelled between 30 and 60 minutes. Participants were also asked how far they were willing to travel. A higher proportion of social media

participants were willing to travel over 120 minutes (20.6%) compared to participants who completed the clinician-distributed survey (8.2%)

Only 24.0% of participants reported having access to a 24-hour helpline through NHS Wales, with more clinician-distributed participants (27.4%) having access compared to those from the social media-distributed group (19.8%). Satisfaction with the helpline varied, with 31.9% of participants indicating they were very satisfied, while 13.0% were very dissatisfied.

Very few participants reported having an emergency treatment plan in place for lupus flare-ups, with only 3.5% of participants reporting that they had one through NHS Wales. This lack of emergency planning was more prevalent amongst participants who completed the social media-distributed survey (93.1%) compared to the clinician-distributed group (82.2%).

Satisfaction with aspects of lupus care

Participants were asked to rate their experiences across different aspects of lupus care in NHS Wales. This section presents key satisfaction ratings, with a focus on notable differences between responses from the clinician-distributed and social media-distributed surveys. Table 4 displays the overall satisfaction ratings for each aspect of lupus care, and each category is discussed individually. Shading is used to highlight higher response levels, as indicated in the key.

Shade	1	2	3	4	5
0%	0-10.99%	11-20.99%	21-30.99%	31-40.99%	>41%

Table 4. Combined service-user aspects of lupus care rankings

		Very poor		Poor		Fair		Good		Excellent		Not applicable	
		n	%	n	%	n	%	n	%	n	%	n	%
Experience of getting a diagnosis	Clinician	26	**16.6%**	14	**8.9%**	36	**22.9%**	39	**24.8%**	26	**16.6%**	16	**10.2%**
	Social media	36	**27.5%**	19	**14.5%**	21	**16.0%**	24	**18.3%**	16	**12.2%**	15	**11.5%**
	Total	62	**21.5%**	33	**11.5%**	57	**19.8%**	63	**21.9%**	42	**14.6%**	31	**10.8%**
Experience of getting medicines	Clinician	7	**4.5%**	5	**3.2%**	29	**18.5%**	61	**38.9%**	52	**33.1%**	3	**1.9%**
	Social media	20	**15.3%**	12	**9.2%**	29	**22.1%**	43	**32.8%**	24	**18.3%**	3	**2.3%**
	Total	27	**9.4%**	17	**5.9%**	58	**20.1%**	104	**36.1%**	76	**26.4%**	6	**2.1%**
Experience of getting supportive treatments	Clinician	13	**8.3%**	31	**19.7%**	27	**17.2%**	40	**25.5%**	32	**20.4%**	14	**8.9%**
	Social media	36	**27.5%**	25	**19.1%**	32	**24.4%**	22	**16.8%**	9	**6.9%**	7	**5.3%**
	Total	49	**17.0%**	56	**19.4%**	59	**20.5%**	62	**21.5%**	41	**14.2%**	21	**7.3%**
Experience of accessing support when needed (e.g. during flare up)	Clinician	16	**10.2%**	40	**25.5%**	26	**16.6%**	33	**21.0%**	31	**19.7%**	11	**7.0%**
	Social media	41	**31.3%**	29	**22.1%**	27	**20.6%**	17	**13.0%**	11	**8.4%**	6	**4.6%**

		Very poor		Poor		Fair		Good		Excellent		Not applicable	
		n	%	n	%	n	%	n	%	n	%	n	%
	Total	57	**19.8%**	69	**24.0%**	53	**18.4%**	50	**17.4%**	42	**14.6%**	17	**5.9%**
Experience of getting emotional support	Clinician	39	**24.8%**	46	**29.3%**	19	**12.1%**	16	**10.2%**	10	**6.4%**	27	**17.2%**
	Social media	63	**48.1%**	35	**26.7%**	12	**9.2%**	7	**5.3%**	3	**2.3%**	11	**8.4%**
	Total	102	**35.4%**	81	**28.1%**	31	**10.8%**	23	**8.0%**	13	**4.5%**	38	**13.2%**
Experience of getting support from lead consultant	Clinician	16	**10.2%**	24	**15.3%**	27	**17.2%**	31	**19.7%**	52	**33.1%**	7	**4.5%**
	Social media	21	**16.0%**	23	**17.6%**	35	**26.7%**	26	**19.8%**	23	**17.6%**	3	**2.3%**
	Total	37	**12.8%**	47	**16.3%**	62	**21.5%**	57	**19.8%**	75	**26.0%**	10	**3.5%**
Experience of getting support from GP	Clinician	19	**12.1%**	29	**18.5%**	44	**28.0%**	36	**22.9%**	20	**12.7%**	9	**5.7%**
	Social media	28	**21.4%**	26	**19.8%**	30	**22.9%**	29	**22.1%**	12	**9.2%**	6	**4.6%**
	Total	47	**16.3%**	55	**19.1%**	74	**25.7%**	65	**22.6%**	32	**11.1%**	15	**5.2%**
Quality of information and advice received to manage condition	Clinician	19	**12.1%**	38	**24.2%**	34	**21.7%**	38	**24.2%**	23	**14.6%**	5	**3.2%**
	Social media	38	**29.0%**	27	**20.6%**	32	**24.4%**	14	**10.7%**	15	**11.5%**	5	**3.8%**
	Total	57	**19.8%**	65	**22.6%**	66	**22.9%**	52	**18.1%**	38	**13.2%**	10	**3.5%**
Overall current medical support	Clinician	19	**12.1%**	22	**14.0%**	28	**17.8%**	45	**28.7%**	36	**22.9%**	7	**4.5%**
	Social media	30	**22.9%**	33	**25.2%**	31	**23.7%**	24	**18.3%**	12	**9.2%**	1	**0.8%**
	Total	49	**17.0%**	55	**19.1%**	59	**20.5%**	69	**24.0%**	48	**16.7%**	8	**2.8%**

Getting a diagnosis

Of all participants, 21.9% (n=63) rated their experience of getting a diagnosis as 'good', and 14.6% (n=42) rated it as 'excellent'. However, 21.5% (n=62) rated their experience as 'very poor'. Social media participants were more likely to report a 'very poor' experience (27.5%, n=36) compared to clinician-distributed survey participants (16.6%, n=26). Conversely, clinician-distributed survey participants were more likely to rate their diagnosis experience as 'good' (24.8%, n=39) compared to the social media group (18.3%, n=24).

Access to medicines

For the overall group, 36.1% (n=104) rated their experience of getting medicines as 'good,' while 26.4% (n=76) rated it as 'excellent'. However, 9.4% (n=27) rated their experience as 'very poor'. A higher proportion of social media survey participants rated their experience as 'very poor' (15.3%, n=20) compared to clinician-distributed survey participants (4.5%, n=7). Conversely, more clinician-distributed survey participants rated their experience as 'excellent' (33.1%, n=52) than social media survey participants (18.3%, n=24).

Getting supportive treatments

When it came to getting supportive treatments, 21.5% (n=62) rated their experience as 'good', and 14.2% (n=41) rated it as 'excellent'. However, 17.0% (n=49) rated their experience as 'very poor'. Social media survey participants were more likely to report dissatisfaction, with 27.5% (n=36) rating their experience as 'very poor' compared to 8.3% (n=13) of clinician -distributed survey participants. In contrast, 20.4% (n=32) of clinician-distributed survey participants rated their experience as 'excellent', compared to 6.9% (n=9) of social media survey group.

