



LUPUS UK CENTRE OF EXCELLENCE INSPECTION SUMMARY

Centre:	The Kellgren Centre for Rheumatology, Manchester Royal Infirmary
Assessors:	<ul style="list-style-type: none">• Paul Howard (Chief Executive)• Elaine Holland (Chair of Trustees)• Ricky Chotai (Trustee)• Peter Norton (Honorary Life Member and Volunteer)
Patient Survey:	<ul style="list-style-type: none">• Open online from 21/08/2023 to 10/09/2023.• Total 45 responses.• Several respondents were excluded because they were not current patients and/or did not have a diagnosis of lupus.• Most questions were completed by 34 people.• The (mean) average patient satisfaction rating with 7/10.
Inspection Date:	13/09/2023

LUPUS UK's Decision	The Kellgren Centre for Rheumatology at Manchester Royal Infirmary should retain the LUPUS UK Centre of Excellence award.
Next Inspection:	<p>LUPUS UK should request a written report from the Centre in September 2024 to report on any changes and progress since the inspection visit.</p> <p>An in-person delegation should schedule the next inspection for September 2025, unless there are concerns requiring an earlier visit.</p>

CRITERIA	DECISION	SERVICE	RECOMMENDATIONS
STAFFING			
<ol style="list-style-type: none"> 1. Dedicated lupus clinic with three or more consultants covering different specialties to be available to see patients, although not necessarily on duty at the same time. 2. At least one consultant with specialist knowledge of lupus with the others having a good 'working knowledge' of lupus. 3. Dedicated Specialist Lupus Nurse with other nursing staff having 'working knowledge' of lupus. 4. Multi-disciplinary approach to patient care. 	CRITERIA MET	<ul style="list-style-type: none"> • The Centre has lupus clinics all day each Wednesday. • Prof Ian Bruce and Prof Ben Parker are the service leads in a team of seven consultants. • Sr. Kripa John is the lead Specialist Nurse for SLE. • The Specialist Nurse team is led by Sr. Emma Powell and all nurses are experienced in the management of patients with lupus. • The department has weekly multi-disciplinary team (MDT) meetings where lupus patients are discussed with colleagues from nephrology, respiratory, immunology and radiology. • Feedback from the online patient satisfaction survey included several comments about the friendliness and expertise of the staff. 	None

CRITERIA	DECISION	SERVICE	RECOMMENDATIONS
APPOINTMENTS/HELPLINE			
<p>5. 'Open Door' system for earlier consultation should problems arise between pre-booked appointments, patients having a 'name' to approach in this regard e.g. medical secretary, Specialist Nurse.</p> <p>6. Patients should be offered an appointment with the Specialist Lupus Nurse following a new diagnosis.</p> <p>7. Helpline with message facility for general patient queries – not emergencies. This may be shared e.g. Lupus/Rheum/Derm and set up following consultation with medical staff/management.</p> <p>8. An email "helpline" facility should be provided in addition to the telephone line.</p> <p>9. Patients who call the helpline should receive a response within two working days.</p> <p>10. Combined clinics being held so that patients do not have to trek between departments/sites or attend different clinics on different days.</p> <p>11. Patients should be presented with the option to request a face-to-face appointment if they are offered a telemedicine consultation.</p>	ROOM FOR IMPROVEMENT	<ul style="list-style-type: none"> There is a dedicated nurse advice line that aims to respond to all calls within 24 hours. The nurse advice line can be used to arrange an urgent appointment with slots kept on Fridays. Newly diagnosed patients will automatically have a nurse appointment. An email "helpline" has been rolled out and is heavily used. The Centre has two combined clinics: Pregnancy and Transition. These are targeted and most effective by ensuring consistent advice for patients. The team has regular Multi-Disciplinary Team (MDT) meetings to discuss patients across several specialties at key decision points. At these meetings, consensus is reached between specialists and then patients advised of decisions. Where possible, the team will attempt to "leapfrog" appointments between the specialties to avoid patients having to attend too many appointments around the same time. All new patients are defaulted to face-to-face appointments. All clinics are a mixture of telephone and face-to-face appointments, with the majority (approx. 80%) of appointments defaulting to face-to-face for lupus clinics. Patients can change the format of their appointment at any time by contacting the support line. Responses to the online survey revealed dissatisfaction from several people who experienced significant delays between follow-up appointments and feeling "neglected" or "overlooked". The (mean) average score for these criteria was 3.1 out of 5. 	<ul style="list-style-type: none"> More effective communication with patients is needed to ensure they know to call the helpline to discuss concerns about appointments. There is concern that some patients are unaware of the email "helpline" service. Details of the service should be prominently displayed in the clinic and in letters. There is a risk that some patients may have appointments with several specialists very close together. This needs to be monitored to ensure the burden of appointments is not unreasonable for patients. Steps need to be taken to ensure patients are aware they can request a change of their allocated appointment format, if needed.

