

Executive Summary

A declaration of collaborative working between Amicus Therapeutics UK Operations and Salford Royal NHS Foundation Trust

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

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.