

Executive Summary

A declaration of collaborative working between Amicus Therapeutics UK and Royal Free London NHS Foundation Trust

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

Flash Mob Audit: Improving knowledge of Fabry Disease

This project will run for 12 months after the commencement date February 2022 and both parties have contributed resources for this initiative.

Expected outcome:

The audit aims to support Cardiology education in Fabry disease and to provide an opportunity to implement learnings through live audits – which support patients and clinicians in addressing the diagnostic odyssey in Fabry disease.

Cardiology and Fabry focussed education will be implemented through live audits of trust cardiology datasets. This will, in turn, support the earlier identification of Fabry disease in patients in line with the UK Rare Disease Framework. The datasets will be audited against a combination of the British Inherited Metabolic Disease Group – Fabry guidelines and the European expert consensus statement on therapeutic goals in Fabry disease by C.Wanner et al. Anonymised combined data will be shared back to the Royal Free London NHS Foundation Trust, will be collated and will then be discussed at a national learning event. The plan is to publish the outcomes to increase awareness of Fabry disease and likely indicators of early diagnosis.

Key Deliverables

- Develop and deliver an educational program to national network of cardiology doctors in training.
- Run national 'Flash Mob Audit' day – which will involve anonymous data collection from trust cardiology datasets.
- Support participants in the analysis and review of the data – and feed back to participants with key outcomes to implement quality improvement locally.
- Write up data outcomes for publication and presentation in various relevant fora.

Financial Arrangements

The project will be supported by a pooling of skills and resources from both Amicus and Royal Free London NHSFT, with a direct financial contribution provided by Amicus of £10907