

Joint Working Executive Summary

Joint working partners	Royal Devon University Healthcare NHS Foundation Trust And Recordati Rare Diseases UK Ltd
Project period	6 months
Project name	Development of an enhanced integrated multi-disciplinary clinic for patients with cutaneous lymphoma
Joint working project summary	<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"> • local CL treatment pathway and optimise clinical management. • patient awareness and confidence in their disease and management decision making, leading to greater treatment adherence. • data collection on disease status (including staging and whole body photographs) and quality of life (QoL) for patients to ensure complete records in database. <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"> • 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. • a reduction in CL outpatient appointments within general dermatology clinics. • improved patient QoL, through greater education of disease area, greater planning and patient consultation to agree treatment protocols, pathways and management decision making. • complete clinical data collection (including imaging) and records for patients – clinical data collection extension of local CL database (EPIC). <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"> • the patient will be that they receive improved care due to the level of expertise in an MDT approach and review of staging. • the patient experience will be greater due to patient education and also chance to meet others in a support group environment. • RDUH trust will be increased experience and expertise for clinicians through 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.

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

Immediate Outcomes	<ul style="list-style-type: none"> • Successful implementation of local CL clinic day with positive feedback from patients and RDUH NHS staff in post-clinic questionnaire. • High attendance rate (<8% no show on the day). • Improvement in patient understanding and confidence in their disease and its management after the clinic compared to start of clinic. 85% of patients reported the outcome of the clinic to be very good or excellent. • High confidence reported by patients regarding NHS staff. • The majority of patients reported they would attend a future clinic (85%). • Creation of updated records including staging in electronic patient record for patients attending the clinic via use of proforma. • Majority of HCPs reported the clinic to be extremely valuable for their education, confidence and experience of CL.
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