Accessing support during flare-ups

In the combined results, 19.8% (n=57) rated their experience of accessing support during flare-ups as 'very poor', while 17.4% (n=50) rated it as 'good', and 14.6% (n=42) rated it as 'excellent'. A higher proportion of social media survey participants rated their experience as 'very poor' (31.3%, n=41) compared to clinician-distributed survey participants (10.2%, n=16). Only 8.4% (n=11) of social media survey participants rated this experience as 'excellent', compared to 19.7% (n=31) from the clinician-distributed group.

Getting emotional support

35.4% (n=102) of participants rated their experience of getting emotional support as 'very poor', while 8.0% (n=23) rated it as 'good', and 4.5% (n=13) rated it as

'excellent'. A substantial difference was seen between the survey groups, with 48.1% (n=63) of social media survey participants rating their experience as 'very poor', compared to 24.8% (n=39) of clinician-distributed survey participants. Only 6.4% (n=10) of clinician-distributed respondents, and 2.3% (n=3) of social media respondents rated emotional support as 'excellent'.

Overall current medical support

Of all participants, 24.0% (n=69) rated their current medical support as 'good', while 16.7% (n=48) rated it as 'excellent', and 17.0% (n=49) rated it as 'very poor'. Social media survey participants were more dissatisfied, with 22.9% (n=30) rating it as 'very poor' compared to 12.1% (n=19) in the clinician-distributed group. Meanwhile, more clinician-distributed survey participants rated their support as 'excellent' (22.9%, n=36) than those from social media (9.2%, n=12).

National Staff survey

The staff survey was distributed via email to lupus clinicians throughout Wales through a lupus clinical lead from Cardiff and Vale UHB. Seventeen responses were received and are referred to as 'Clinical participants' throughout the report.

The following section separately discusses the responses to each of the questions, with the open-ended questions thematically analysed and summarised.

Clinician background

The majority of clinical participants were consultant rheumatologists (12), with additional input from 2 consultant paediatric rheumatologists, 2 clinical nurse specialists in rheumatology, and 1 senior rheumatology registrar. There was at least one clinician response from each of the seven Welsh Health Boards. This including Cardiff and Vale (5), Cwm Taf Morgannwg (3), Aneurin Bevan (2), Hywel Dda (3), and Betsi Cadwaladr (2). Two clinical participants indicating that they work across multiple health boards, including Powys (2) and Swansea Bay (1).

The years of experience among clinicians ranged from 11 to 37 years, averaging 25.4 years in practice. Clinicians reported seeing between 3 and 250 people with lupus annually, with an average of 59, and most based their estimates on clinical experience rather than database records. The frequency of consultations with people with lupus varied, with most clinicians seeing people with lupus weekly (7 responses) or monthly (6), while others reported daily, bi-monthly, or clinic-based frequencies.

Satisfaction with lupus care

Most clinicians were somewhat satisfied with the care they are able to provide to people with lupus, with only one clinician reporting being very satisfied. Figure 10 shows the overall clinician satisfaction with the care they are able to provide.

Despite general satisfaction with individual care quality, clinical participants identified several areas for improvement. Key concerns included time constraints during clinics, which hinder comprehensive management of health concerns, and delays in appointments due to staff shortages and the lasting impact of COVID-19. The absence of a dedicated lupus centre in Wales and limited opportunities for multidisciplinary team (MDT) discussions were also cited as significant challenges. To enhance lupus care, clinicians suggested the establishment of a lupus-specific helpline, increased clinic capacity, dedicated lupus nurses, and improved regional collaboration.

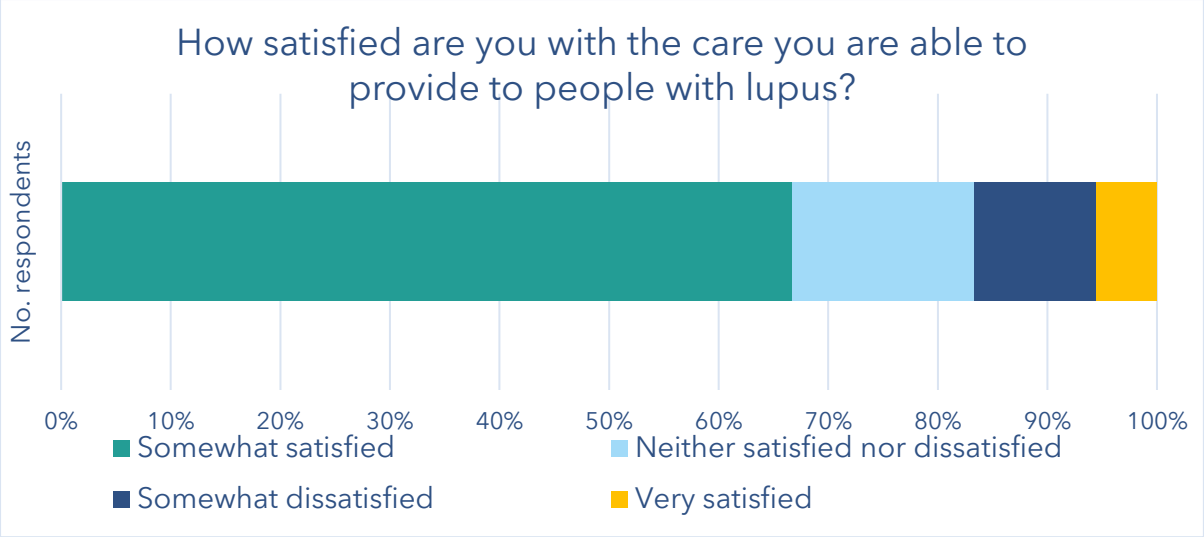

Figure 10. Clinician satisfaction with lupus care

Dedicated lupus clinics

The majority of clinicians (11) reported that their Health Boards do not offer dedicated lupus clinics, while 5 confirmed that such clinics are available in Cwm Taf Morgannwg, Hywel Dda, Cardiff and Vale, and Swansea Bay University Health Boards.

Among those with access to dedicated lupus clinics, recommendations for improvement included increasing the frequency of clinics from monthly to fortnightly to better meet demand. Clinicians also suggested expanding the number of clinics and staffing levels, making clinics more efficient, and enabling consultants from different specialities to collaborate in real-time during clinic sessions—a practice disrupted by the pandemic. Enhanced clinic capacity and the inclusion of a dedicated lupus specialist nurse were highlighted as key components for improving care.

A majority of clinicians (76%) believe that all Welsh Health Boards should offer dedicated lupus clinics, though resource constraints and concerns about underfilled slots for lupus cases were raised. Some respondents proposed a combined clinic for autoimmune diseases, connective tissue diseases (CTD), and for those presenting with complex presentations, as a more feasible and efficient alternative. For paediatric rheumatology, centralising a clinic or integrating it with adult services to ensure smooth transition was also recommended by two participants.

When asked what a dedicated lupus clinic should involve from a drop-down list of seven options, clinicians all agreed that they should involve a dedicated session for lupus/CTD only, a medical consultant with a specialist interest in connective tissue diseases, and tests such as blood pressure, urine and body mass index (BMI). Other suggestions for a dedicated lupus clinic included lupus specialist

nurse input (16), access to biologics (15), Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) or BILAG disease activity measuring (15), and participation in BILAG Biologics Register (BILAG BR) studies (14). . These elements were seen as crucial for ensuring high-quality care for people with lupus.

Biologic clinics and therapy

The majority of clinicians (12 out of 17) believe that those with lupus requiring biologic treatments should be seen in a dedicated lupus clinic, although three clinicians were unsure, and two did not support the idea. Those in favour highlighted that those needing biologics often have more complex, multi-systemic issues that require specialised care, and more time than typical follow-up slots allow. While some suggested that local solutions could be feasible, most emphasised the importance of having access to clinicians with specific expertise in lupus management.

