

FH in the North East

The Story So Far

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Clinical Commissioning Groups

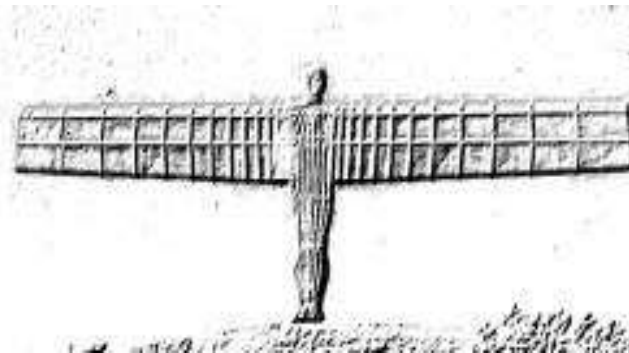
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Chapter One

Creating a Cascade Service

Northern Lipid Forum

in association with



FH: can we deliver the new NICE Quality Standard?

*Hilton Newcastle Gateshead Hotel
Bottle Bank, Gateshead,
Newcastle upon Tyne NE8 2AR*

Tuesday 15th October 2013

NICE Quality Standard (QS41 August 2013)

Familial Hypercholesterolaemia

8 prioritised statements derived from CG71, designed to drive measurable quality improvements

Statement 1. Diagnosis

Statement 2. Specialist referral

Statement 3. DNA testing

Statement 4. Diagnosis in children under 10 years

Statement 5. Cascade testing

Statement 6. