University Hospitals Sussex NHS Foundation Trust

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Collaborative Working Project executive summary

Project title	University Hospitals Sussex - St Richards / Worthing Hospitals rare disease service review
Partner organisation/s	Sanofi UK, 410 Thames Valley Park, Drive, Reading.RG6 1PT University Hospitals Sussex NHS Foundation Trust, Worthing Hospital, Lyndhurst Road, Worthing, West Sussex, BN11 2DH
Project rationale	University Hospitals Sussex NHS Foundation Trust (UHS) is an NHS Foundation Trust which provides clinical services to people in Brighton and Hove, parts of East Sussex and West Sussex. They run seven hospitals across Brighton & Hove and West Sussex and serve a population of around 1.8 million people across the catchment area. St Richard's Hospital is a medium-sized District General Hospital located in Chichester, West Sussex with 500 inpatient beds and serves a population of approximately 350,000 people. Worthing Hospital is a medium-sized District General Hospital located in Worthing, West Sussex. It is also the Trust headquarters with 594 inpatient beds and serves a population of approximately 350,000 people. The purpose of the project is to conduct a review of the current diagnostic journey through secondary care (Respiratory, Haematology, Neurology, Cardiology, Paediatrics) for patients with rare diseases listed below from first admission/referral to the point of testing for a differential diagnosis. The review will aim to identify bottlenecks and delays in diagnosis with proposals for alternative patient pathways if required. At present, UK data documents a diagnostic odyssey with an averaging of 5-10 years[1] The first part of this project will to be to establish the average timeframe for a patient to achieve a diagnosis. There are approximately 70 LSDs, of which only some have a treatment available[2]. This review will focus on those rare disease tests prioritised by the project lead at the HCO namely Pompe (acid alpha-glucosidase), Fabry (alpha-galactosidase), Gaucher (glucocerebrosidase) and other metabolic diseases referred to as “Ref C” which may include some for which Sanofi have treatments available.

	When looking at the prevalence of rare diseases, the definition of a rare disease is one that affects fewer than one in every 2,000 people[1]. Thus, the numbers of patients are likely to be low. The outcomes of this analysis (options appraisal) will provide the NHS (National Health Service) with relevant information to evaluate the current service with proposals for alternative patient pathways if required. To do this requires dedicated project management support, to work alongside the biochemistry unit to help co-ordinate and deliver on this service review and evaluation. Ref: 1. UK_Strategy_for_Rare_Diseases.pdf (publishing.service.gov.uk) 2. Treatment for Lysosomal Storage Disorders - PubMed (nih.gov)
Project period	*Q1 2024 – Q3 2024*
Project objectives	This project aims to: - • Carry out a retrospective analysis of patient journeys at both St Richards and Worthing Hospitals (UHS Hospitals), who have been tested for a list of defined rare diseases which includes Lysosomal Storage Disorders (LSDs) • Improve the identification and time to diagnosis for these patients through a review of the patient journeys. The objectives are to: • Identify and review patients tested for the selected list of rare diseases which includes Lysosomal Storage Disorders (LSDs) since 2018. • Map patient journeys from first presentation into secondary care to Point of testing (PoT). • Identify common patterns of missed diagnosis within these journeys. • Create options appraisal with suggested changes for the future pathway.

	Measures will include: • Time taken from first referral into St Richards / Worthing Hospitals to point of LSD testing. • Anonymised patient data reviewed by clinicians and collated to analyse the efficiency of the current patient pathway, e.g., Patient A -1st referred to department A, x number of appointments, x number of tests/procedures before being referred to department B, then department C, until final point of testing for LSD. • Analysis and mapping out the current journey and evaluating options, looking to improve the patient journey to earlier testing. This collaborative working project aims to deliver the following predicted benefits for Patients, the NHS and Sanofi: **Patients** • Earlier diagnosis of LSD for patients. • Quicker and more equitable access to care. **NHS** • Understanding of the patient pathway, leading to opportunities to implement changes that improves the service for all patients with LSDs which makes it more efficient and hits NHS objectives and KPIs eg GIRFT (get it right first time) initiative • Provide a model for reviewing patient pathways for rare diseases that could benefit other NHS Trusts who are also looking to review their diagnostic services by 2025. **Sanofi**

	• Greater clarity of the LSD patient diagnostic journey within St Richards and Worthing Hospitals, helping Sanofi to tailor our offerings in the future through education and pathway mapping. • Improvements in the patient pathways may lead to more patients receiving Sanofi products in these disease areas and/or in a more timely manner
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