



AHSN North East and North Cumbria

Primary Care Lipid Lowering and Familial Hypercholesterolaemia (FH)

Standard Operating Procedure (SOP)



Policies and Procedures Referenced in this Document

- NEELI (Northern England Evaluation and Lipid Intensification) guidelines: <https://ntag.nhs.uk/wp-content/uploads/2022/09/NEELI-edit-v2022.2-FINAL-NTAG.pdf>
- NICE CG181, NICE TA393, NICE TA394, NICE TA733, NICE TA805
NICE CG181 <https://www.nice.org.uk/guidance/cg181>
Alirocumab (Praluent) <https://www.nice.org.uk/guidance/ta393>
Evolocumab (Repatha) <https://www.nice.org.uk/guidance/ta394>
Inclisiran <https://www.nice.org.uk/guidance/ta733>
Icosapant ethyl (Vazkepa) <https://www.nice.org.uk/guidance/ta805>
- AAC National Pathway – <https://www.england.nhs.uk/aac/wp-content/uploads/sites/50/2020/04/Summary-of-national-guidance-for-lipid-management-for-primary-and-secondary-prevention-of-cardiovascular-disea.pdf>

Introduction

Cardiovascular Disease (CVD) is a major burden of ill-health in England, second only to all cancers. In the North East and North Cumbria area, CVD accounts for 24% of all deaths and 15% of all disability adjusted life years (DALYs)¹

The NHS and Public Health England (PHE) have identified the prevention of cardiovascular disease as a major national priority and produced a set of joint ambitions for the next ten years, aiming to prevent ill-health and to reduce the health inequalities associated with CVD². The PCN contract Directed Enhanced Service (DES) 2022/23 aims to reduce the impact of the A, B, Cs of CVD (atrial fibrillation, high blood pressure/hypertension and cholesterol). From April 2022, reduction of CVD risk via lipid modification and detection of FH will be incentivised³. In addition new lipid lowering drugs are available for some patients requiring lipid lowering optimisation.

A NHS England nationally mandated FH and lipid optimising programme is currently being led by the Academic Health Science Network (AHSN). The NHS Long Term Plan has a target to identify 25% of people with FH by 2025.

The key lipid-related interventions to reduce CVD risk are:

- Offer a CVD risk assessment patients who are likely to be at (as yet undetected) high risk of CVD;
- Offer lipid-lowering medication to eligible patients;
- Ensure patients prescribed lipid lowering medications are taking them;

¹ <https://www.gov.uk/government/publications/cardiovascular-disease-prevention-state-of-the-north-east-2019>

² <https://www.england.nhs.uk/ourwork/clinical-policy/cvd/>

³ <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0951-iv-network-contract-des-guidance-21-22-update.pdf>

- Ensure patients taking lipid-lowering medication have achieved the target reduction in cholesterol levels. For every 1mmol/L reduction in LDL-C there is a 24% reduction in major coronary events⁴
- Identify and manage patients with FH.

This work might be done by practice clinicians, practice or PCN pharmacists or lipid specialist nurses.

Refer to NEELI Guidelines for clinical management: <https://ntag.nhs.uk/wp-content/uploads/2022/09/NEELI-edit-v2022.2-FINAL-NTAG.pdf>

Further advice is available from your local secondary care lipid clinic, details of which are at the back of the NEELI Guidelines.

The purpose of this document is to support practices to deliver appropriate lipid-lowering treatment and to identify and manage FH. There is also an associated Handbook which contains further detail about the programme.

1. If using an external HCP - Identifying patients to review by gaining access to General Practice systems

- 1.1 If an external HCP is working on the practices' behalf then contact needs to be made with the Information Governance Lead in each practice to seek permission to access the primary care electronic patient record (ePR). The work can be done remotely. See Appendix 4 for practice checklist.
- 1.2 An honorary contract between the practice and the HCP will be needed. The HCP will require NHS smartcard controlled access to the ePR for the duration of the work.
- 1.3 The scope of the external HCP should be agreed prior to any work starting. For example, the practice may wish the external HCP to case finding and suggest a management plan for an internal staff member to take forward.
- 1.4 The external HCP should discuss the process and meet practice staff as appropriate. It would normally be intended for the external HCP to case find, speak to the patients who meet the search criteria and optimise lipid management on a shared decision basis (between HCP and patient), if appropriate. Optimisation may involve amendment to oral lipid lowering therapy or referral to secondary care for genetic testing for FH identification or PCSK9 inhibitor therapy.
- 1.5 All contact with patients should be recorded as consultations in the primary care ePR.
- 1.6 The external HCP should document a plan in the ePR, including a **target non-HDL cholesterol**, and any steps suggested should that target not be achieved. If the external HCP is a prescribing pharmacist they should be able to prescribe amendments and issue prescriptions where appropriate. However, local agreement with the practice should cover the level of communication required

