Disclosure statement: Wessex AHSN and Amgen

Project title

Familial Hypercholesterolaemia (FH) Genetic Pathway Mapping - Dorset

Organisations involved

Wessex Academic Health Science Network (trading as Health Innovation Wessex, HIW), Amgen

Summary

The current pathway for genetic testing for Dorset patients with suspected familial hypercholesterolaemia (FH) will be mapped to analyse areas for improvement and co-produce (with stakeholders) an action plan to implement positive service changes.

Background

Cardiovascular disease (CVD) affects around seven million people in the UK and is a significant cause of disability and death. The NHS Long Term Plan (LTP) (2019) includes an ambition to prevent 150,000 strokes, heart attacks and cases of dementia over the next ten years.

The LTP also includes reference to familial hypercholesterolemia (FH), an inherited condition which leads to raised cholesterol in about 250,000 people across the UK. Our ambition is to improve detection of FH from the current 4% to 15% of the prevalent population by 2023. The NHS Long Term Plan has also set the ambitious target of finding 25% of the predicted FH patients in England by 2029.

There is an urgent need to review, treat and optimise these patients in a timely manner. There is increasing pressure and a growing rate of referrals into the hyperlipidaemia management pathway along with increasing needs for genetic screening/identification of familial hypercholesterolaemia patients. Clinical teams leading prevention in primary and secondary care have identified that the lipid services across the Wessex geography need to change to meet increasing demands and to ensure patients receive the best possible care with the best possible experience of the service.

In Dorset specifically, the CVD prevention team has a target to identify an additional 2,000 FH patients with the support of Health Innovation Wessex (HIW), as detailed in the Dorset HIW delivery plan for 2023-24. This project to support the pathway and genetic testing crucial to this action is business critical.

Project approach

The mapping of the FH genetic referral pathway aims to:

- Define & evaluate the current pathway reflecting end to end improvements and focusing on addressing unwarranted variation
- Enable a clear overview of the genetic referral process
- Combine data analysis with feedback from interviews with individuals and the wider stakeholder group around the pathway analysis, to develop an options proposal for adoption within Dorset
- Support implementation of changes where appropriate.

Project objectives

- Collect data along the patient pathway to gather evidence of potential inefficiencies and areas for improvement
- To analyse areas for improvement to streamline the access to genetic testing for patients with suspected FH in Dorset
- Develop an options appraisal for new improved patient pathway throughout Wessex AHSN for patients with lipid disorders/query FH
- Implement changes to the pathway agreed by the project group.

Benefits

The project will improve access, care and education for patients; create more efficient NHS pathways for lipid/FH management with enhanced education for healthcare professionals; and improve engagement and insights into Dorset hyperlipidaemia / FH services and the Wessex health system for Amgen.

Funding dates

Funding was received for the period September 2023 to February 2024.

Funding details

There are no direct costs for this project. Estimated activity and indirect costs are as follows:

Indirect staff costs incurred by Amgen

Meetings involving 2 Amgen personnel to scope, draft and finalise the process map, workshop delivery and review meeting.

Total indirect outlay by Amgen during the project: £1,320