

Executive Summary for the Joint Working Agreement between Alnylam UK and UHB

Alnylam and University Hospital Birmingham (UHB) will enter a collaboration (Joint Working Agreement (JWA)) to enable the provision of a dedicated nurse specialist (inherited conditions) for 12 months. The overarching aim is to improve patient pathways and time to diagnosis, as well as to facilitate quicker referrals to tertiary centres and quicker access to therapy for hereditary ATTR (hATTR) amyloidosis patients. In detail, the objectives of this JWA are to coordinate cascade patient screening, to cross-link databases with the National Amyloidosis Centre (NAC), to provide quicker reviews of test results with patients and to facilitate quicker management of patients in MDTs with the NAC. Alnylam will provide the funding for the nurse specialist. UHB will provide medical consultant expertise to manage patients, genetic counsellor services and access to clinical and biochemical tests, including B-type natriuretic peptide (NT-pro BNP), high-sensitive troponin I (hsTrop-I), electrocardiogram, echocardiogram, scintigraphy or cardiovascular magnetic resonance scanning. A publication reporting the outcomes of this collaboration, such as number of patient referrals or changes in time to diagnosis, will be made available afterwards.