⁴ Cholesterol Treatment Trialists' (CTT) Collaboration Efficacy and safety of more intensive lowering of LDL cholesterol: a meta-analysis of data from 170 000 participants in 26 randomised trials. *Lancet*. 2010;**376**:1670–1681

between prescribing pharmacist and practice staff and discuss which systems are in place for this process. This will include at least the following points:

- Does the patient's GP wish to know the outcome of each consultation in the form of a 'task'?
- What is the process for amending the repeat prescription template?
- Does a practice prescriber wish to issue a prescription, if required?
- What is the process for booking an appointment for blood tests?
- What is the process for reviewing blood tests?
- What is the process for scheduling an on-going review?

1.7 The practice or PCN may wish to consider appointing a 'Lipid Champion' to drive the work.

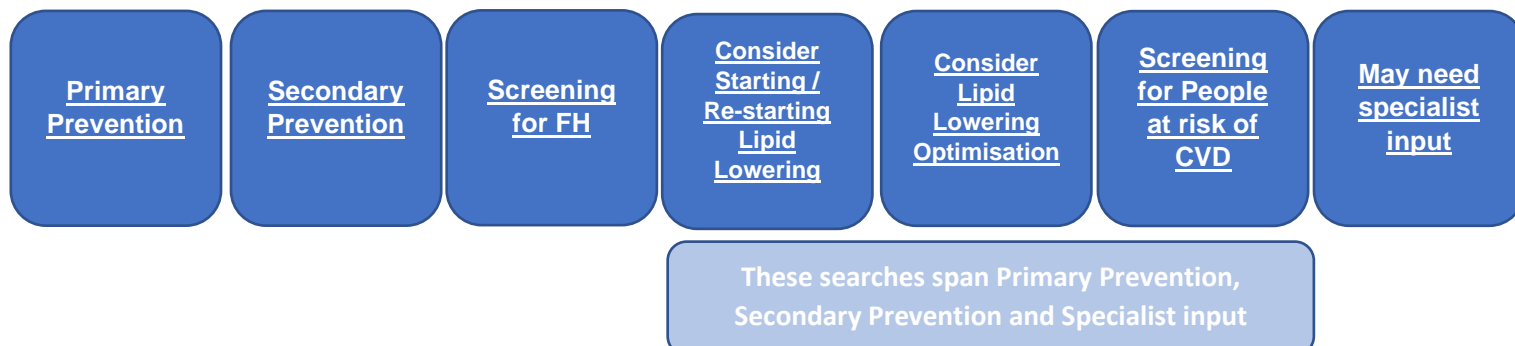
2. Resources To Support Lipid Management

The following approaches can be used to improve lipid management:

- A suite of searches to systematically identify patients who need review/ assessment/ intervention can be used. This approach is ideally undertaken by someone with dedicated time for the work. In SystmOne, an added possibility is the ability to automate the searches so the relevant clinician(s) are sent notifications at appropriate time intervals.
- A series of LTC templates which prompt users to consider lipid optimisation.
- A series of optional protocols and alerts which prompt lipid optimisation interventions in real time e.g. to prompt the recording of target non-HDL-C when starting lipid lowering, to flag patients who might benefit from lipid-lowering.
- Tools to improve QoF performance and payments.

3. Systematic Searches To Identify Patients For Intervention

3.1 A suite of searches for SystmOne and EMIS, created by the [Clinical Digital Resource Collaborative \(CDRC\)](#), can be used to identify patients to review with regards to optimisation of treatment and the identification of possible FH. CDRC's searches are organised into groups to allow for manageable numbers of patients depending on the level of resource you have available, as shown below.



3.2 Please contact - contact-CDRC@ahsn-nenc.org.uk to register your interest, and if you need help with searches/ templates.

3.2 a) **SystemOne:**

To access CDRC SystemOne resources, please follow the step-by-step instructions on the CDRC website, [found here.](#)

[Please click here to access the CDRC SystemOne Lipid Management resource guide.](#)

3.2 b) **EMIS:**

CDRC's EMIS Lipid Management searches are freely accessible and will need to be downloaded and imported into your EMIS system.