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COMMUNICATION			
<p>12. Patients having reasons for additional tests, investigations (other than usual accepted routine clinic testing e.g. blood, urine) and medications explained to them.</p> <p>13. Patients being informed of any possible side-effects of tests, investigations and medications.</p> <p>14. Patients being informed of results of tests and investigations as necessary.</p> <p>15. Consultants/Specialist Nurse to update GPs by letter following each patient visit to clinic with patients having the option of receiving copies of these letters.</p> <p>16. Centres of Excellence should demonstrate how they are involving patients in the development of their services.</p>	ROOM FOR IMPROVEMENT	<ul style="list-style-type: none"> An appointment with a nurse is arranged for all patients due to start a new treatment. The specialist pharmacist provides standardised education about treatments for all clinicians so that information given to patients is consistent. If tests are flagged as abnormal it will appear on the MyMFT app. Subsequently a clinic nurse will call to discuss the results and arrange follow-up. Following all appointments, patients and GPs receive clinic letters informing them of the discussion, management plan and any further actions needed. Results letters are generated where actions need to be taken. GP letters are usually sent electronically on the same day as generated. All patients signed up to myMFT app will automatically see all results and correspondence as soon as they are available. Paper copies can be generated on request. To date, there is no local user group for the clinical services, but they have always engaged their patient cohort for research projects. The (mean) average score for these criteria from the online survey was 4.3 out of 5. 	<ul style="list-style-type: none"> The Centre should find a way to engage and involve patients in the development of their services. As a first step, staff from the team should join a North West Lupus Group Coffee & Chat meeting to hear patient experiences. The Centre should identify several patients who are happy to contribute suggestions and provide feedback about changes to their service.

CRITERIA	DECISION	SERVICE	RECOMMENDATIONS
FACILITIES			
<p>17. Easy access to the clinic – either at ground level or with patient-friendly lift.</p> <p>18. Comfortable surroundings/lighting/colours in clinic.</p> <p>19. Privacy in changing/consultation rooms.</p> <p>20. Toilets, preferably in department or close by, with disabled/nappy changing facilities.</p>	CRITERIA MET	<ul style="list-style-type: none"> • The clinic is all on the ground floor and easily accessible. • Phlebotomy is available within the clinic. • A room with sensory equipment and dimmable lights is available for patients who struggle in the main waiting room. • Gowns are stored in each consulting room. • Curtains are up in each consulting room for privacy. • There are warnings on the door to prevent intrusion if the changing curtains are in use. • Two accessible toilets are in the entrance to the clinic. • Hooks for coats/bags are fixed to the wall. • The (mean) average score for these criteria from the online survey was 4.7 out of 5. 	N/A

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INFORMATION & EDUCATION			
<p>21. Up-to-date lupus information (leaflets etc.) always available and sited at discretion of consultant/Specialist Nurse.</p> <p>22. A pack of LUPUS UK literature should be supplied following a new diagnosis.</p>	REQUIRES MONITORING	<ul style="list-style-type: none"> The waiting room has access to patient information leaflets, as well as information regarding clinical research studies and patient events. <ul style="list-style-type: none"> Whilst well-stocked on the inspection day, the range of leaflets was reported as limited in the weeks beforehand. Booklets about MSK conditions and treatments provided by Versus Arthritis are available next to the consultation rooms for dispensing by clinicians. Staff frequently signpost patients to the LUPUS UK website and provide printed materials. Staff choose an appropriate time to supply literature, often at a second appointment. The (mean) average score for these criteria from the online survey was 3.6 out of 5. 	<ul style="list-style-type: none"> The Centre should ensure they always have an adequate supply of LUPUS UK publications. A website link for ordering free supplies has been shared with the Centre staff.

CRITERIA	DECISION	SERVICE	RECOMMENDATIONS
NETWORKING			
<p>23. Consultants/nursing staff happy to liaise with LUPUS UK Regional Group/Contact/National Office.</p> <p>24. Liaison of consultants/researchers with other hospitals/Lupus Centres within the UK and overseas.</p>	ROOM FOR IMPROVEMENT	<ul style="list-style-type: none"> For many years the lead consultants have been supportive of LUPUS UK nationally and the North West Lupus Group. The North West Lupus Group have had infrequent contact with the Centre staff in recent years, particularly during the COVID-19 pandemic. The team is regularly approached by overseas rheumatology trainees, looking to expand their lupus experience in the UK. Recently they have provided educational placements for clinical fellows from Ireland, Sri Lanka and Egypt. The team recently established collaborations with a team in Kenya investigating infection risk in the UK and Kenya, and with a national collaboration from Sri-Lanka where they have helped establish a lupus register. Prof Bruce and Prof Parker have been members of BILAG for many years and attend national meetings regularly. Prof Bruce and Prof Parker run the regional referral network for the North West. Prof Bruce is a member of The Systemic Lupus Erythematosus International Collaborating Clinics Group (SLICC). 	<ul style="list-style-type: none"> Assistance from Centre staff to re-launch the Coffee & Chat meetings would be gratefully received.

CRITERIA	DECISION	SERVICE	RECOMMENDATIONS
RESEARCH			
25. Ongoing lupus-connected research projects within the hospital/Lupus Centre.	CRITERIA MET	<ul style="list-style-type: none"> The Centre is a very research active department, supporting and leading NIHR infrastructure (Manchester Biomedical Research Centre and Manchester Clinical Research Facility). They offer a range of clinical research studies such as the national IMID Bioresource study (led from Manchester), many national and local observational studies (they lead the BILAG- Biologics Register) and smaller more intense experimental medicine studies, facilitated by their research fellows. Prof Parker leads on many early and late phase trials include TULIP, BEAT-Lupus and SLEEK. 	<ul style="list-style-type: none"> The Centre should liaise with LUPUS UK's Health Information Officer, Debbie Kinsey, to help disseminate research results and share opportunities to be involved in research.
TRAINING			
26. Organised and regular training of junior doctors and nursing staff in the management of lupus and research methodology.	CRITERIA MET	<ul style="list-style-type: none"> As a teaching hospital, they host medical students on an almost continual basis, as well as colleagues and visiting fellows. 	<ul style="list-style-type: none"> LUPUS UK's book for physicians, "Lupus: Diagnosis & Treatment" could be given to fellow/students working in the clinic. A free supply can be requested.