Executive Summary

Project Name:

Collaborative working between (1) the Royal Free London NHS Foundation Trust, National Amyloidosis Centre (**NAC**) and (2) Alnylam UK Ltd (**Alnylam**) relating to the optimisation of the process for reviewing patients diagnosed with wild-type transthyretin-mediated amyloidosis with cardiomyopathy (**ATTR-CM**)

Start Date and Duration:

The project shall begin on 30 June 2026 and continue for a duration of 29 months.

Background:

Following diagnosis, the NAC aims to review patients with ATTR-CM (**Relevant Patients**) at least once every 12 months (**Existing Process**). Given the volume of patients and capacity constraints at the NAC:

- it is becoming increasingly difficult to provide all Relevant Patients with a follow-up review within a 12-month period;
- a large number of assessments to enable a review with a clinician are carried out remotely (with support of the patients' GP and/or local cardiologist). This can lead to delays, inefficiencies, travel to different centres for the patient and higher costs for the NHS;
- it is difficult to provide all patients with individual support post clinician review to support any change in management.

Project Summary:

The project is a collaborative working initiative to support the NAC in creating a streamlined and efficient patient journey for their annual therapy review, which includes assessments, an appointment with a lead clinician at the NAC for assessment and support post appointment. The NAC will develop a protocol on an optimised version of the Existing Process and management of ATTR-CM patients to share with the UK amyloidosis network to disseminate expertise and create consistency and equity in patient care.

Project objectives and potential outcomes:

- Increase the capacity of the NAC to streamline, accelerate and optimise the end-to-end Existing Process to enable each Relevant Patient to have a follow-up review within 12 months of their previous review.
- Increase the number of patients reviewed by the NAC.
- Develop a protocol on an optimised version of the Existing Process and management of ATTR-CM patients to share with the UK amyloidosis network to disseminate expertise and create consistency and equity in patient care.

Expected Benefits:

Anticipated benefits for Patients:

- Improve access to specialised assessments
- Improved patient outcomes and experience
- More individualised counselling about their disease and treatment, leading to better understanding, engagement, and treatment adherence/compliance

- Through patient satisfaction questionnaires and responsive service design, the project ensures care is patient-centred and continuously improving

Anticipated Benefits for NAC:

- Optimised resource use and reduced pressure on existing resource
- Cost savings through improved efficient management of service
- Increase capacity of the NAC to optimise, streamline and accelerate the Existing Process, enabling the NAC to meet its objectives
- Provide the NAC with support to share information to other sites in the UK amyloidoisis network
- Provide the NAC with data to support a business case to be presented to NHS England for the future funding towards the Existing Process.

Anticipated Benefits for Alnylam:

- Alnylam is expected to benefit through the potential earlier diagnosis of ATTR-CM patients
- Increase in the appropriate use of medicines, including Alnylam's product, aligned to local or national guidance.

Contribution to the Project:

Alnylam Contribution:

Total Contribution: £470,149 divided as follows:

£338,848 towards funding for the following resources to support the project objectives:

- ATTR healthcare assistant;
- Echo Technician;
- Clinical Fellow;
- ATTR Pathways Manager;
- ATTR Nurse;
- Homecare technician.

Alnylam support towards project management: £131,301 based on attendance of the project lead and medical director attending quarterly review meetings and dedicating 4 hours per month to general project management over 29 months.

NAC Contribution:

Total Contribution: £846,570.23 divided as follows:

- medical assessments (£749,000 in value) not currently provided by the NAC as part of the Existing Process; and
- £97,570.23 of consultant and nurse time.

No actual sums will be paid by the NHS as part of the project. The contribution is based on the value of the medical assessments and human resource time spent on the Project (based on the applicable published NHS salary bands).

The type of resource and level of experience required takes into account the anticipated number and complexity of Relevant Patients, with approximately 3,000 patients expected to be managed through the Existing Process over the term of the Project.