[Please click here to access the CDRC EMIS Lipid Management Searches and resource guide.](#)

3.3 CDRC's Lipid Management Searches

As mentioned CDRC's Lipid Management searches have been organised into manageable groups. Information on all available searches and resources can be found by clicking on the weblinks above. if you are reading this document on a hard copy, this information is found at <https://cdrc.nhs.uk/support-faqs/>

As this resource will be used primarily by those in Primary Prevention and Secondary Prevention, the relevant searches will be listed below.

3.3 a) **Primary Prevention:**

Search Name	Patients Returned
? Lipids 6.1 Primary Prevention – Possible poor lipid lowering therapy concordance	Patients with repeat lipid lowering therapy who have not been issued a prescription in the last 3 months
? Lipids 6.2 Primary Prevention – Consider starting lipid lowering	Patients who appear eligible for lipid lowering for primary or secondary prevention who don't have a recorded reason why not.
? Lipids 6.3 Primary Prevention – Consider setting lipid target	Patients with repeat lipid lowering therapy who do not have a lipid target
? Lipids 6.4 Primary Prevention – Lipid target set but not achieved	Patients with a lipid target which has not been achieved
? Lipids 6.5 Primary Prevention – On low/mod LLT – Consider LLT Intensification	Patients on moderate or low potency lipid lowering without a documented reason. There is a subset search limited to people with manifest ASCVD only.
? Lipids 6.51 Primary Prevention – On low/mod LLT – Consider LLT Intensification (unless target already achieved)	As for 6.5 but excludes patients who have reached their target cholesterol There is a subset search limited to people with manifest ASCVD only

3.3 b) Secondary Prevention:

Search Name	Patients Returned
? Lipids 7.1 Secondary Prevention – Possible poor lipid lowering therapy concordance	Patients with repeat lipid lowering therapy who have not been issued a prescription in the last 3 months
? Lipids 7.2 Secondary Prevention – Consider starting lipid lowering	Patients who appear eligible for lipid lowering for primary or secondary prevention who don't have a recorded reason why not.
? Lipids 7.3 Secondary Prevention – Consider setting lipid target	Patients with repeat lipid lowering therapy who do not have a lipid target
? Lipids 7.4 Secondary Prevention – Lipid target set but not achieved	Patients with a lipid target which has not been achieved
? Lipids 7.5 Secondary Prevention – On low/mod LLT – Consider LLT Intensification	Patients on moderate or low potency lipid lowering without a documented reason. There is a subset search limited to people with manifest ASCVD only.
? Lipids 7.51 Secondary Prevention – On low/mod LLT – Consider LLT Intensification (unless target already achieved)	As for 7.5 but excludes patients who have reached their target cholesterol There is a subset search limited to people with manifest ASCVD only
? Lipids 7.6 Secondary Prevention – Consider intensification to very high intensity lipid lowering	Patients eligible for secondary prevention who are not on very high intensity lipid lowering
? Lipids 7.61 Secondary Prevention – Consider intensification to very high intensity lipid lowering (unless already achieved)	As 7.6 but excluding patients who have reached their target cholesterol
? Lipids 7.7 Secondary Prevention – Consider intensification – ASCVD and LDL >2.6	Patients with established atherosclerotic ASCVD with nonHDL C unless they have achieved a stated target
? Lipids 7.71 Secondary Prevention – Consider intensification – ASCVD and LDL >2.6 (unless target nonHDL already achieved)	As 7.7 but excludes patients who have a lipid target and achieved this target.
? Lipids 7.72 Secondary Prevention – Consider intensification – ASCVD and LDL >2.6 (target nonHDL set and already achieved)	As 7.7 but includes patients who have a lipid target and achieved this target.

3.3 c) Familial Hypercholesterolaemia:

For Advice & Guidance please email: nuth.fhservicereferrals@nhs.net

Search Name	Patients Returned
? Lipids 2.0 Case Finding - Consider screening for familial hypercholesterolaemia	Patients who should be screened for FH; may likely have a secondary cause of hyperlipidaemia; may be appropriate to consider genetic testing
? Lipids 2.01 Case Finding - Consider screening for familial hypercholesterolaemia (also eligible for IIF FH Referral)	

<p>? Lipids 2.02 Case Finding - Consider screening for familial hypercholesterolaemia – highest risk patients</p> <p>? Lipids 2.1 Case Finding – Eligible for IIF FH referral but FH less likely</p> <p>? Lipids 2.2 Case Finding – Code for FH but not genetic code – consider need for genetic testing</p>	
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3.3 d) PCSK9i

