

The role of the FH Nurse

Lorna Ingoe

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Background

Familial Hypercholesterolaemia [FH] Cascade Service

- Started in 2015
- Housed within Northern Genetics Service at Centre for Life

FH Team:-

- Consists of two full time nurses, Aimee Potter and Susan Musson and Lorna Ingoe who is lead for primary care project and part time.
- Part time administrator Diane Castledine

Referral to Service

- Patients referred from Lipid clinics across North East and Cumbria
- Nurse led Adult clinics in South Tees, North Tees, Morpeth, Hexham, Bishop Auckland, Cumberland infirmary, West Cumberland infirmary, Queen Elizabeth hospital, RVI, Centre for life and Sunderland.
- Paediatric clinics in Sunderland Royal, South Tees, Cumbria and Great North Children's hospital

Clinics

Consist of:

- Meeting the index / Proband to identify family members at risk of FH by completing a family tree
- Indirect contact using reply slips or Direct contact made
- If out of area, information sent to facilitate testing in other FH services around the country.
- Appointment consists of, counselling for DNA test, consent, information about how this can affect insurance and job opportunity's.
- Bloods tests;- Lipid profile, Lipoprotein(a) if raised in the family and DNA analysis.
- Buccal mouth swabs in children or if needle phobic

Post Clinic

- Results take 4-6 weeks and test costs about £70
- Results given via telephone
- GP informed and post clinic letter sent with results and copy of DNA report
- Referred to Lipid clinic or Paediatric clinic if positive result
- Entry onto PASS which is a national database and Paediatric register

Identifying Familial Hypercholesterolaemia in Primary Care

Objective:

To identify indexes/probands in primary care within DDES Commissioning Group (Durham Dales Easington & Sedgefield) between October 2018 and September 2019 by FH Nurse Specialists based within Northern Genetic Service, Newcastle upon Tyne.

How?

Identifying registered patients using PRIMUS tool, prioritising according to relative risk of diagnosis of FH.

Identifying Familial Hypercholesterolaemia in Primary Care

Results of PRIMUS in DDES

- Dales Locality – 12 Practices
 - 477 Very high risk patients
 - 151 with provisional or definite diagnosis of FH
- Easington Locality - 16 Practices
 - 947 Very high risk patients
 - 169 with provisional or definite diagnosis of FH
- Sedgefield Locality - 10 Practices
 - 519 Very high risk patients,
 - 96 with provisional or definite diagnosis of FH

DDES TOTAL PATIENTS

1943

416

Identifying Familial Hypercholesterolaemia in Primary Care

- Screen patients using SystemOne/ Emis Web
- Exclude those with molecular diagnosis of FH (FH Nurse Specialists to check diagnosis & cascade testing is complete)

RAG rating:

Red – unlikely FH (secondary causes)

Amber – require further information to complete Simon Broome criteria/ Dutch Lipid Score, GP & FH Nurse Specialists to contact patient to complete scoring

Green – likely to be FH

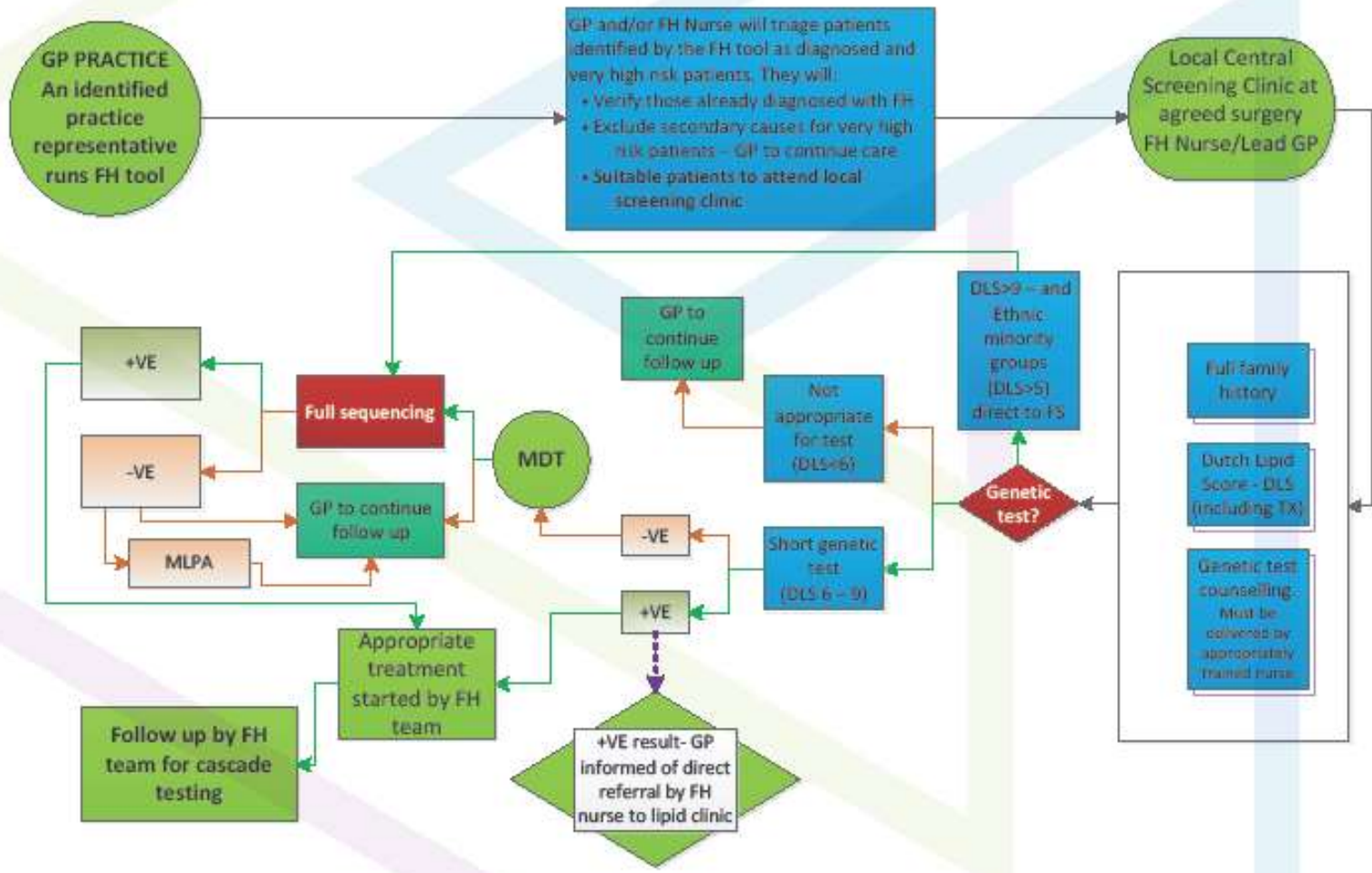
GP & FH Nurse Specialists to invite patient to GP practice for assessment visit

Identifying Familial Hypercholesterolaemia in Primary Care

Assessment Visit:

- Past medical history
- Medication
- Previous relevant blood results
- Social history – smoking/ drinking
- Physical examination – corneal arcus (if applicable), tendon xanthomas
- Dutch Lipid Score
- Pedigree – first and second degree relatives
- Counselling – genetic testing, FH in primary care project
- Obtaining written informed consent
- Enter consultation on SystemOne/ Emis Web
- Collect information on RedCap

FH Pathway (September 2018)



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