When ranking the most important factors for administering biologic therapy, the top priority for clinicians was *'administering the therapy at a local unit'*, followed by *'offering the therapy at a site chosen by the patient*'; *'Administering the therapy at a dedicated lupus clinic'* and *'at a BILAG-registered site to enable participation in relevant research studies'* were also considered important but ranked lower on average.

Challenges and enablers in providing lupus care

Responses regarding the perceived standard of care for people with lupus by clinicians reveal a generally positive perception, but also highlight some areas needing improvement. Most aspects such as getting a diagnosis, receiving medicines, and accessing support during flare-ups were rated as "Good" by the majority of clinical participants. However, support for the emotional impact of lupus and support from general practitioners (GPs) received mixed reviews, with several rating them as "Neutral" or "Poor".

Table 5 below shows clinicians perceptions on each of the aspects of lupus care. Shading is used to highlight higher response levels, as indicated in the key.

Table 5. Clinician satisfaction scores for aspects of lupus care

Aspect of lupus care	Excellent		Good		Neutral		Poor		Very Poor		Not Applicable	
	N	%	N	%	N	%	N	%	N	%	N	%
Support from a GP	0	0.0%	8	47.1%	6	35.3%	3	17.6%	2	11.8%	1	5.9%
Support for the emotional impact of lupus	0	0.0%	8	47.1%	6	35.3%	5	29.4%	2	11.8%	1	5.9%
Overall current medical support for lupus	1	5.9%	11	64.7%	5	29.4%	2	11.8%	1	5.9%	1	5.9%
Support from a lead consultant	1	5.9%	13	76.5%	4	23.5%	3	17.6%	2	11.8%	1	5.9%
Advice and information received to manage lupus	1	5.9%	13	76.5%	5	29.4%	2	11.8%	0	0.0%	1	5.9%
Getting medicines for lupus	3	17.6%	11	64.7%	4	23.5%	0	0.0%	1	5.9%	1	5.9%
Getting supportive treatments to manage lupus	3	17.6%	11	64.7%	6	35.3%	2	11.8%	0	0.0%	1	5.9%
Accessing support when a person needs it	3	17.6%	12	70.6%	4	23.5%	2	11.8%	0	0.0%	1	5.9%
Getting a diagnosis of lupus	3	17.6%	13	76.5%	1	5.9%	0	0.0%	0	0.0%	1	5.9%

Key	
	25-49.9%
	50-74.9%
	75-100%

Challenges

Clinicians identified several challenges that hinder their ability to provide optimal care for people with lupus. A lack of time and staff shortages were the most common issues, resulting in long waiting lists and insufficient clinic slots. The complexity of lupus, which involves managing a wide spectrum of symptoms, further complicates care, particularly when clinicians must balance lupus management with other conditions. Administrative burdens, such as responding to complaints, and the need for MDT consultations, which often cause delays, add to these difficulties. The frequent turnover of senior staff, resource limitations, and the lack of a dedicated lupus specialist nurse were also highlighted. Some clinicians noted that even in clinics dedicated to lupus, there are insufficient slots to meet demand, and securing access to advanced therapies and necessary assessments remains a significant challenge.

Enablers

Conversely, several factors make lupus care more manageable in Wales. Good access to specialist teams, particularly renal experts, and strong collaborations with local paediatricians and hospital pharmacies were mentioned as key enablers. Most rheumatology units in Wales have access to biologic therapies, reducing the need for people to travel for treatment. The availability of dedicated lupus or CTD clinic sessions and close teamwork within departments were considered to enhance the quality of care and support delivering care local to those with lupus. Effective coordination between departments, improved laboratory setups to reduce false positives, and access to emotional support groups in the community were also beneficial. Additionally, sharing care protocols with GPs and minimal delays in starting intravenous treatments were seen as contributors to effective lupus management.

Strengths and areas for improvement

Strengths

Clinicians highlighted several strengths in the provision of lupus care in Wales. Access to renal specialists was considered a key benefit. The recent BSR audit of lupus services was also considered to have had a positive impact on care. Dedicated lupus clinics, effective teamwork among medical consultants, and efficient systems for providing GP advice and discussing presentations with complex presentations among medical consultant groups were working well. The development of dedicated paediatric rheumatology MDT was another notable success. Some clinicians believed that people with lupus living in Wales received personalised and local care, with access to biologic therapies for lupus and reduced travel times to more local services.

Areas for improvement

Clinicians emphasised the need for more consultant rheumatologists and greater investment in the overall rheumatology service to establish specialised clinics combining expertise in lupus, autoimmune diseases and CTD. The creation of more specialist and non-medical posts, such as nurse consultants, in particular for rheumatology, was suggested to have potential to improve care. Clinicians also recommended appointing CTD/lupus leads and establishing CTD specialist nurse roles to assist in assessments and streamline care. The introduction of peer support groups, improved access to dedicated CTD clinics, and increased emotional support were additional recommendations. Improving access to essential disease assessments, such as lung function tests, and creating a national MDT to discuss people with complex presentations were also seen as priorities. Expanding rheumatology capacity, particularly for managing those with complex presentation of lupus, was considered essential to improving care.

These responses are illustrated in Figure 11, which outlines the factors clinicians believe would improve care for people with lupus in Wales.

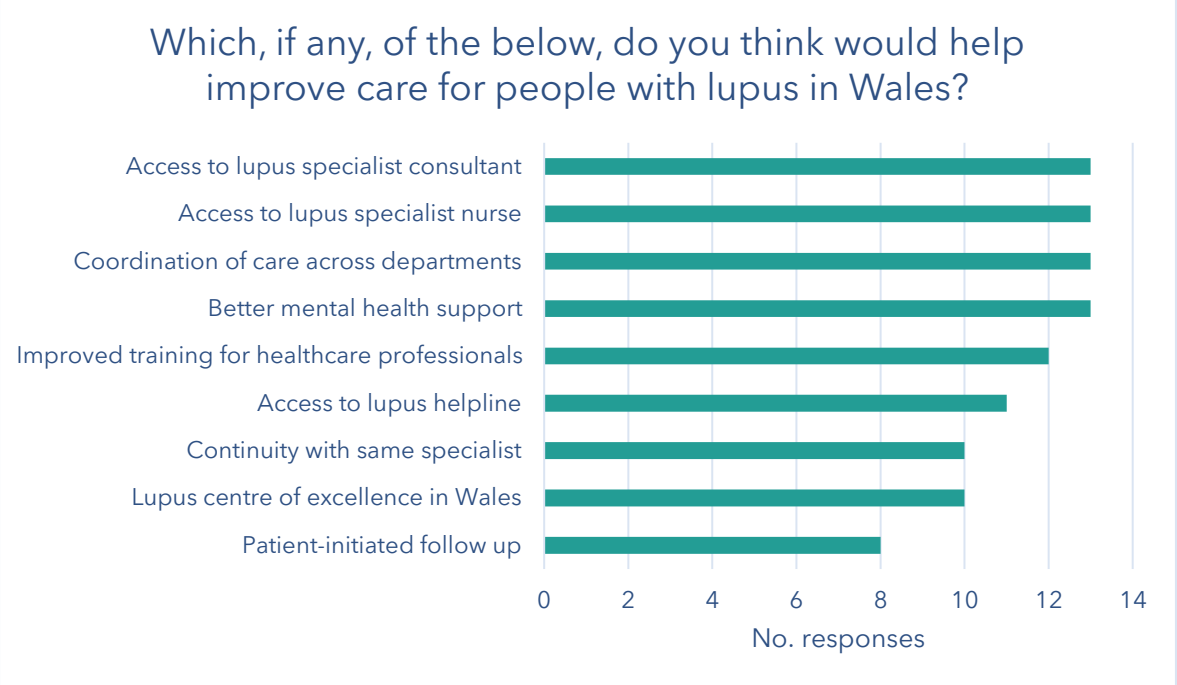

Figure 11. Factors for improving care for people with lupus in Wales, from the perspective of clinicians

Evaluating the quality of lupus care

Most healthcare providers indicated that they do not have formal methods for evaluating the quality of care provided to people with lupus. Several clinical participants stated that they are not currently conducting evaluations or have no specific evaluation methods in place. A few had participated in audits or conducted in-house surveys of people with lupus, and expressed interest in

exploring electronic Patient-Reported Outcome Measures (ePROMs) in the future to better assess care quality.

