

Collaborative Working Project executive summary

Project title	The Salford (The Mark Holland Metabolic Unit) Enzyme Replacement Therapy (ERT) Infusion Service Evaluation
Partner organisation/s	Sanofi, 410 Thames Valley Park Drive, Reading, RG6 1PT. Northern Care Alliance, Salford Royal, Stott Lane, Salford, M6 8HD
Project rationale	<p>Patients with rare inherited metabolic disorders (including Lysosomal Storage Disorders, Pompe, Gaucher & Fabry) may only have their treatment initiated at one of the 8 paediatric and adult metabolic centres in England.</p> <p>Salford Adult Metabolic Treatment Centre (The Mark Holland Metabolic Unit) is the most northerly centre with the largest geographical catchment area for adults.</p> <p>Significant number of patients requiring Enzyme Replacement Therapy (ERT) for Lysosomal Storage Disorders are required to commence therapy via IV infusion. The number of infusions at the treatment centre can vary depending on their treatment as well as the patient's treatment status (Naive, treatment change or restart). Once treatment is established, the treating physician can decide that the patient can then be infused at home by the Homecare nurses or learn to be independent.</p> <p>Salford's infusion suite is not dedicated to the Metabolic Service, it is shared with the Neurology and Renal departments.</p> <p>Recently the Salford metabolic service has experienced a backlog of patients waiting to be started on ERT. This is a consequence of competition for infusion space and an influx of new patients. As a result, patients with LSDs have had to wait up to 9 months to have their therapy started. This has improved by various interventions initiated by the team to reduce the waiting list.</p> <p>It was therefore identified that a service evaluation was needed to determine going forward what future improvements to the service could be made.</p>
Project period	Q1 2024 to Q3 2024

Project objectives	<p>The project aims are:</p> <ul style="list-style-type: none">• Review the current pathways and processes for patients in need for establishing on ERT and identify areas to gain efficiencies to avoid long waiting times <p>The objectives are:</p> <ul style="list-style-type: none">• To analyse capacity issues within their infusion suite and access options• To measure delays in patient discharge out to homecare• To forecast future increased demands on the service.• Review staffing levels• Create options appraisal to identify potential areas requiring transformation• Look at a leaner approach to the service <p>Potential benefits to patients, NHS and Sanofi are:</p> <p>Patients</p> <ul style="list-style-type: none">• Reducing delays to patients starting treatment• Improvement of clinical care• Provide a better patient experience <p>NHS</p> <ul style="list-style-type: none">• Evaluation of current metabolic service to provide a baseline for areas requiring future transformation• Completion of workforce review <p>Sanofi</p> <ul style="list-style-type: none">• Improve reputation and relationship with the Salford metabolic centre• As Sanofi manufactures products in this therapy area, a potential increase in the use of Sanofi treatments may occur, in line with local and national guidelines <p>To achieve these objectives the parties will pool indirect resources of approximately £7,000.</p>
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