The role of the FH Nurse

Lorna Ingoe
Susan Musson
Aimee Potter
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 SystmOne/ Emis Web
- Collect information on RedCap
FH Pathway (September 2018)

GP PRACTICE
An identified practice representative runs FH tool

Local Central Screening Clinic at agreed surgery FH Nurse/Lead GP

GP and/or FH Nurse will triage patients identified by the FH tool as diagnosed and very high risk patients. They will:
- Verify those already diagnosed with FH
- Exclude secondary causes for very high risk patients – GP to continue care
- Suitable patients to attend local screening clinic

Full Family History
Dutch Lipid Score - DLS (including FH)
Genetic test counselling: Must be delivered by appropriately trained nurse

MDT

Not appropriate for test (DLS >6)

-VE

Short genetic test (DLS 6-9)

+VE

Follow up by FH team for cascade testing

+VE result - GP informed of direct referral by FH nurse to lipid clinic

MLPA

GP to continue follow up

-VE

Full sequencing

Appropriate treatment started by FH team

+VE

DLS >9 – and Ethnic minority groups (DLS >5) direct to FS

-VE

GP to continue follow up
Contact Details

Susan Musson Susan.Musson@nuth.nhs.uk
Aimee Potter Aimee.Potter@nuth.nhs.uk
Lorna Ingoe Lorna.Ingoe@nuth.nhs.uk

Genetic Nurse Specialists
Familial Hypercholesterolaemia Service
Institute of Genetic Medicine
International Centre for Life
Central Parkway
Newcastle upon Tyne
NE1 3BZ

Tel: 0191 2418828