The majority of clinicians (14 out of 17) believe that using a patient-reported outcome measure (PROM) would be beneficial for evaluating the quality of life of people with lupus in Wales. One clinician specifically mentioned the Lupus QoL tool as a potential option. However, three participants were uncertain about the effectiveness of using PROMs for this purpose.

Opportunities suggested by clinicians throughout the survey have been collated and summarised in Table 8.

5. Interviews and focus groups

Fifteen online interviews were conducted, lasting an average of 87 minutes (range: 61-132 minutes). Participants ranged in age from 25 to 74 years, with the majority (73%, n=12) being female. Most participants (86%, n=13) identified as White, with one individual (7%) identifying as Asian or Asian British. In terms of disease severity, 40% reported experiencing regular moderate flare-ups, while 27% described their symptoms as mild or only occasional flare-ups, and 13% reported having very few or no symptoms. The healthcare experiences of interview participants varied considerably. While 40% rated their care as good or excellent, nearly half (47%) expressed dissatisfaction, rating their overall care as poor or very poor. A detailed breakdown of participant characteristics for interviews is not provided to maintain participant anonymity.

Additionally, four online focus groups were held, each lasting an average of 138 minutes (range: 119-156 minutes), with a total of 15 participants. None of these individuals participated in the interviews. The focus group attendees ranged in age from 25 to 72 years (mean 51.5), with 14 (94%) female and 1 (6%) male. A breakdown of age and sex by focus group is not provided to maintain focus group anonymity. Participants were from various health boards, including Cardiff and Vale UHB (n=3), Cwm Taf Morgannwg UHB (n=5), Betsi Cadwaladr UHB (n=2), Aneurin Bevan UHB (1), and Hywel Dda UHB (n=3), and one in Powys Teaching Health Board, but did not receive treatment for lupus through NHS Wales. Reported experiences of overall healthcare varied across the groups, with 5 participants rating their experience as excellent, 3 as good, 1 as fair, 2 as poor, and 4 as very poor. There was a fairly even split between the number of participants involved in focus groups from both survey versions; 8 (53%) from the clinician survey, and 7 (47%) from the social media survey. Table 6 details the characteristics of each of the four focus groups.

Table 6. Characteristics of participants in each of the four focus groups

Focus group	Health board	Overall Experience of Healthcare	Survey version completed
Focus group no. 1 **Date:** 18/06/2024 **No. participants:** 5	Cardiff and Vale UHB (1) Cwm Taf Morgannwg UHB (3) Betsi Cadwaladr UHB (1)	Excellent (2) Good (2) Fair (1)	Clinician (4) Social Media (2)
Focus group no. 2 **Date:** 11/07/2024 **No. participants:** 4	Cwm Taf Morgannwg UHB (2) Betsi Cadwaladr UHB (1) Aneurin Bevan UHB (1)	Excellent (3) Good (1)	Clinician (2) Social Media (2)
Focus group no. 3 **Date:** 12/07/2024 **No. participants:** 3	Cardiff and Vale UHB (1) Hywel Dda UHB (1) Not NHS Wales (1)	Poor (2) Very poor (1)	Clinician (1) Social Media (2)
Focus group no. 4 **Date:** 17/07/2024 **No. participants:** 3	Cardiff and Vale UHB (1) Hywel Dda UHB (2)	Very Poor (3)	Clinician (1) Social Media (2)

Navigating the healthcare system

Diagnoses and misdiagnoses

A frequent challenge faced by many people with lupus was the difficulty in obtaining an accurate diagnosis. For many, the time to a diagnosis was long, and fraught with delays, multiple misdiagnoses and frustration. For some, symptoms were initially attributed to other conditions like rheumatoid arthritis, fibromyalgia, or heart disease, before lupus was considered. For example, one participant was initially told they had heart failure but later discovered it was interstitial lung disease caused by lupus. Another participant experienced delays because their symptoms were dismissed during repeated visits to A&E, with doctors treating the immediate symptoms without exploring the underlying causes. These misdiagnoses were often felt to have led to delayed treatment, worsening of symptoms, and increased emotional distress. Some participants were treated for conditions unrelated to lupus, while others experienced feeling dismissed by healthcare providers, who they felt downplayed or overlooked the possibility of lupus. This was reported to have created a sense of confusion and helplessness, with participants feeling trapped in a system they felt was unequipped to handle the complexity of lupus. Participants suggested that improved recognition of lupus symptoms by healthcare professionals, notably GPs and A&E clinicians, could enable more timely and accurate lupus diagnosis.

Monitoring

The inconsistent monitoring of lupus symptoms and disease progression was a recurring issue, specifically in the survey responses. Regular and comprehensive monitoring was seen as essential, yet some participants expressed uncertainty about how frequently they should be monitored. People with lupus reported being unsure of when their next tests or follow-up appointments were due or in some cases had not received face-to-face care for lupus since the COVID-19 pandemic.

For those at risk of organ damage, this was particularly problematic, as frequent tests, such as urine monitoring, blood tests, and eye examinations, are necessary to detect complications. While some participants mentioned that they received regular monitoring, others felt that their follow-up care was inconsistent or inadequate. A common sentiment was that there was a lapse in communication between healthcare providers and people with lupus about what the monitoring schedule should look like. As a result, many participants reported feeling as though they had to advocate for appropriate tests to be done.

> *"my condition was well controlled, but I think it's quite different now that I don't actually get any blood tests unless I go to the GP and ask for one every 3 months because of my medication*

requirement. And other than that, yeah, there's nothing regular." (P102)

Interviews and focus group participants reported a preference for an individualised monitoring plan, with several participants suggesting that having a structured and transparent plan would not only help in the management of their condition, but also provide reassurance and reduce the emotional burden of living with lupus.

There were also concerns that blood tests were sometimes the sole metric used to assess their condition, despite the fact that blood results do not always correlate with how a person feels. This disconnect between laboratory tests and patient-reported symptoms created further frustration, as many felt that their subjective experiences of pain and fatigue were not being adequately addressed. During focus groups the usefulness of a lupus specific PROM was discussed as an option to help address subjective aspects of health, and participants all felt it would be helpful. They liked the idea of being able to monitor their wellbeing over time, but noted that day-to-day, the severity and impact of lupus symptoms can change so drastically that a PROM may struggle to reflect this if only completed every few months during appointments. They also added that a suitable PROM would be a helpful prompt to encourage discussions around mental health and emotional wellbeing, which was much needed.

Co-ordinating care between specialties

The 'fragmented' nature of lupus care across specialties posed another challenge for many participants, as many felt that lupus specialists were working in silo's rather than collaboratively.

"nobody deals with you as a whole, and that's what we need. We need rheumatologists, dermatologists, the heart people, the brain people, the nerve people….(P187)"

Coordinating between different specialists, such as rheumatologists, nephrologists, dermatologists, and cardiologists, was often felt to be left to the person with lupus, rather than the care team. One participant, who was seen by several specialties including rheumatology, neurology, and cardiology, described frequently needing to act as a go-between to ensure that test results were shared between departments.

