

Executive Summary

A declaration of collaborative working between Amicus Therapeutics UK Operations and Salford Care Organisation Part of Northern Care Alliance)

Salford Care Organisation and Amicus Therapeutics are engaged in a collaborative working project called:

Fabry Family Screening

This project will run for an initial 24 months after the commencement date and both parties have contributed resources to this initiative.

Start date – H1 2025

End date – H1 2027

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

Project aims and objectives:

The overall aim of the project is to improve the number of individuals who are screened for Fabry disease following the diagnosis of Fabry disease in a family member (the proband) – Leading to earlier diagnosis

To support priority one of the UK Rare Disease Framework - Helping patients get a final diagnosis faster

To demonstrate an improvement in the coordination of care provided for Fabry patients and their families - Leading to better patient experience

To demonstrate the value of a genetic practitioner to facilitate the improvement in screening uptake.

Key Deliverables:

To increase the number of Fabry proband family mapping histories recorded

To increase the number of family members receiving genetic screening

To develop a business case to show the value of genetic practitioner in the Fabry screening service.

Create an SOP that all professionals at Salford managing patients within the Fabry service can follow.

To evaluate the project to inform any further developments of the service