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Quick guide for the Familial Hypercholesterolaemia quality improvement tool

Around 80-90% of familial hypercholesterolaemia (FH) cases remain undiagnosed. If left untreated, about 50% of men and 30% of women with FH will develop coronary heart disease before they are 55[1]. Early identification and effective treatment of FH patients can help to ensure normal life expectancy.

This quality improvement tool helps GP practices to case find patients who may have FH but also may be missing a coded diagnosis. The tool will also identify those at greatest risk of developing the disease (ranked in order of likelihood), so that they can be monitored or reviewed.

Additionally, any patients who are currently untreated will be highlighted for review and, through use of the tool, practices can optimise lipid lowering treatment regimes for all patients with the disease.

The FH quality improvement tool uses the CHART analysis software which presents data at both practice and patient levels. Users can quickly drill down to examine detailed patient care within a comprehensive datasheet and produce patient lists quickly and easily.

CHART also provides the ability to create mail merge lists for patient recall invitation letters and is compatible for use with all GP clinical systems.

Obtaining the FH quality improvement tool

Use of the Familial Hypercholesterolaemia tool is FREE to practices in England registered with the PRIMIS Hub service.

Join now for free at **nottingham.ac.uk/primis/joinus.aspx**

Contacting PRIMIS

Helpdesk
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The Familial Hypercholesterolaemia quality improvement tool can help practices by:

- generating a list of patients who may have FH but who do not have a coded diagnosis
- establishing a more accurate prevalence rate for FH within the practice population
- identifying patients who are at increased risk of developing FH and categorising them by level of risk (using the FAMCAT algorithm)
- highlighting patients with the disease who are currently untreated
- identifying opportunities to optimise lipid lowering treatment regimes for all patients with the disease
- providing a mail merge function to generate letters to send to high risk patients about collecting their family history
- offering a comparative analysis service via CHART Online, which enables comparison with other practices, locally or nationally
- highlighting recording rates of important family history information
- contributing to the delivery of the NHS Outcomes Framework and the Clinical Commissioning Group Outcomes Indicator Set
- providing data in a format for appraisal and revalidation and providing a method for GPs to reflect on their clinical practice practices by:

FH management - CHART dashboard summary

The FH quality improvement tool displays the results as an interactive practice level summary.

Users can quickly drill through the summary report to access detailed patient level data and pre-filtered patients lists.

Summary sheet

The summary sheet includes a range of data tables offering an instant view of practice level data:

	Diagnosed	Very High Risk	High Risk	Population Risk
BREAKDOWN OF ABOVE PATIENTS INTO RISK GROUPS	8	82	491	4149
Of whom were diagnosed inlast 12 months	2			
Of whom have been screened in last 12 months	0	2	4	17
Of whom have not been screened in last 12 months	6	80	487	4132

PATIENTS SCREENED IN LAST 12 MONTHS	Diagnosed	Very High Risk	High Risk	Population Risk
Number of patients screened/assessed in last 12 months	0	2	4	17
Screening Methods				
Of whom were assessed by Dutch Critera in last 12 months	0	0	0	0
Of whom were assessed by Simon Broome in last 12 months	0	1	0	0
Of whom had Hyperlipidaemia screen in last 12 months	0	1	4	17
Referred to Specialist or Consultant				
Of whom were referred to a Specialist/Consultant in last 12 months	0	0	1	0

LIPID LOWERING DRUGS IN LAST 6 MONTHS	Diagnosed	Very High Risk	High Risk	Population Risk
All patients	8	82	491	4149
Of whom have a contraindication to statins	0	0	1	8
Of whom are on high potency statins	4	26	170	870
Of whom are on medium potency statins	1	0	8	43
Of whom are on low potency statins	0	1	0	9
Of whom are on another lipid lowering drug	0	2	0	6
Of whom have no statin contraindication and are not on any of the above drugs	3	53	312	3213

About this quality improvement tool

The PRIMIS Familial Hypercholesterolaemia quality improvement tool was developed in collboration with the Applied Genetics and Ethnicity research group at the University of Notttingham.

This tool is based on the FAMCAT algorithm[2] developed by academics in the Applied Genetics and Ethnicity research group.

Footnotes

[1] Youngblom E, Knowles JW. Familial Hypercholesterolemia. 2014 Jan 2. In: Pagon RA, Adam MP, Ardinger HH, et al., editors. GeneReviews [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2015. Available from: http://www.ncbi.nlm.nih.gov/books/NBK174884/ Accessed January 6th, 2017

2Weng SF, Kai J, Neil HA, Humphries SE, Qureshi N. Improving identification of familial hypercholesterolaemia in primary care: Derivation and validation of the familial hypercholesterolaemia case ascertainment tool (FAMCAT). Atherosclerosis 2015; 238(2):336-43 doi:10.1016/j.atherosclerosis.2014.12.034.

PRIMIS' development of this tool was part supported by independent funding from Amgen.

PRIMIS quality improvement tools are designed to signpost practices to patients who may be of interest and/or concern and not to replace clinical decision making.

The FH quality improvement tool works with CHART and CHART Online.

Five key actions following use of the FH tool

Review any patients at very high risk of developing FH who have not had recent screening

Click through the summary sheet to access this patient list. The inbuilt mail merge function can also assist with generating invitation letters.

Review any patients with FH who have not had recent screening

Patients with a coded diagnosis of FH who have not had screening in the last 12 months may also benefit from review to ensure they are on the best treatment.

Improve recording of important family history information through systematic collection

Patients classified as being at high risk of FH who do not have a family history recorded should be encouraged to collect systematic family history. High risk patients may well become very high risk once an accurate family history has been recorded (and this is positive). The mail merge function can assist with generating letters to send to these high risk patients about collecting their family history.

Assess current treatment regimes

Review the type and dosage of lipid lowering therapy for patients who are diagnosed with FH. If diagnosed patients are not currently being treated (and are not contraindicated), consider commencement of lipid lowering medication.

Review coding standards within the practice

Use the information provided with the report to assess the accuracy of coding, particularly in relation to confirming FH diagnoses, drug allergies and contraindications and important family history codes. Consider the reasons why any data items are missing and how to prevent recurrence for other patients.