

Joint Working Executive Summary

JW Partner(s)	Royal Cornwall Hospital Trust And Recordati Rare Diseases UK Ltd
Project Period	18 months (amended to allow for data analysis and project delays)
Project Name	Development of an annual enhanced integrated multi-disciplinary clinic for patients with mycosis fungoides cutaneous T-cell lymphoma
Joint Working Project Summary	<p>A joint working project between Royal Cornwall Hospital (RCH) NHS Trust and Recordati Rare Diseases UK Ltd (RRD) to develop and implement a programme designed to improve mycosis fungoides cutaneous T-cell lymphoma (MF-CTCL) patient care by way of a dedicated annual integrated multidisciplinary clinic to improve:</p> <ul style="list-style-type: none"> • local MF-CTCL treatment pathway and optimise clinical management • patient awareness and confidence in their disease and treatment decision making, leading to greater treatment compliance • data collection on disease status and quality of life (QoL) for patients to ensure complete data records in database. <p>The integration of care of MF-CTCL patients within the Royal Cornwall Dermatology Department is anticipated to improve patient-centred care leading to:</p> <ul style="list-style-type: none"> • a reduction in MF-CTCL outpatient appointments within general dermatology clinics • improved identification and treatment of MF-CTCL patients through the development of an efficient patient pathway with review annually to ensure a proactive approach to treating MF-CTCL and increased experience and expertise within the centre • improved patient QoL, through greater education of disease area, greater planning and patient consultation to agree treatment protocols, pathways and treatment decision making • complete clinical data collection and records for patients – creation of local MFCTCL database. <p>Through running this annual MF-CTCL clinic and achieving the above objectives the impact of this project on:</p> <ul style="list-style-type: none"> • the patient will that they receive improved care due to the level of expertise in an MDT approach and annual review of staging. • the patient experience will be greater due to patient education and also chance to meet others in a support group. • RCH trust will be increased experience and expertise for clinicians though holding a dedicated MF-CTCL clinic supported

	by expert advice from regional MDT lead and therapy area training. Also increased appointments in general clinics for other patients.
Expected Outcomes	<p><u>Patients</u> 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 Cornwall Hospital NHS Trust</u> The creation of annual integrated multidisciplinary MF-CTCL clinic 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 MF-CTCL • a reduction in MF-CTCL outpatient appointments within other clinics freeing up appointments for other patients • increased experience and expertise in MF-CTCL clinical management through whole day clinic focus and clinical support from regional expert • complete data records for all MF-CTCL patients and annual review of staging • improved patient attendance rate for annual 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 MF-CTCL, some of which may be prescribed RRD medicines. • Increased company awareness via publication and presentation of the project and its outcomes.
Project timeframe	September 2022 – March 2024 (plus publication time at end of project)
Resource contribution	Significant resource contributions to the initiative will be provided by both parties. Royal Cornwall Hospital NHS Trust indirect contribution £19,200 Recordati Rare Disease UK Ltd contribution £18,100

Outcomes	<ul style="list-style-type: none">• All patients seen in clinic were successfully staged and treatment adjusted appropriately when required.• Patient knowledge and confidence regarding their condition and treatment improved. 77% reported the clinic as being beneficial.• Majority of patients had improved or stable quality of life scores.• Few patients required unplanned hospital visits between clinics.• Increased awareness, understanding and confidence from health care professionals regarding MF-CTCL.• 100% Net Promoter score from clinical team.• Two MF-CTCL specialist nurse posts created.• PIFU pathway initiated.• Dermatology pharmacist appointed.• Commitment to annual clinic.• Quality in Care Dermatology award for Patient Care Pathway.
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