Joint working executive summary

Project title	Barts Health and Sanofi Joint Working Project – Familial Hypercholesterolaemia screening service in the Barts Health locality
Partner organisation/s	Barts Health NHS trust Sanofi Pharmaceuticals
Project rationale	Familial hypercholesterolaemia (FH) is an inherited condition caused by an alteration in a gene, which results in a high cholesterol concentration in the blood. Raised cholesterol concentrations are present from birth and lead to early development of atherosclerosis and coronary heart disease. The condition is transmitted from generation to generation in such a way that brothers and sisters and children of a person with FH have a 1 in 2 chance (50:50 risk) of also having FH.The prevalence of heterozygous FH in the UK population is estimated to be at least 1 in 500, which means that 110,000 people in the UK, and over 5000 in the population served by Barts Health NHS Trust, are affected. If left untreated, more than 50% of men with heterozygous FH will develop coronary heart disease by the age of 50 years and more than 30% of women by the age of 60 years. Life expectancy is restored to near normal with early preventive treatment, particularly statins and smoking cessation. For every 1000 FH patients appropriately treated, 101 cardiovascular events are avoided. Despite being a major teaching hospital and acute provider in North East London, there is currently no dedicated FH service within Barts Health and NICE guidance and Quality Standards related to the condition are not being met. This project aims to jointly develop a dedicated Familial Hypercholesterolaemia service, including genetic screening and cascade testing to increase the diagnosis and optimal treatment of people with FH in the Barts Health Locality.
Project period	The project will start February 2018 and run for 24 months, finishing January 2020 ***This project was terminated early by mutual agreement in November 2019.***
Project objectives	Expected benefits for patients As a result of this project it is expected that more patients with heterozygous FH will be identified and treated appropriately increasing the number reaching target lipid levels, which in turn is expected to lead to improved long-term outcomes Expected benefits for the NHS

	CV disease costs the NHS billions of pounds every year in unplanned admissions and treatment. By identifying more undiagnosed patients with FH earlier in their life, unplanned and emergency activity can be reduced through earlier intervention with appropriate treatments in line with local and National guidance (https://www.nice.org.uk/guidance/cg71) Expected benefits for Sanofi Sanofi manufactures a PCSK9i inhibitor (alirocumab - Praluent) which is licensed for use in patients with heterozygous FH and is recommended for use by NICE and locally within the Barts Health locality. By increasing the numbers of patients diagnosed with FH, Sanofi anticipates a proportion of these will require a PCSK9i and a proportion of these will receive Praluent in line with local guidelines
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