

Executive Summary

A declaration of collaborative working between* Amicus Therapeutics UK Operations and Salford Royal NHS Foundation Trust (Part of Northern Care Alliance)

Salford Royal NHS Foundation Trust and Amicus Therapeutics are engaged in a collaborative working project called:

Fabry Disease Symptom Tracker App

This project will run for an initial 15 months after the commencement date 15th December 2022 and both parties have contributed resources for this initiative.

Any payments made as part of the collaboration are made to Northern Care Alliance as per trust process

Expected outcomes:

Patients with Fabry Disease will be better supported with the implementation of portable technology - leading to better patient outcomes

Improved insight into patient experience and the clinical management of their Fabry disease

Increased reliability and quality of symptoms reporting - in order to improve review and positively impact patient quality of life and optimize review modality.

Key Deliverables:

Number of downloads of the Fabry symptom tracker app by patients & regular user interactions.

Patient reported outcomes better managed via threshold monitoring & reporting.

Development of resource to educate LSDU staff and other appropriate HCPs within Salford NHS Foundation Trust on the symptoms and the management of Fabry disease

To educate and engage Fabry patients on benefits of symptom tracking for their ongoing care.

Evaluation of the project that will better inform modifications to the Fabry symptom tracker app.