Search Name	Patients Returned
<p>? Lipids 5.1 Management - Consider lipid lowering - May need more detailed input</p> <p>? Lipids 5.2 Management - Referral criteria for PCSK9i but poor concordance with current treatment</p> <p>? Lipids 5.3 Management - Referral Criteria for PCSK9i - Consider primary care intensification</p> <p>? Lipids 5.4 Management - Referral Criteria for PCSK9i - Consider referral</p>	<p>People who may need specialist lipid input such as requiring PCSK9i or potential contra-indication regarding statin therapy</p>

3.3 e) Inclisiran

Search Name	Patients Returned
<p>? Lipids 5.1 Management - Consider lipid lowering - May need more detailed input</p> <p>? Lipids 5.31 Management - Referral criteria for PCSK9i but poor concordance with current treatment</p> <p>? Lipids 5.32 Management - Referral Criteria for PCSK9i - Consider primary care intensification</p> <p>? Lipids 5.33 Management - Referral Criteria for PCSK9i - Consider referral</p>	<p>People who may be eligible for Inclisiran or have a potential contra-indication regarding statin therapy</p>

Initiating Inclisiran

Eligibility: fasting lipids LDLc >2.6. Inclisiran is not licensed for TCI and TIA as those patient groups were not included in the trials.

Counselling Points to raise: new to the market, promising results in trials for reducing cholesterol by up to 50%, lack of long-term data, common side effect injection site reaction, s/c injection twice yearly. Provide patient information leaflet (PIL) - obtained from Novartis. Send in the post if telephone consultation. Can also be sent via AccuRx if appropriate.

If the patient wishes to receive Inclisiran then it must be documented that the patient is aware that there is no long term outcome or safety data but we know that Inclisiran lowers cholesterol and therefore ought to significantly reduce the risk of heart attack or stroke. We do not expect any long term side effects because of its mode of action but to watch out for minor reactions at the injection site.

Inclisiran should be added onto the EMIS or SystmOne current medicine record under 'Automatic'

Dosage frequency: dose 1 at time 0, dose 2 at 3 months, dose 3 at 9 months and 6 monthly thereafter. It should be given subcutaneously preferably into the abdomen, though the thigh and upper arm are suitable alternative sites. Refer to SPC data sheet for further prescribing information. Practice nurse to administer and book next appointment at that contact. The prescription should be generated and passed onto a prescriber for signing. This should be submitted at the end of each month to the NHSBSA on a FP34(c) form in order to claim payment. The injection should be acquired from AAH at a cost of £45 for reimbursement of £55. At subsequent dose appointments, nurse to take repeat bloods at the same time.

The code 'Inclisiran indicated' should be used to provide a due diary/recall date for the next dose.

Housebound patients will require district/community nurse input for fasting blood tests and administration.

Long-term data for Inclisiran will be reported in ORION-4, expected in 2026/27.

ORION-4 is underway in approximately 15,000 ASCVD subjects, to measure the benefit of Inclisiran on cardiovascular outcomes. www.orion4trial.org/homepage-uk

3.4 LTC Templates

A suite of optional templates are available to embed lipid management into routine LTC review. This allows lipid modification work to be undertaken gradually over a longer period in a more sustainable fashion (link will be made available when ready).

3.5 Protocols and Alerts

Details of the available optional protocols and alerts can be found here – (link will be made available when ready). The practice needs to request activation of these resources, and once activated, the practice can decide which of the resources to use locally and which to disable.

Vazkepa:

This drug is available for Primary Care to prescribe in line with [NICE TA805](#)
For more information, please refer to [NICE TA805](#), [HEART UK](#) and the [NEELI guidelines](#).

4. Stratifying the list

4.1 Our suggested approach is to prioritise patients with the highest recent non HDL-C value.

5. Initial review for lipid optimising

5.1 From the patient list created in the primary and secondary prevention searches above, please clarify their highest non-HDL-c value and current non-HDL-c value. For more information look at the NEELI Guidelines. Once you have both values, then look for the other items below:

5.1.1 Past Medical History

This will inform as to any possible secondary causes e.g. uncontrolled diabetes mellitus, untreated hypothyroidism, chronic renal failure, nephrotic syndrome, cholestasis, hypopituitarism, anorexia, hypertension, mental illness. Please check, renal function, liver function, thyroid function, urine protein/ albumin and HbA1c. Please ensure any secondary causes are treated as this may impact lipid level. Clarify if for primary prevention or secondary prevention.