Many participants noted a lack of communication between departments, with test results and reports not being shared effectively. This was, in some cases, reported to have resulted in delayed treatments or the need to act as intermediaries, pushing for information to be passed between their various healthcare providers. In some cases, people had to advocate for their own care by requesting that all

specialists be kept informed about their treatment plans. These discussions highlighted the need for better coordination between specialties to provide holistic care for people with lupus, especially when dealing with multiple organ systems affected by the disease. A recurring suggestion to enable better coordination between lupus specialists, was the idea of multidisciplinary discussions between specialists. A few participants advocated for a 'centre of excellence', as there is not one currently in Wales. The few people with lupus who had attended specialists centres in England, reported better outcomes, satisfaction, and a more holistic approach in comparison to the treatment they had received in Wales. When asked "*What would you want from a Centre of Excellence*", one participant in a focus group responded:

> *"Well, rheumatology nurses would be fabulous. A designated hotline that they actually answer or return your calls within a timely manner. Rheumatologists that specialise in lupus and actually understand the illness and that it doesn't come alone, and people that will deal with you as a whole…" (P187)*

Specialist care and multidisciplinary teams

Access to specialist care and MDTs was highlighted as a key factor in providing comprehensive lupus care and thought to be associated with more positive outcomes and experiences for people with lupus. Some participants were able to receive care from lupus specialists such as lupus specialist nurses, who provide essential care and support for people with lupus, helping them to manage the complex nature of the condition.

MDTs for lupus were typically reported to include rheumatologists, nephrologists, and other relevant experts, which ensured that the needs of people with the most complex presentations were met. For those participants who were treated in such centres, the coordinated care was considered as providing better and more efficient management of lupus. Care provided by MDTs was considered to facilitate regular monitoring and timely adjustments to treatment plans, ensuring that those with lupus felt well-supported. Specialists were frequently described as knowledgeable and empathetic, providing a sense of reassurance to people with lupus who expressed feeling misunderstood or dismissed by non-specialists.

Points of access to healthcare –Specialists vs Generalist care

Participants highlighted a stark contrast between care provided by lupus specialists and general practitioners or non-specialist rheumatologists. Specialist care was generally associated with more accurate diagnoses, more effective treatments, and greater confidence in managing the disease. In contrast, generalists, such as GPs and clinical staff in A&E departments, were felt by a

number of participants to lack the specific knowledge needed to manage the complexities of lupus, which they felt led to suboptimal care.

> *"Specialists just give you that reassurance that you're not going mad. They know what you're talking about. You're in the right place and you're asking the right questions" (P251)*

Access to specialist care was considered as essential, with many feeling that their GPs, though often well-intentioned, were not equipped to handle the complexities of their condition.

> *"So my GP refuses to deal with me majority of the time because they told me, 'we are not competent enough.'". (P259)*

Many participants reported that a lupus-specific phoneline, staffed by specialists, would support their lupus care. This is something that some participants had access to, but where it was available, it was mostly felt to be inadequate, with slow response times.

> *"We used to have a rheumatology helpline….you used to be able to ring up and say to them, 'can you give me some steroids', or 'this is what my symptoms are, what do you think?' But they've changed that now. So I had a flare, I rung them up, and I honestly felt like I was really, really, really ill, and the woman said, 'oh, there's a two week call back time on this.', and I said 'I can't wait two weeks for you to tell me that I need the steroids because I need them now'. So she said 'well, I'm sorry, but we can't do anything about it. We haven't got the staff'. (P188)*

This recurring suggestion highlighted the desire for a reliable point of contact where individuals with lupus could access timely advice and support, particularly when they had questions or concerns about their care. The phoneline was seen as especially beneficial for those newly diagnosed, offering reassurance and expert guidance during a critical time in their treatment journey.

Accessing healthcare outside NHS Wales

A clear theme that emerged from the interviews and focus groups was the need for a number of responders to turn to private healthcare when their healthcare requirements were not being met by NHS Wales. Several participants expressed frustration with the lack of access to timely and specialised care, which often led them to seek private healthcare options. Some regularly travelled to private clinics in England, such as the London Lupus Centre, or Birmingham's Lupus Specialist centre. This was both costly and time consuming, but they felt that it was the only way for them to access specialist consultations, timely treatments, and more

comprehensive care plans. One participant described waiting over a year for an urgent dermatology appointment, only to ultimately decide to go private due to the severity of their symptoms:

> *"The first appointment they'd be able to offer me would be December the following year... I went to a private specialist, and within six weeks I was being treated" (P14)*

Some participants reported financial challenges in accessing private healthcare.

Flare ups and urgent treatment

Timely access to urgent treatment during lupus flare-ups was a major concern for many participants. The unpredictable nature of lupus can mean that flare-ups could happen suddenly, requiring immediate intervention to prevent complications. However, many participants experienced long waiting times to see specialists, with some having to turn to private care for faster treatment.

> *"You're not able to say 'well you're on the waiting list. I'll see you in 18 weeks.' By 18 weeks the person's going to be a complete mess, maybe dead" (P242)*

For those without access to urgent care, this was reported to have led to worsening symptoms, prolonged illness, and increased suffering. Participants emphasised the need for more responsive care pathways, including quicker access to specialists who could adjust treatments during flare-ups. The absence of reliable helplines or support services during these critical times was also very frequently mentioned. Some participants suggested that it would be beneficial to have a specialist healthcare professional available by phone to provide emergency guidance, while others recommended that lead rheumatology consultants could offer emergency treatment packs to those with unstable lupus, facilitating immediate intervention when necessary.

Conversely, for non-urgent medications that helped people manage the day-to-day symptoms of lupus, such as antimalarials like hydroxychloroquine, participants expressed satisfaction with their availability. The availability of biologic treatments for more severe cases also received some positive feedback, with several participants noting improvements in their condition following access to these advanced therapies.

Challenges in being heard

Not feeling listened to

A recurring theme was the feeling of not being listened to by healthcare providers. In seeking a diagnosis, many participants felt that their concerns were dismissed or minimised, particularly when their symptoms did not align with blood test results or when they presented with less visible symptoms like fatigue or pain. The lack of acknowledgment from healthcare providers such as GPs and emergency department staff, often left participants feeling isolated in managing their condition.

When it came to ongoing care, many participants reported positive interactions and support from clinicians who took the time to get to know them, listen and explain their treatment options. In some cases, people had direct contact numbers for their rheumatology consultant's secretary and were able to be seen urgently if needed. These positive relationships with healthcare providers played an important role in improving confidence in the system, and satisfaction with the care received. However, many participants expressed a desire for more empathy and understanding from their doctors, as well as a willingness to listen to individual-reported symptoms rather than relying solely on clinical metrics.

Some participants considered that they were not listened to due to their personal characteristics, specifically being a woman or an older woman. In one case, a woman reported needing to bring a male relative to appointments to advocate for her care.

"I have to do my own research"

A recurring theme throughout the interviews was the extent to which participants had to take on the responsibility of researching their own condition, often due to a lack of sufficient information from healthcare professionals. Many of individuals with lupus found themselves turning to various external sources for information, including charities like Lupus UK and their magazine, online support forums, and social media groups. Some even reviewed medical journals and clinical studies to find out information, which they felt was something that healthcare professionals should discuss more openly.

> *"He [Consultant] said to me 'you have to become a professor of what you've got, because there will be times when people aren't listening to you or they're not clued up' and he said 'if you want to stay alive, you have to', and so I have." (P32)*

Many participants reported finding support and information through Lupus UK. The charity was praised by many for offering accessible and detailed guidance on

managing lupus, which many found lacking from their healthcare providers. Lupus UK also built a sense of community around lupus for many.

