HEART UK FAMILIAL HYPERCHOLESTEROLAEMIA PRIMARY CARE AUDIT PROGRAMME

There is an enormous opportunity to prevent the occurrence of coronary heart disease (CHD) by exploiting the information contained within GP electronic patient records to flag and diagnose people with the inherited lipid disorder familial hypercholesterolaemia (FH).

HEART UK are committed to supporting the rollout of FH primary care audit programmes based on the Medway model and are seeking to work with NHS bodies to implement the FH Audit tool (or similar audit tool) and support FH clinics. Please contact Simon Williams at HEART UK (sw@heartuk.org.uk) to discuss how your CCG could become involved.

>100,000
The estimated number of people in the UK that don’t know they have FH

50
50% - The risk of developing CHD in men by age 50 if untreated

60
30% - The risk of developing CHD in women by age 60 if left untreated

101
The number of cardiovascular events avoided for every 1000 FH patients diagnosed and optimally treated.

£2,700
THE QALY

£2.3M
The potential saving to the NHS if 50% of all FH cases were diagnosed and managed
A PROOF OF PRINCIPLE – THE MEDWAY STUDY.

Two simple interventions more than doubled the number of people diagnosed with FH in NHS Medway CCG. The first intervention was an FH Audit Tool utilising Audit+ software (provided by BMJ). The tool provided a systematic audit of electronic medical records within GP practices, first identifying all patients diagnosed with FH or possible FH and next electronically flagging patients with a recorded total cholesterol of ≥7.5 mmol/L or LDL-C ≥ 4.9 mmol/L (in adults), for further assessment and possible diagnosis. The baseline prevalence of FH was found to be one in 750 people. After 2 years of using the FH Audit Tool, the prevalence of patients diagnosed with FH had increased to one in 450. The second intervention was a nurse-led programme, which further increased the number of patients diagnosed with FH to one in 357, closer to the expected prevalence from epidemiological studies.

Figure 1: The results of a FH audit in NHS Medway CCG.
HEART UK are seeking to work with CCGs to implement FH Primary Care Audit programmes similar to Medway based on a two phased approach.

**Phase 1:** Implementing the FH audit tool (or similar) into GP’s IT systems

**Phase 2:** To provide training to Healthcare professionals within the CCG to diagnosis FH and support implementation of FH Nurse Advisor Clinics.

The figure below is based on a CCG implementing a two phased approach similar to the Medway pilot for a 12 month period.

**Figure 2: Possible increase in number of people diagnosed with FH in 12 months.**

By working with CCGs, HEART UK aim to deliver measureable improvements in diagnosis of FH, measureable improvements in management of FH, continued long-term detection of FH in primary care, quality healthcare in accordance with government policy and clinical guidance and a reduction in heart disease — saving lives.

**What are the numbers?**

- **226,000** Patient population of an average sized CCG
- **450-1200** The estimated number of FH patients in an average sized CCG
- **100-280** The estimated number of children <18 years with FH in an average sized CCG
- **40,000** The possible number of new FH patients diagnosed and managed in 12 months if every CCG in England implemented a FH Primary Care Audit Programme

**HOW TO I BECOME INVOLVED?**

If you are a commissioner, GP, nurse, or other Healthcare Professional (HCP) please contact Simon Williams (sw@heartuk.org.uk), who can provide projected numbers for your CCG or area, an outline project proposal and discuss the next steps to develop a programme in your area. If you are a member of the public or an FH patient interested in the project – please contact Simon to discuss how you might be able to support improving diagnosis of FH.
ROLLING OUT MEDWAY - FREQUENTLY ASKED QUESTIONS

Who can I contact for further details?
For any queries about the project please contact Simon Williams, Communications and Policy Director at HEART UK (sw@heartuk.org.uk)

Does HEART UK have an outline proposal to help with preliminary discussions within my CCG?
HEART UK have developed - ‘How can Clinical Commissioning Groups improve diagnosis of familial hypercholesterolaemia?’ which provides CCGs with a project outline to improve diagnosis and management of FH within a CCG based on the Medway FH Audit and FH Nurse Advisor Clinic. The booklet provides information about the importance and benefits of diagnosing and managing FH; the impact of improving diagnosis; and background information about the Medway FH Audit to inform and support discussions within the CCG and with HEART UK. The booklet is available upon request from HEART UK - please contact Simon Williams (sw@heartuk.org.uk).

Who will oversee the project?
The FH Primary Care Audit (FHPA) working party was formed in 2015 to support HEART UK establish the Medway model in other CCGs throughout England. Members of this group will form a steering committee at launch of the first project. A key individual from within the CCG will be invited to participate in this group. This committee is responsible for defining the outline of the project, implementing the project, approving documentation and ensuring outcomes measures are provided and communicated.

What are a CCGs commitments?
The overarching commitment is to improve care for FH patients, to address under diagnosis of this patient group and to prevent heart disease.

Participating CCGs would agree and deliver pre-defined milestones and targets, agree and deliver outcomes data at pre-defined time-points and agree to work with the steering committee to communicate outcomes.

In addition the CCG would support GPs and practice nurses to;

- Participate in the project and run the audit on their clinical systems
- Participate in training to recognise and diagnosis FH
- Conduct clinics for FH patients (initially with the support of a HEART UK nurse)

What are the measures of success?
Improving diagnosis and a reduction in lipid levels will be key measures to determine success. Outcome measurements at a CCG level will be provided at audit initiation (baseline) and the audit loop will be closed and data gathered at 3, 6, 9 and 12 month time points after establishing the baseline. Outcome measurements will include (but are not limited to);

1. Diagnosis assessment: Number and proportion of patients in population diagnosed with FH.
2. Screening assessment: All patients at risk of FH (screened and unscreened).
**How will the results of any project be communicated?**

HEART UK suggests that core outcomes of this programme should include communications at national and international conferences, a HEART UK annual report and peer reviewed publications.