5.1.2 Treatment targets

Not for FH genetic testing

If for primary prevention target equals 40% reduction in highest non-HDL-C i.e. non-HDL-c $\times 0.6$ = target. If for secondary prevention, target equals non-HDL-C less than or equal to 2.5mmol/L.

For FH genetic testing

If for primary prevention, target equals 50% reduction in highest LDL-C i.e. LDL-C $\times 0.5$ = target. If for secondary prevention, target equals non-HDL-C less than or equal to 2.5mmol/L.

5.1.3 Medication

Compliance/ side effects with medication reviewed along with a check for other medication which can cause a secondary hyperlipidaemia e.g. anticonvulsants, antipsychotics, steroids, cyclosporin, anti-retrovirals, retinoids. Please follow Summary of National Guidance from NEELI Guidelines for lipid optimisation.

Ezetimibe adds high intensity statin options

Dose (mg/day)	Reduction in LDL cholesterol				
	5	10	20	40	80
Fluvastatin	–	–	21%	27%	33%
Pravastatin	–	20%	24%	29%	–
Simvastatin	–	27%	32%	37%	42%*
Atorvastatin	–	37%	43%	49%	55%
Rosuvastatin	38%	43%	48%	53%	–
Atorvastatin +ezetimibe	–	52%	54%	57%	61%

20%–30%: low intensity
31%–40%: medium intensity
Above 40%: high intensity

Ezetimibe when combined with any statin is likely to give greater reduction in non-HDL-C/LDL-C than doubling the dose of the statin.

LDL=low-density lipoprotein.
 *MHRA advice: there is an increased risk of myopathy with high-dose (80 mg) simvastatin. This dose should be considered only in people with severe hypercholesterolaemia and high risk of cardiovascular complications who have not achieved their treatment goals on lower doses, when benefits are expected to outweigh potential risks.

D10

If patient are statin intolerant refer to NEELI guideline statin intolerance (<https://ntag.nhs.uk/wp-content/uploads/2022/09/NEELI-edit-v2022.2-FINAL-NTAG.pdf>) and discuss what has been tried.

5.1.4 Social History

Other risk factors which could be highlighted to patient e.g. alcohol excess, smoking. This should be addressed as part of all vascular risk reduction.

6. Initial review for suspected FH

Screening for FH needs some knowledge to help look for secondary causes of hyperlipidaemia which might look similar to FH. Follow local lipid procedures according to your local lipid service. At the moment, this is likely to be through Advice and Guidance.

You might want to consider using the form in Appendix 2 following the notes in 6.1 – 6.2, below.

6.1 From the list created in the search above (? Lipids 2.0 – 2.2), please clarify their highest LDL-C value (please note, this may need to be calculated using The Friedewald's equation which can be found on MDCalc www.mdcalc.com/ldl-calculated). Please note, triglycerides must be less than 2.3 for consideration for FH. For more information look at the NEELI Guidelines.

Once you have the highest LDL-C value, look for the other items below:

6.1.1 Past Medical History

This will inform as to any possible secondary causes e.g. uncontrolled diabetes mellitus, untreated hypothyroidism, chronic renal failure, nephrotic syndrome, cholestasis, hypopituitarism, anorexia, hypertension, mental illness. Please ensure any secondary causes are treated as this may impact lipid level.

6.1.2 Medication

Compliance/ side effects with medication reviewed along with a check for other medication which can cause a secondary hyperlipidaemia e.g. anticonvulsants, antipsychotics, steroids, cyclosporin, anti-retrovirals, retinoids. Please include start/ stop dates for lipid lowering therapy to determine if the lipid result is on, or off, treatment.

6.1.3 Previous Blood Results

To include pattern of lipids (recent or long term change), renal function, liver function, thyroid function, urine protein/ albumin and HbA1c.

6.1.4 Social History

Other risk factors which could be highlighted to patient e.g. alcohol excess and smoking.

6.1.5 Physical Signs Recorded

Elevated BMI (signposting to exercise opportunities), **documented premature corneal arcus (<45yrs) or documented tendon xanthoma.**

6.1.6 Family History

Check if a family history of premature MI, CABG, PCI or definite coronary artery disease on coronary angiogram (<60yrs in a first degree or <50yrs in a second degree relative) is documented. Please document details of family history (who, what and when).

