

Executive Summary

Project Name:

Joint working between (1) the National Hospital for Neurology and Neurosurgery (**NHNN**), (2) the National Amyloidosis Centre (**NAC**) and (3) Alnylam UK Ltd (**Alnylam**) in relation to the development and implementation of a multidisciplinary team and service evaluation

Start Date and Duration:

15 November 2024 to 31 March 2026

Project Summary:

As part of the existing clinical process, patients diagnosed with hereditary transthyretin-mediated amyloidosis (**hATTR**) and with suspected peripheral neuropathy (**Patients**) at the NAC are referred by their managing health professional to the NHNN.

The joint working project will develop and implement a process to triage and then assess these Patients at a multidisciplinary team meeting. The project will also include an evaluation of the service pathway for diagnosis and treatment of hATTR in the UK (**Service Evaluation**).

Expected Benefits:

Anticipated benefits for Patients:

- Fewer but more effective and directed visits to hospitals.
- Better information on their condition and treatment options due to assessment being undertaken by experts in hATTR and peripheral neuropathy.
- Patient assessment is co-ordinated and more appropriately based on clinical need than under the current system. This in turn would provide patients with a better experience of the healthcare system.
- The development of a procedure to support earlier diagnosis of patients with hATTR.

Anticipated Benefits for NHNN:

- Opportunity to advance clinical understanding of hATTR and peripheral neuropathy alongside the specialist expertise at the NAC through discussion and evaluation of Patient cases.
- Opportunity to increase the capacity of the NHNN to assess Patients based on clinical need within a shorter timeframe.
- Opportunity to improve the service for hATTR patients across neurology/neuropathy care including at the NHNN.
- If deemed necessary, provide data to support a business case to be shared with NHS England (or other relevant decision-making body agreed by the Parties) to improve the provision of neurology/peripheral nerve clinical input into the care of patients with hATTR under the care of the NAC.

Anticipated Benefits for the NAC:

- Opportunity to advance clinical understanding of hATTR and peripheral neuropathy alongside the specialist expertise at the NHNN through discussion and evaluation of Patient cases.
- If deemed necessary, provide data to support a business case to be shared with NHS England (or other relevant decision-making body agreed by the Parties) to improve the provision of neurology/peripheral nerve clinical input into the care of patients with hATTR under the care of the NAC.
- Service Evaluation will provide data to the NAC which may be useful for its operations.

Anticipated Benefits for Alnylam:

- Alnylam is expected to benefit through the potential earlier diagnosis of hATTR patients with polyneuropathy.
- Improvement in patient care through alignment with local or national guidelines.