

## Joint Working Executive Summary

<b>Joint working partners</b>	Royal Devon University Healthcare NHS Foundation Trust And Recordati Rare Diseases UK Ltd
<b>Project period</b>	6 months
<b>Project name</b>	Development of an enhanced integrated multi-disciplinary clinic for patients with cutaneous lymphoma
<b>Joint working project summary</b>	<p>A joint working project between Royal Devon University Healthcare (RDUH) NHS Foundation Trust and Recordati Rare Diseases UK Ltd (RRD) to develop and implement a programme designed to improve cutaneous lymphoma (CL) patient care by way of a dedicated integrated multidisciplinary clinic to improve:</p> <ul style="list-style-type: none"> <li>• local CL treatment pathway and optimise clinical management.</li> <li>• patient awareness and confidence in their disease and management decision making, leading to greater treatment adherence.</li> <li>• data collection on disease status (including staging and whole body photographs) and quality of life (QoL) for patients to ensure complete records in database.</li> </ul> <p>The integration of care of CL patients within the Royal Devon Dermatology Department is anticipated to improve patient-centred care leading to:</p> <ul style="list-style-type: none"> <li>• improved identification and treatment of CL patients through the development of an efficient patient pathway with review annually to ensure a proactive approach to treating CL and increased experience and expertise within the centre.</li> <li>• a reduction in CL outpatient appointments within general dermatology clinics.</li> <li>• improved patient QoL, through greater education of disease area, greater planning and patient consultation to agree treatment protocols, pathways and management decision making.</li> <li>• complete clinical data collection (including imaging) and records for patients – clinical data collection extension of local CL database (EPIC).</li> </ul> <p>Through running this project and CL clinic day and achieving the above objectives the impact of this project on:</p> <ul style="list-style-type: none"> <li>• the patient will be that they receive improved care due to the level of expertise in an MDT approach and review of staging.</li> <li>• the patient experience will be greater due to patient education and also chance to meet others in a support group environment.</li> <li>• RDUH trust will be increased experience and expertise for clinicians though holding a dedicated CL clinic day supported by expert advice from regional supranetwork dermatologists and dermatopathologist and disease appropriate training. Also increased appointments in general clinics for other patients.</li> </ul>

<p><b>Expected outcomes</b></p>	<p><b><u>Patients</u></b></p> <p>Better experience of the healthcare system through:</p> <ul style="list-style-type: none"> <li>• optimisation of the clinical management of their disease with improved treatment decision making and clinical outcomes</li> <li>• greater education regarding their disease and treatment options leading to greater planning and patient consultation to agree treatment decision making</li> <li>• improved quality of life</li> <li>• improved confidence in the Trust and their treatment</li> <li>• support from other patients and patient support group.</li> </ul> <p><b><u>Royal Devon Hospital NHS Trust</u></b></p> <p>The creation of an integrated multidisciplinary CL clinic day will lead to:</p> <ul style="list-style-type: none"> <li>• the development of a local, efficient, patient pathway with annual review to ensure a proactive approach to treating CL</li> <li>• a reduction in CL outpatient appointments within other clinics freeing up appointments for other patients</li> <li>• increased experience and expertise in CL clinical management through whole day clinic focus and clinical support from regional expert</li> <li>• complete data records for all CL patients (including imaging) and annual review of staging</li> <li>• improved patient attendance rate for follow up due to dedicate patient focused clinic.</li> </ul> <p><b><u>Recordati Rare Diseases UK Ltd</u></b></p> <ul style="list-style-type: none"> <li>• Improved understanding of the challenges and support needed to implement an integrated multi-disciplinary care pathway.</li> <li>• Recognition as a trusted partner for Joint Working projects with the NHS.</li> <li>• Ability to take and share the learning from this project to other regions in the UK to support improved patient care.</li> <li>• More appropriate use of medicines for patients with mycosis fungoides cutaneous T-cell lymphoma, some of which may be prescribed RRD medicines.</li> </ul> <p>Increased company awareness via publication and presentation of the project and its outcomes.</p>
<p><b>Project timeframe</b></p>	<p>February 2024 - August 2024 (plus publication time at end of project)</p>
<p><b>Resource contribution</b></p>	<p>Significant resource contributions to the initiative will be provided by both parties.</p> <p>Royal Devon University Healthcare Trust indirect contribution £9,700</p> <p>Recordati Rare Disease UK Ltd indirect/direct contribution £10,250</p>