

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:

Pompe physiotherapy service improvement

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

Start date – H2 2024

End date – H2 2026

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

Project aims and objectives:

To improve efficiency with which Pompe patient are reviewed by a physiotherapist.

To improve patient outcome measures and overall patient experience.

To demonstrate the value of an enhanced physiotherapy service.

To support priority three of the Rare Disease Framework – Improving the coordination for care for patients living with rare diseases

Expected outcomes:

Evidence to support development of a business case for a successful and sustainable physiotherapy model in the specialist centre.

To improve frequency and range of monitoring techniques to increase demonstrable objective/tangible monitoring data collected by the physiotherapist and available for review by the Pompe MDT – quantifying disease progression/decline stability.

To improve the patient experience of the Pompe specialist service

Key Deliverables:

Increase in number of contacts with a physiotherapist for each Pompe patient.

Reduce the time to first appointment with a physiotherapist following treatment decision.

To increase the quantity of patient reported outcome measures used.

Improvement in quality of life for Pompe patients using approved outcomes measures.

A business case demonstrating the value of an enhanced physiotherapist to the service.