**What are the benefits to my practice?**

We know that GPs face a challenge to identify patients who may have an underlying inherited lipid disorder. A diagnosis is often overlooked in routine care and an opportunity for early and effective intervention is missed. The FH audit tool is designed to provide GPs with a tool to help identify FH patients and enhance clinical care. These patients already have a documented elevated lipid level in your clinical systems—we are providing a tool to flag these patients for assessment. By identifying and diagnosing FH patients you are providing your patients with an optimum standard of care, without which they are at a high risk of having a cardiovascular event.

**What are the benefits to my patients?**

Appropriate diagnosis and management of FH would lead to a reduction in the risk of cardiovascular events for your patient and their family members. FH confers a high risk of cardiovascular disease. Untreated the lifelong elevated lipid level means leads to a greater than 50% risk of coronary heart disease by age 50 in men and a 30% risk of CHD in women by aged 60. FH is a preventable cause of CHD. Effective treatments for FH include lifestyle modification, including dietary fat restriction, exercise and avoidance of smoking, and lipid-lowering treatments such as HMG CoA (hydroxymethylglutaryl co-enzyme A) reductase inhibitors (i.e. statins). Statins are an effective therapy and clinical trials have shown CHD risk reductions of up to 80% compared with that of the general population, especially if treatment is initiated prior to the onset of CHD. The early onset of atherosclerosis caused by lifelong exposure to elevated LDL-C highlights the importance of early identification and effective therapeutic intervention.

**What are the benefits to my CCG?**

A FH audit will support your CCG to deliver high quality, consistent care for FH patients and improved health outcomes. The FH Audit Tool supports efficient and effective use of information and resources and will lead to better skilled personnel. More FH patients will be diagnosed, treated and managed appropriately thereby preventing cardiovascular disease and events. In addition implementing an FH audit within your CCG will support you to achieve national guidance’s and quality standards.

**What is the workload for my practice?**

Based on the Medway study, a practice with about 10,000 registered patients would initially have 60 patients flagged as ‘at risk and unscreened’. These are patients with elevated levels of LDL-C that have not been screened via Simon Broome criteria. Practices can chose to assess each flagged patient at their next appointment or work with a HEART UK nurse and establish a FH clinic to systematically assess all patients flagged as ‘at risk’. After a full review, a practice of 10,000 would expect to have around 30 patients with FH (includes those already diagnosed) for treatment and management. Continuing the audit over time will flag new patients for assessment on an ongoing basis but this is likely to around fewer than 2-3 patients each month.

**Is there information available to support me to diagnose FH?**

Yes, HEART UK will provide each participating practice an ‘FH support pack’ which provides information on diagnosis via Simon Broome and Dutch lipid Network Clinic Score, patient information, support and guidance for using the FH tool and guidance for managing FH patients. At the start of the project you will also be invited to attend a seminar where you will have the opportunity to ask questions. In addition a HEART UK nurse will be available and can arrange to meet you at your practice to answer questions.

**Is my role as a GP really that important?**

Yes, GPs are well placed to lead on the identification of new index cases of FH—the majority of cholesterol measurements are requested within primary care, and GPs have access to electronic patient records that contain decades of patient data including cholesterol measurements and family history of CHD which lend themselves to simple electronic prompts and audits.
My practice isn’t that big will I really make a difference?

Yes. Every patient you identify and treat will lead to a reduction in your patient’s risk of CHD and helps identify additional family members, including children, at risk of FH. Families groups often go to the same practice and even in smaller practices there can be a cluster of FH patients from the same family.

About the FH Audit tool (BMJ software)

The FH Audit tool was developed via a collaboration between NHS Medway CCG and BMJ utilising their clinical decision support software (‘Audit +’). In 2014 the FH Audit tool was revised and the tool now includes the ability to track changes in lipid levels pre and post diagnosis for patients diagnosed with FH. The FH Audit Tool has been reviewed by the HEART UK FH Primary Care Audit (FHPCA) Working Group and validated via BMJ quality assurance processes. The new tool is being rolled out within NHS Medway CCG and over the next 12 months this revised FH tool will be tested.

The FH Audit tool is compatible with most GP patient electronic record systems, except practices using System One/TPP but we believe access to TPP will be provided shortly via the national GPSoC Framework Agreement. The FH Audit tool and software is loaded remotely, requiring no additional work for the practices or clinicians. At a practice level individual patient data can be reviewed, audits can be conducted daily (if desired) and an audit list generated. Each CCG or test bed would be provided with a centralised reporting tool (Audit Central) which extracts numerical clinical audit data from GP practices. Patient data is retained within the practice, only aggregated data is viewed in Audit Central and therefore there are no information governance concerns. Audit Central will allow outcome measurements to be assessed at pre-defined time points without adding extra burden on GP practices.

WHERE CAN I FIND MORE INFORMATION ABOUT AUDIT + AND AUDIT CENTRAL?

More information about the FH Audit tool and BMJ software can be provided and is available upon request from HEART UK.

Please also see

1. HEART UK website

2. BMJ website

Does the incorporation of Audit + and Audit central only provide my CCG/practice with the FH Audit tool?

No. In addition to the FH Audit tool, BMJ are making available an early cancer referral audit designed in partnership with Macmillan and the National CKD audit commissioned by HQIP (Healthcare Quality Improvement Partnership). Other audit tools are available and can be requested directly from BMJ.

Do I have to use the FH Audit tool from BMJ?

HEART UK would like to consider and investigate other audit software/tools to diagnose FH. If you have an in house tool or other option please discuss this with HEART UK.

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