

Title	Improving the identification and treatment of patients with Familial Hypercholesterolaemia (FH) and high-risk secondary prevention cardiovascular disease in relation to lipid optimisation
Organisations Involved	Health Innovation North East North Cumbria (HI NENC) and Amgen Limited in collaboration with the Integrated Care System for North East North Cumbria (NENC ICS)
Joint Working Project Description	<p>The overall aims of this project are to:</p> <ul style="list-style-type: none"> • Identify patients at high risk of FH, evaluate treatments, educate and help patients reduce excess cardiovascular disease associated with FH. • Increase the utilisation of the genetic screening programme across the AHSN footprint through better patient identification. • Identify patients at high risk of CVD (>10% 10 year CV risk) and ensure appropriate treatment and management. • Improve the patient experience by providing more specialist care within primary care and ensure better utilisation and more appropriate referrals to the specialist service base with the NHS Trust. • To continue to refine and develop the FH service model to be adopted both regionally and nationally
Expected Outcomes	<p>The expected outcomes from this project were as follows:</p> <ul style="list-style-type: none"> • A written document to inform the treatment of Familial Hypercholesterolemia (FH) patients in primary care including information on implementing patient identification using a Familial Hypercholesterolemia (FH) patient identification tool and clinical review at a practice level. • A toolkit to include training materials on Familial Hypercholesterolemia (FH) and its treatment for healthcare professionals in primary care and the use of the Familial Hypercholesterolemia (FH) patient identification tool. • Implementation of NICE CG71 and the NHS long term plan. • To scale the programme across the NENC ICS region by: <ul style="list-style-type: none"> ○ Working with the CVD programme team and wider NENC CVD stakeholders to develop strategy and operational pieces of work to deliver reduced cardiovascular disease for patients. ○ Design and develop educational materials to enable spread and adoption across the System.

	<ul style="list-style-type: none"> ○ Develop materials to support service transformation and lipid optimisation. ○ Support workforce development within the lipid pathway; supporting the System to address disparities in health inequalities. <p>The project incorporates the principles of improved patient education, medicines optimisation and treatment close to home.</p>
<p>Actual Outcomes</p>	<ul style="list-style-type: none"> ● A dedicated FH audit tool was created to identify high-risk patients in primary care by scanning electronic medical records within GP IT systems and assigning an FH risk score. An FH Specialist Nurse then triaged the practice lists, counselling and obtaining consent from relevant patients for testing. This pilot was initially implemented across nine practices. ● Following the success of the pilot, the FH case-finding initiative was submitted for inclusion in a national programme. To enhance cost-effectiveness for primary care and align with the NHS Long Term Plan and Primary Care Network DES, lipid optimisation was incorporated. The submission was successful, and the initiative has evolved into the National FH & Lipid Optimisation Programme, now being deployed across all 15 AHSNs/HINs in England. ● In parallel with the pilot, discussions began with the Accelerated Access Collaborative to explore service models supporting the management of FH and dyslipidaemia. In collaboration with NHSE, Amgen and Sanofi supported service transformation, resulting in 13 projects launched nationwide. ● A Primary Care Standard Operating Procedure (SOP) was developed to standardise the identification, management, and optimisation of patients with FH and elevated cholesterol. The SOP includes a process map, CDRC search codes, and references to local and national guidelines. ● A lipid optimisation handbook was created to support primary care education and consolidate learning resources. ● An accredited genetic counselling course was developed in partnership with Northumbria University. ● Standardised GP letters were produced for patient communication. ● SOPs were also developed for clinical pharmacists and pharmacy technicians, including process maps to expand their roles in FH and lipid identification and optimisation.

	<ul style="list-style-type: none">• Educational videos were produced, including “What is FH” and “Demystifying Genetics.”• A “spread and adopt” approach was taken, with all project resources shared across Health Innovation Networks and made publicly available on the HI NENC website.• Educational initiatives were delivered to both primary and secondary care teams involved in lipid management, including a series of “Lunch & Learn” sessions and the coordination of the annual North East Lipid Forum meeting.• An FH pathway mapping project was conducted to enhance identification and reduce variation across the North East. This involved interviews with healthcare professionals across Durham, Darlington, and Tees Valley. The findings have informed the ICS, LSAG (Lipid Specialist Advisory Group for the North East), and Health Innovation NENC, leading to key improvements in FH detection.• The project has significantly increased FH detection in the North East, rising from 2% to 14.6% over its duration (data from NEQOS).• The partnership has been nominated for the HSJ Partnership Awards.• The project was also selected to present a poster at the 2025 Great North Pharmacy Research Collaborative Conference, showcasing the value and impact of sustained partnership working over seven years. Winner of best collaboration with Pharma award.
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GBR-NP-0725-80008 October 2025