6.2 Should the patient fulfil either of the criteria (has to be over 18, and if under 18, see paediatric guidelines in NEELI) highlighted in bold in 4.1.5 or 4.1.6 AND have a lipid profile with triglycerides <2.3 and Total Cholesterol >7.5mmol/L, non-HDL-C >5.9, complete the Northern Genetics Service Familial Hypercholesterolaemia DNA Analysis Request Form (Appendix 2). The greyed section **C. Physical Examination*** is not necessary to complete in primary care.

6.3 Whilst the patient is waiting for an FH test, follow section 5 and optimise patient's lipids.

6.4 Any patients who have a genetic diagnosis of FH need to be referred to the Northern Genetics Service using the form in Appendix 3 – Referral of patients with definite familial hypercholesterolaemia (FH) to the genetic cascade clinic.

7. Contacting patients

7.1 Patients will be contacted in the normal way for each practice.

7.2 Signpost the patient to extra information on HEART UK, British Heart Foundation (BHF) and NHS choices website. Some useful resources are listed below:

If for FH genetic testing:

- Demystifying FH genetics video for patients produced by AHSN NENC in collaboration with HEART UK and Northern Genetics Service:
<https://www.youtube.com/watch?v=BShTduBO-F0>
- Familial Hypercholesterolaemia Booklet from Heart UK which can be downloaded here: <https://www.heartuk.org.uk/literature/booklets>

If for lipid optimisation only:

<https://www.heartuk.org.uk/cholesterol/overview> covers what is cholesterol, having high cholesterol and information about results and tests. There is also a section on diet and exercise.

8. Recording consultation

8.1 Record each patient contact as a consultation on EMIS or SystmOne.

8.2 Follow local process for requesting bloods and a prescription if required. This step should be agreed, and in accordance, with the local practice.

8.3 Code patients using:

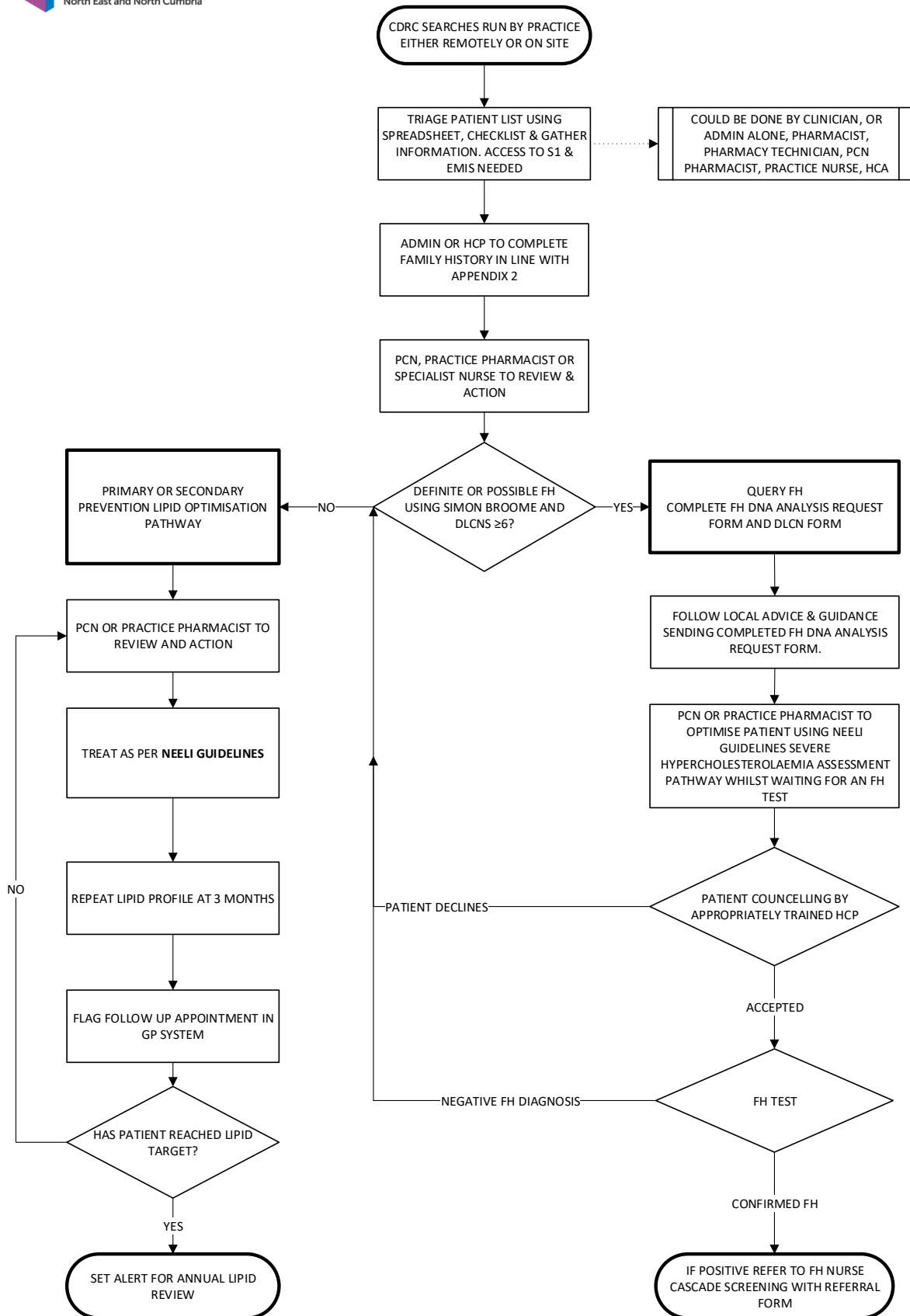
Item	SNOMED
Referral	
Referral for assessment for familial hypercholesterolaemia (FH)	1326191000000103
Seen in lipid clinic	185177002
Testing	
FH comprehensive genetic test (index patient)	925221000000106 – currently not available in EMIS
FH targeted genetic test (relative of index patient/ cascade)	925221000000100 – currently not available in EMIS
Results - outcome	
FH comprehensive genetic test result (index patient)	163841000237109
FH targeted genetic test result (relative of index patient/ cascade)	163841000237107
Results – genetic result	
Apolipoprotein B gene mutation positive	204871000237101
Proprotein convertase subtilisin/ kexin type 9 gene mutation positive	204881000237104