> *"I went on the Lupus UK website, and I bought a load of books on lupus….. and attended a few of the Lupus UK conferences, particularly when I was diagnosed, and they were amazing. They would bring in particular speakers with a range of different topics….I've actually met some of my best friends through the conferences" (P251)*

Many participants expressed the need for clearer guidance from healthcare providers regarding available support, resources, treatment plans, and what to expect in managing their condition.

Peer support for lupus

The role of peer support was consistently highlighted as a critical resource for those living with lupus. Many participants found comfort in connecting with others who had similar experiences, whether through formal support groups such as those run by Lupus UK or online platforms, primarily Facebook.

> *"there's a lupus Facebook group and I find it really helpful just getting other people's experiences, like who have lupus and just, yeah, talking to them about symptoms and things can be quite good" (P257)*

Others also noted that while online forums and Facebook groups provided valuable information, they could be overwhelming, especially for those newly diagnosed. One participant shared:

> *"I found it [social media groups] quite overwhelming, I think, especially when you're newly diagnosed, it's quite depressing….you're just reading the worst kind of scenario" (P282)*

Peer support provided emotional relief, practical advice, and a sense of community that was often missing from their interactions with healthcare providers. Participants valued the opportunity to share their experiences, ask questions, and receive reassurance from others who understood the challenges of living with lupus. This sense of community was reported to help alleviate feelings of isolation and provided an additional layer of support outside the healthcare system, and one that was of real personal value to some. During discussions, these participants felt that the NHS should improve their signposting to reliable online platforms and support networks, specifically for those who are newly diagnosed with lupus.

"It would be good for the NHS to have a series of resources, you know, including a list of social media groups or whatever that people could log on to if they wanted to" (P133)

Lived experience of lupus

Impact on daily life

The impact of lupus on daily life was profound for many participants. Fatigue and joint pain were frequently mentioned as major limitations, preventing individuals from engaging in activities they once enjoyed or performing everyday tasks.

"every single day I feel hungover" (P259)

Participants described how lupus affected their ability to work, socialise, and care for their families, often leading to feelings of guilt or inadequacy. The physical limitations imposed by lupus, coupled with the emotional strain of managing a chronic illness, significantly affected the quality of life for many people with lupus.

"I have a huge number of ways I've adapted my life to cope with mostly the debilitating fatigue and then all over body pain." (P133)

Impact on ability to work

Many participants expressed that their employment had been impacted by their condition, resulting in reduced hours, job changes, unemployment or retirement. The unpredictability of symptoms, combined with the fatigue and pain associated with the disease, made it difficult for some participants to maintain regular employment. Some used flexible working hours or adjusted duties at work to maintain employment. A supportive and understanding employer was considered to be important in participants managing their condition while maintaining employment. Several people had had to quit university, jobs, and find alternative careers that they could manage around lupus. The financial strain of not being able to work, along with the loss of independence, added another layer of stress for many participants.

Mental health impact

The emotional toll of living with lupus was a prominent theme throughout the interviews, with many participants describing how the chronic and unpredictable nature of the disease affected their mental health and emotional wellbeing. The challenges of managing constant symptoms, dealing with flare-ups, and navigating a healthcare system that, for some, felt dismissive, left many participants feeling isolated, anxious, and depressed.

Several participants highlighted the absence of mental health services or support networks specifically designed for people with lupus. The lack of emotional care left participants feeling as though they had to manage not only the physical aspects of the disease but also the psychological burden on their own. This lack of recognition of the emotional impact of lupus left many participants feeling that their mental health was neglected within their overall treatment plan, and they advocated for more holistic care that included mental health and emotional wellbeing support.

> *"it would be lovely if it [Mental health support] was offered, if someone had said, 'would you like an hour of counselling', or a couple of hours of counselling to chat through everything, that would be absolutely brilliant. It would be wonderful and I'm sure it, you know, it would really benefit a lot of people." (P32)*

The reoccurring opportunities for improvements suggested by service-user throughout all stages of the evaluation have been collated and summarised in table 7.

6. Opportunities for improvement

Opportunities suggested by people with lupus

Table 7: Key opportunities to enhance lupus services in NHS Wales, based on from survey responses, interviews, and focus groups.

Opportunity*	Description
1. Regular monitoring and follow-up	Enable people with lupus to access to routine monitoring and provide a clear monitoring plans upon diagnosis to support ongoing care and provide reassurance.
2. Dedicated specialist healthcare professionals	Increase access to specialist healthcare professionals with expertise in lupus to manage the day-to-day care of people with lupus, coordinate with specialists, and provide support during flare-ups.
3. Improve treatment navigation/signposting	Ensure those who are newly diagnosed with lupus receive clear guidance on their condition, treatment expectations, and available support resources.
4. Expand mental health and emotional wellbeing support	Enable access to services to support mental health and emotional wellbeing in lupus care routinely, ensuring that people with lupus have access to counselling and psychological services from diagnosis and whenever it may be needed.
5. Facilitate quicker access to urgent care	Provide rapid access to medication and emergency support for people with unstable or severe symptoms when required. Alternatively, offer an emergency treatment pack for use in emergencies.
6. Dedicated hotline for support and advice	Provide a dedicated phoneline to offer those with lupus access to timely advice, signposting to resources, and support for managing their condition, helping them navigate healthcare services and connect with specialists when needed.

7. Enhance healthcare provider training on lupus	Improve access to resources for GPs and emergency clinical staff to support better recognition of lupus symptoms, and management. This could include the development of treatment pathways.
8. Increase access to holistic MDT treatment	Establish a/multiple specialist centres, with clinics for people with lupus, meeting the requirements set by Lupus UK, in a move towards a holistic approach to treatment. Alternatively, facilitate access to specialist lupus clinics in England for people with lupus who live in Wales.

*The table is organised by the number of quotes from survey responses, with the most frequently mentioned improvements listed first.

Opportunities suggested by clinicians and lupus service providers

Table 8: Key opportunities for enhancing the lupus services within NHS Wales, from the perspective of staff, taken from the national staff survey.

Opportunity	Description
1. Expand clinic capacity	Improve clinic efficiency and availability by increasing frequency of appointments to better meet individual needs.
2. Strengthen emotional support	Integrate dedicated mental health and emotional wellbeing support (incl. peer support groups such as Lupus UK) into the routine care to ensure a more holistic approach to managing the condition.
3. Implement a lupus PROM	Adopt a lupus-specific PROM to facilitate self-care, enable symptom and disease monitoring, and enable timely access to appropriate follow-up and review on the basis of need. This will help assess peoples quality of life, wellbeing and care quality.
4. Increase specialist staffing	Recruit additional healthcare professionals, including medical, nursing and allied health staff, with expertise in lupus and connective tissue diseases. This will help facilitate the multi-professional input required for effective MDTs.
5. Enhance regional collaboration	Foster stronger collaboration between health boards to enable regional working to provide the specialist services required in a high value, sustainable and accessible way, and enhance access to MDT support.
6. Improve access to biologic therapies	Facilitate access to dedicated clinics for people with complex lupus presentations requiring biologic treatments.

7. Establish dedicated specialist clinics	Works towards establishing specialist clinic(s) across Wales that meet the Lupus UK criteria for centres of excellence, facilitating better care for people with complex presentations.

7. Discussion

Discussion on service-user experience

The experiences of people with lupus from survey responses and during interviews and focus groups revealed a broad range of challenges, highlighting gaps in care provision, while also identifying areas of good care. Although many service users reported positive interactions with healthcare professionals, particularly specialists including specialist lupus nurses and rheumatology consultants, the overall experience was often marked by delays, fragmented care, and unmet needs in both physical and emotional support.

