



Collaborative Working Project Summary Outcomes Report for the Haemophilia Outcomes Management System at the Royal Free Hospital, London

Project title	Haemophilia Outcomes Management System (HOMS)
Project timeframe	August 2021 to September 2023
Project Partner(s)	Royal Free London NHS Foundation Trust (Royal Free); Novo Nordisk
The Challenge	<p>Whilst there has been great progress in the development of therapeutic interventions and outcome tools in haemophilia over recent decades, there has been limited investment in delivering this at the patient level.</p> <p>To improve the quality of care from the patient’s perspective, there was agreement that an information management system that is both patient and outcome focused was required to enhance the clinician’s understanding of the effect of disease and treatments on a patient’s daily life. This project sought to address some of these issues through the digitalisation of haemophilia patient forms and documentation to optimise patient flow and outcomes within the Trust.</p>
The Objective	<p>This project aimed to develop a hospital-based information system to house templates for recording haemophilia and bleeding-disorder-specific information, record and track disease-specific outcomes, aggregate tasks to allow multiple investigations or interventions in a single clinic visit and identify patients needing additional investigations or interventions according to clear thresholds.</p> <p>The intended benefits of the project included:</p> <ul style="list-style-type: none"> • simplified / improved communication with staff in the centre • simplified data collection and potential improvements in patient experience during clinic appointments • Implementation of best practice in haemophilia management with minimal intervention, with a simple interface for all team members • More efficient use of healthcare resources

<p>What we did</p>	<ul style="list-style-type: none"> • The multi-disciplinary team at the Royal Free defined the data required to inform outcome-focused decision-making, and tested / validated the forms and functionality once developed by the programming team (an external IT provider) • The Royal Free team supervised and managed the work of the programming team, and defined the content and layout of reports from the system to allow regular review of how system use would inform clinical practice in the centre • Novo Nordisk contributed funding for system development. • The Novo Nordisk Digital Health team provided guidance on best practices for digital health platform development and any potential regulatory implications regarding Software as a Medical Device (SaMD) • The Novo Nordisk Real World Evidence (RWE) Team provided <ul style="list-style-type: none"> ○ Guidance on optimising data collection tools and incorporating appropriately converted data collection tools for digital use ○ Advice on using data to improve patient experience and outcomes based on company experience across several disease areas ○ Insights into electronic data capture comparability, including how to ensure future uses of HOMS are in line with compliance requirements ○ Perspectives on potential connection of data collection tools developed by this project to other resources (e.g. registries)
<p>Outcomes</p>	<p>Data collection</p> <ul style="list-style-type: none"> • Patient in-clinic data collection via iPad went live in Feb 2023 – feedback from patients has been very positive • The physiotherapy module went live in March 2023 • The surgical module is part completed – this work identified training needs and education has been implemented to address these • The laboratory dataset has been defined • The treatment module is under development <p>Database development</p> <ul style="list-style-type: none"> • Database framework and pathways are in place • Dashboards for the implemented modules have been developed • Additional IT support will be required to complete implementation, a new vendor will be contracted to achieve this <p>The collaborative working aspect of this project has completed and the Royal Free will be completing the database development independently. Novo Nordisk will have no further involvement in this project.</p>
<p>Lessons learned</p>	<p>Long-term viability of IT vendors is critical to be able to complete a project of this type.</p>

	<p>The project lead needs to be able to devote enough time to project management, which can be challenging around their clinical and academic responsibilities.</p>
Acknowledgements	<p>The multi-disciplinary team at the Haemophilia and Thrombosis Centre, Royal Free Hospital.</p> <p>Patients who contributed to feedback on the development of data collection systems.</p>