Low density Lipoprotein receptor gene mutation positive	204891000237102
Apolipoprotein E gene mutation positive	204901000237101
Genetic variant causing familial hypercholesterolaemia not detected	204931000237105
Genetic variant of uncertain significance (VUS) detected	204921000237108
Clinical diagnosis	
Heterozygous FH	238079002
Homozygous FH	238078005
Polygenic hypercholesterolaemia	238077000
Pure hypercholesterolaemia	267432004
Familial combined hyperlipidaemia	238040008
Lipoprotein (a) hyperlipoproteinaemia (disorder)	Unavailable at present
Familial type 3 hyperlipoproteinaemia	398796005

Appendix 1



FH & LIPID OPTIMISATION PROCESS MAP



Appendix 2

FAMILIAL HYPERCHOLESTEROLAEMIA DNA ANALYSIS REQUEST FORM

Completion of this form is required as a prerequisite to molecular analysis

Patient Surname:		Forename:		Requested by:	
				Reference No: XYZ/000	
Date of birth dd/mm/yyyy:/...../.....	Male/ Female		Patient postcode:	
NHS Number:		Sample Collection Date:...../...../..... dd/mm/yyyy			
Family file number:	Ethnic origin:		Consent Obtained Testing <input type="checkbox"/> Yes <input type="checkbox"/> No Storage <input type="checkbox"/> Yes <input type="checkbox"/> No		
PROBAND WITH UNKNOWN MUTATION					
Dutch Lipid Clinics Network Score					
<u>A. Family History</u>					
Enter Number of relatives at 50% risk:		<input type="text"/>		Number of relatives at 25% risk	
I.	First degree relative with premature CHD and/or CVD*	<input type="checkbox"/> Yes <input type="checkbox"/> No		0	
II.	First degree relative with LDL cholesterol >5.5	<input type="checkbox"/> Yes <input type="checkbox"/> No		0	
III.	First degree relative with xanthoma or corneal arcus	<input type="checkbox"/> Yes <input type="checkbox"/> No		0	
IV.	First degree relative age <18 with LDL cholesterol >3.9	<input type="checkbox"/> Yes <input type="checkbox"/> No		0	
*Premature CHD and/or CVD in men <55 years, women <60 years					
<u>B. Personal History</u>					
I.	History of premature CHD (M <55, F <60)	<input type="checkbox"/> Yes <input type="checkbox"/> No		0	
II.	History of premature PAD or CEVD	<input type="checkbox"/> Yes <input type="checkbox"/> No		0	
<u>C. Physical Examination* (Not required in Primary Care)</u>					
I.	Tendon xanthomas (TX1 - 2pts; TX2 - 4pts; TX3 - 6pts)	<input type="checkbox"/> Yes <input type="checkbox"/> No		6	
II.	Premature corneal arcus (<45 years)	<input type="checkbox"/> Yes <input type="checkbox"/> No		4	
<u>D. Fasting LDL cholesterol with triglycerides <2.3**</u>					
**LDL cholesterol for calculation of the score is highest without drug treatment.					
I.	LDL cholesterol >8.5	<input type="checkbox"/> Yes <input type="checkbox"/> No		8	
II.	LDL cholesterol 6.5 – 8.4	<input type="checkbox"/> Yes <input type="checkbox"/> No		5	
III.	LDL cholesterol 5.0 – 6.4	<input type="checkbox"/> Yes <input type="checkbox"/> No		3	
IV.	LDL cholesterol 4.0 – 4.9	<input type="checkbox"/> Yes <input type="checkbox"/> No		1	
Add HIGHEST score from each of domains A + B + C + D =				Total	
Genetic studies can be ordered with a score of >6. (index cases >18 years only)					
Enter fasting lipid profile results used for diagnosis/DLCN Score Date:...../...../.....					
Total cholesterol (mmol/L)				HDL-cholesterol (mmol/L)	
Triglycerides (fasting) (mmol/L)				LDL-cholesterol (mmol/L)	
Lipoprotein(a) (mg/L <input type="checkbox"/> nmol/L <input type="checkbox"/>				Age at diagnosis (years)	