A recurring challenge was the difficulty in accessing specialist lupus care, both for diagnosis and ongoing management. Many individuals described long waiting times for specialist appointments and noted that access to healthcare professionals with lupus-specific expertise was inconsistent. This variation in access contributed to frustration and gaps in the continuity of care, particularly for those living in more rural or remote areas. Those with lupus consistently expressed a desire for more regular interaction with healthcare professionals with a knowledge of, and expertise in managing lupus. There may be opportunities to increase the availability of specialist healthcare professionals, whether by expanding the role of existing clinicians, or by sharing expertise across health board boundaries through regional provision. Welsh health boards should explore how to enhance the provision of specialist support in ways that best meet the needs of their populations.

Navigating the healthcare system was reported by service users to be particularly challenging following their initial diagnosis. Many described feeling overwhelmed by the complexity of lupus and unsure of how to access the various specialities involved. A clearer framework for treatment navigation, especially at the point of diagnosis, would help those diagnosed with lupus to understand what to expect and how to engage with different services effectively. Providing more structured information on treatment options, monitoring plans, and available resources could improve patient outcomes by empowering them to manage their condition with greater confidence.

Access to medicines for lupus was the highest-rated aspect of lupus care in the survey across both versions, with 180 participants (62%) rating their experience as ‘Good’ or ‘Excellent’. This positive feedback may be attributed to the availability of biologic therapies in Wales, which are not restricted to specialist centres as they are in England.

Peer support networks and partnerships with organisations like Lupus UK were consistently highlighted as beneficial in the findings, with potential to improve service navigation and emotional well-being. There was therefore strong encouragement for closer collaboration with third-sector organisations, such as Lupus UK, who could provide essential peer support, enabling individuals to connect with others who have similar experiences. Integrating these resources into the lupus care pathway would offer practical support and guidance, encouraging a more connected and supportive framework for lupus care.

Another significant issue raised by service users was the difficulty in managing lupus flare-ups. Given the unpredictable nature of lupus, many individuals struggled to access timely care during periods of worsening symptoms. Long delays for urgent appointments or a lack of appropriate interventions during flare-ups were a source of significant distress for people with lupus. Despite a lupus helpline being something that should routinely be offered to people with lupus under the care of a rheumatology care team in Wales as part of standard care, many participants reported that this was often not the case, with access generally perceived as inadequate. A phoneline, available during working hours, was frequently suggested as a potential solution, serving as a central point for information, guidance and signposting to relevant services. However, this may not be suitable for people in an emergency situation requiring an urgent response or treatment, for example. Some suggested that having more rapid access to treatment or clearer options during these acute episodes could help reduce the impact of flare-ups. Therefore, health boards should consider exploring approaches to facilitate more responsive care during these critical periods, potentially by improving access to urgent care support such as emergency medication packs, and offering guidance on managing flare-ups to those newly diagnosed. Although not suggested by patient participants, one potential approach could be the adoption of a 'Patient held record' – a document held by the person with lupus which includes a summary of their condition, current medications, and contact information for their treating clinician. This could help provide essential information to healthcare providers in emergency settings, aiding in improve management. The emotional and psychological toll of living with lupus was another key theme, with many service users highlighting the lack of mental health and emotional wellbeing support as a major gap in their care. While physical symptoms were often addressed, emotional wellbeing was less frequently discussed or supported, despite the chronic and life-changing nature of lupus. Integrating mental health and emotional wellbeing services into the routine care of people with lupus could provide valuable emotional support and improve overall wellbeing. Whether through increased access to counselling, recommended peer support groups, or healthcare professionals trained in

assessing and managing emotional wellbeing, there are a range of options health boards could explore to meet this need.

Fragmented care and poor communication between different specialties were also raised as a significant issue for many. Service users described feeling as though they were responsible for coordinating their own care, with little support in managing the complexity of their condition. The establishment of more holistic, multidisciplinary care pathways, with the support of peer support groups could offer a way to improve coordination between specialties, ensuring that people with lupus receive more integrated, continuous care.

Service users consistently raised concerns about the lack of knowledge of lupus among general practitioners and frontline healthcare workers. Given the complexities of lupus and its varying presentations, many felt that GPs and emergency clinicians lacked the training necessary to recognise and respond to lupus symptoms appropriately. Improved training for healthcare providers, particularly those in primary care, could enhance early diagnosis and improve management during acute episodes. However, retraining all primary care clinicians may not be feasible; therefore, developing care pathways to enable non-specialists, such as GPs and emergency clinicians, to access the necessary resources and expertise for managing lupus would be beneficial. While not raised directly by patient participants, one suggestion to aid in improving non-specialist recognition and management of the condition could be a patient-held record. The overarching aim would be to increase awareness and understanding of lupus across all levels of care. A framework or pathway for managing people with lupus, to help guide non-specialists may be beneficial.

Finally, the issue of regular monitoring and follow-up was noted as an area that could be improved. Patients often expressed a lack of clarity regarding the monitoring of their condition, and a need for more consistent and structured follow-up care to ensure that their condition is monitored effectively and any changes in health status are addressed promptly. These findings align with the BSR audit of clinicians which found that improvements were needed in urine protein quantification, blood pressure monitoring, consistent eye disease monitoring for those on hydroxychloroquine, and prednisolone reduction (Wright et al., 2023). Service-users suggested that clear, individualised monitoring plans would offer reassurance and improve their confidence in managing lupus. Health boards could consider how best to provide ongoing, regular monitoring, possibly through creating monitoring plans with those with lupus, improving the availability of appointments, and developing clear care pathways designed to track disease progression.

Discussion on clinician experience

The clinician perspectives gathered through the national staff survey provide valuable insights into the current state of lupus care in NHS Wales. Overall, clinicians expressed a mix of satisfaction and frustration with the care they were able to provide to people with lupus, citing systemic challenges such as workforce shortages, time constraints, and a lack of dedicated resources. These limitations, while not unique to lupus care, have a significant impact on the ability of healthcare professionals to offer comprehensive, patient-centered treatment for a condition as complex as lupus.

A major theme that emerged from clinician feedback was the need for more lupus-specific expertise and resources. Many clinicians felt confident in their ability to provide adequate care for individuals with lupus. However, they recognised a clear demand for more specialised services, such as dedicated lupus clinics. These clinics would support the management of patient with the most complex presentations or cases requiring expertise not available locally. Workforce shortages and time constraints were frequently cited as barriers to providing optimal care for people with lupus. Many clinicians reported feeling pressured to manage large caseloads with limited time per individual, which made it difficult to provide the level of detailed, individualised care that lupus often requires. There was strong support for increased investment in rheumatology services across the board, including the recruitment of healthcare professionals such as rheumatology consultants, specialist nurses, non-medical consultants, and administrative staff to help manage the growing demand for care. Clinicians, particularly those working in regions without dedicated lupus clinics, suggested that establishing these facilities would significantly improve patient outcomes by providing more tailored care, including better access to disease activity monitoring through the use of a lupus-specific PROM, biologic therapies, and multidisciplinary team input. Improving clinic efficiency by redirecting patients who do not require rheumatology expertise to alternative resources would also help ensure that this valuable, limited resource is available for those who need it most.

There was broad support for the idea of having more rheumatologists or consultants with a special interest in lupus and complex connective tissue diseases, particularly in regions where clinicians felt overburdened by a high demand, relative to the availability of lupus specialist. Many emphasised that dedicated lupus specialists would help manage the complex, multi-system nature of lupus more effectively, providing both those with lupus and non-specialist healthcare professionals with more support and focused guidance.

