

Collaborative Working Project Executive Summary

Project title	Collaborative working agreement between Sanofi and University Hospitals Birmingham NHSFT (UHB) to undertake a review of the Late Onset Pompe Disease Diagnostic Pathway
Partner organisation/s	University Hospitals Birmingham, Mindelsohn way, Birmingham B15 2GW Sanofi, 410 Thames Valley Park Drive, Reading RG6 1PT.
Project rationale	<p>The inherited metabolic disease centre based at Queen Elizabeth Hospital Birmingham (University Hospitals NHS Foundation Trust (UHB) provides care and treatment for patients and families affected by inherited metabolic diseases (IMD). The metabolic treatment centre provides care for over 500 patients with an IMD diagnosis. At present UHB manages 35 patients who have been diagnosed with Late- onset Pompe disease.</p> <p>One of the key priorities of the NHS Rare Disease Framework is helping patients to get a faster diagnosis and quicker access to specialist care centres like the inherited metabolic centre at UHB. Literature suggests the current pathways are associated with significant delays in patients with suspected Late-onset Pompe disease being identified and receiving appropriate treatment.</p> <p>UHB would like to explore the current patient journey and any delays to diagnosis their patients may have experienced.</p>
Project period	Q3 2024 start date. Q4 2024 end date
Project objectives	<p>The collaborative working project will deliver the following proposed benefits for Patients, the NHS and Sanofi.</p> <p>Patients</p> <ul style="list-style-type: none"> • Potential future earlier identification of patients with Late-onset Pompe disease. • Potential future earlier access to specialised services for appropriate clinical care.

	<p>NHS</p> <ul style="list-style-type: none"> • Review of the current diagnostic patient journey for 35 diagnosed patients with Late-onset Pompe disease. • Mapping of the patient diagnostic journey to identify gaps and issues to be addressed and consider if there are any changes that could be made to improve the overall diagnostic pathway. • To gain a better understanding of the future needs of patients with Late-onset Pompe disease to improve their diagnostic journey. <p>Sanofi</p> <ul style="list-style-type: none"> • Greater clarity of the patient diagnostic journey to support specific needs of the health professionals within UHB and referring hospitals. • Improved reputation with relevant NHS referral/ metabolic treatment centres. <p>This project was completed by pooling resources of £6700 (60% NHS : 40% Sanofi)</p>
<p>Contact details</p>	<p><u>Sanofi</u></p> <p>Paul Naish, Head of Market Access UK & IE</p> <p>GB-MarketAccess@sanofi.com</p> <p><u>UHB</u></p> <p>Dr Shyam Madathil, Consultant Physician, University Hospitals Birmingham</p> <p>Switch board number 0121 371 2000</p> <p>Website www.uhb.nhs.uk</p>