Additional Information

Appendix 3

The Newcastle upon Tyne Hospitals 

NHS Foundation Trust

REFERRAL OF PATIENTS WITH DEFINITE FAMILIAL HYPERCHOLESTEROLAEMIA
(FH) TO THE GENETIC CASCADE CLINIC

Date	
Referring GP	
Sign	
Address	
Post Code	
Telephone Number	

Patient name		
Address		
Post code		
Telephone number	Home	Mobile
DOB	Age	
NHS No		

BIOCHEMICAL RESULTS MUST ACCOMPANY THIS REFERRAL

Highest total cholesterol / LDL known to patient (pre-treated if available)		
Date	Total cholesterol	HDL
	Triglycerides	LDL
Most recent lipid profile		
Date	Total cholesterol	HDL
	Triglycerides	LDL

Is this patient currently taking any medication? Please list below.	
Medication	Dose
Past Medical history	

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Height		cm
Weight		kg
BMI		
Alcohol intake		(units per week)
Smoking status		

Relevant family history (CVD PVD CVA)

Familial Hypercholesterolaemia Service
 Institute of Genetic Medicine
 International Centre for Life
 Central Parkway
 Newcastle upon Tyne
 NE1 3BZ
 Tel: 0191 241 8658
nuth.fhserVICereferrals@nhs.net

Appendix 4

Lipid optimisation practice checklist for use with external HCP supporting the work.

Action by Lipid optimisation Pharmacist	Yes/ No
Information Governance form signed	Y/N
Access to EMIS/ SystmOne authorised	Y/N
SMART card synchronised	Y/N
Access to ICE via practice - form signed	Y/N
<u>Prescribing Pharmacist to:</u> Code patients using pre-agreed codes (clarified with GP practice)	Y/N Other:
Amend the repeat prescription template	Y/N
Issue the prescriptions	Y/N Other:
Send task to patient's GP to inform of outcome of each consultation	Y/N Other:
Book appointment for bloods Order bloods for Practice appointment	Y/N Y/N Other:
Task to GP to review bloods	Y/N Other:
Task to GP to schedule annual review	Y/N Other:

Agreed with:

Practice manager Date.....

Lead GP Date.....

Pharmacist..... Date.....

Appendix 5: AHSN NENC CVD FACTS team and contacts



Find Assess Correct Treat Sustain (FACTS) CVD is part of the Academic Health Science Network (AHSN) for the North East and Cumbria's CVD Prevention Programme. The programme encompasses the NHS England nationally mandated FH and lipid optimising work. The NHS Long Term Plan has a target to identify 25% of people with FH by 2025, and from April 2022, detection and management of cholesterol in the context of CVD risk, including FH, better management of cholesterol will be required as part of the PCN directed enhanced service 2022/23.

This SOP is designed to support practices to identify patients with FH, and those who could benefit from lipid optimisation, to reduce the risk of future vascular disease in the NENC population.

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