Clinicians frequently cited capacity issues as a barrier to timely and effective care. Several clinical participants noted that long waiting times for appointments were a significant issue, compounded by staff shortages and the high demand on rheumatology services. This problem was particularly acute when it came to managing urgent care needs, such as lupus flare-ups. While some health boards had good systems in place, such as rheumatology helplines that they felt enabled people to access in a timely manner, others highlighted the need for a more responsive system to address the acute care needs of people with lupus. Many clinicians felt that improving rapid access to treatments during flare-ups could prevent more severe complications and reduce the reliance on emergency departments.

The importance of multidisciplinary care was a recurring theme in clinician feedback. Many clinical participants emphasised the need for better coordination across specialties to manage the diverse manifestations of lupus. Clinicians working in health boards where MDTs were well-established, noted the benefits of this approach, particularly in managing people with complex presentations that required input from multiple specialists. However, there was also recognition that this level of integrated care was not always feasible, particularly in regions with fewer specialist services or where resources were stretched. There was a suggestion from clinicians that regional or national MDTs could be a solution as recommended in the Lupus UK centre of excellence standards. This would allow for the pooling of expertise across health boards and ensuring that people in more remote areas could still access specialist input.

Similarly to the feedback from service users, responses from clinical participants highlighted the lack of mental health and emotional wellbeing support for people with lupus. Many clinicians noted that while they were able to address the physical aspects of lupus, the emotional and psychological toll of living with a chronic condition often went unaddressed. This was due to a lack of mental health training and capacity within a short clinic to discuss all aspects of care. Therefore clinicians advocated for better access to mental health and emotional wellbeing services as part of routine lupus care, suggesting that this support should be integrated into lupus clinics or made available through dedicated pathways. This reflects recognition of the need for holistic care approaches that take into account both the physical and emotional wellbeing of people with lupus.

Training was another key area for improvement. Several clinicians suggested that additional training for GPs and emergency clinicians could help improve early recognition of lupus symptoms and reduce delays in diagnosis. Alternatively, the development of care pathways to aid GPs in their management of people with

lupus would be helpful. This would also alleviate some of the burden on specialist services by ensuring that more frontline healthcare workers are equipped to manage the condition effectively and are not referring people to specialists unnecessarily.

Differences and alignment in the perceptions of the service

The evaluation revealed both alignment and differences in the perceptions of lupus care between people with lupus and clinicians providing lupus care. While they shared opinions on key areas for improvement, their perspectives on the quality of care, support during flare-ups, and emotional support differed. Service users called for better guidance and navigation of the healthcare system, especially at the point of diagnosis. However, clinicians focused more on improving coordination across specialties and enhancing collaboration between health boards. Both perspectives aligned on the value of multidisciplinary team in lupus care, though clinicians were more focused on systemic improvements, while people with lupus viewed personal support to be of more importance.

Both service users and clinical participants emphasised the need for greater mental health and emotional support in lupus care. People with lupus often reported dissatisfaction with the emotional support available, with many rating it as 'poor' or 'very poor.' Clinicians agreed, advocating for more dedicated mental health resources, such as counselling and support groups. This shared recognition underscores the need for a more holistic approach to managing lupus, integrating mental health and emotional wellbeing support alongside physical care.

A clear contrast emerged in the perception of access to urgent care. People with lupus expressed dissatisfaction with access to urgent care during flare-ups, while clinicians rated their ability to provide timely support more favourably. The difference could reflect peoples' need for more immediate, in-person care, whereas clinicians may view current systems such as the existing helplines as sufficient for acute care needs, but this was not the view of those using the service. Additionally, it may be that the clinicians who completed the survey are those who are more engaged and provide better access to care than others.

There was general agreements on the importance of expanding access to specialist care and increasing clinic capacity. Service users emphasised the need for more regular monitoring and consistent follow-up, while clinicians cited workforce shortages and limited clinic slots as barriers. Both groups support the establishment of more dedicated lupus clinics and an increase in specialist staffing, recognising that this would improve the quality and consistency of care.

8. Strengths and limitations

The study's strengths lie in its mixed-methods approach, combining both quantitative data from surveys and qualitative insights from interviews and focus groups. This methodology enabled a comprehensive understanding of the perspectives of lupus care from both patients and clinicians, providing a broad overview of experiences while also delving into more in-depth insights. Direct engagement with people with lupus through these various methods ensured the evaluation was rooted in the lived experiences of people with lupus, offering a detailed understanding of their needs, particularly in terms of timely access to care and emotional support.

One key strength of the study was the broad dissemination of the service user survey, which was distributed by clinicians to people coded with lupus in hospital databases, and also shared on social media platforms by a service user representative and charity organisations. This approach maximised its reach, allowing the study to capture responses from individuals at different stages of their lupus journey, rather than limiting the sample to those diagnosed and actively receiving care from a clinician. Furthermore, aspects of the study were co-designed with Lupus UK and clinical leads in rheumatology, including a focus group run by Lupus UK to help co-design the service-user survey. This collaboration ensured that the scope of the evaluation and questions asked were relevant and targeted to the people the condition affects. Early collaboration with lupus networks also facilitated a wide reach through social media. The study also successfully gathered data from people within all seven Welsh Health Boards, supporting the representative nature to the study and providing important findings for system-wide change.

However, there are several limitations to the study. One key limitation is that interviews and focus groups were conducted online, which may have restricted participation from individuals who are not computer literate or do not have reliable access to technology. This may have inadvertently excluded certain voices, such as those from older generations or socioeconomically disadvantaged groups.

In recruiting participants, we did not attempt to validate the lupus diagnosis due to the logistical challenges involved. However, we distributed a survey through clinicians to people who were coded with having lupus in their medical records. Participants recruited via social media were not subject to this validation, so we cannot confirm that all had a confirmed diagnosis.

Another limitation is the underrepresentation of younger participants and ethnic minorities, particularly Black and Asian individuals, who are disproportionately affected by lupus. This limitation restricts the ability to generalise the findings across all people with lupus in Wales and beyond. While the majority of participants were older and female, which aligns with the broader lupus demographic, this overrepresentation may have overlooked the unique experiences of men and younger people with lupus. Important issues such as work-life balance, early-career struggles, and challenges faced by those of younger women may not have been fully captured, limiting the study's capacity to address the needs of these specific groups. However, the small number of men included in the qualitative stages of the evaluation accurately reflects the demographic profile of lupus, which predominantly affects women.

Finally, the reliance on self-reported data from participants, while valuable, may introduce bias, as those who chose to participate could be more engaged or have had more extreme experiences than the broader lupus population.

9. Conclusion

In conclusion, this comprehensive evaluation of the lupus service in NHS Wales highlights both strengths and areas for improvement. Service users praised the care provided by rheumatology consultants and the availability of advanced treatments like biologics, especially when care was offered in dedicated lupus clinics. Clinicians echoed these positive aspects, emphasising effective collaboration across specialties in managing people with complex presentations. However, significant challenges were identified, including delays in accessing urgent care during flare-ups and insufficient integrated emotional and mental health support. People with lupus and clinicians providing lupus care both raised concerns about fragmented care and insufficient coordination between specialists and non-specialists were also noted, contributing to a sense of unmet need.

The evaluation highlights a number of opportunities to improve access to specialist lupus services, enhance communication between healthcare providers, and integrate mental health and emotional wellbeing support into routine and emergency care during flare-ups. Suggestions from both people with lupus and clinicians providing lupus care, such as clear individualised monitoring plans and a lupus advice phoneline, could help address these gaps. By looking at ways to make these improvements, NHS Wales has the potential to enhance the effectiveness and responsiveness of care for people with lupus in NHS Wales, leading to improved patient satisfaction and better health and wellbeing.

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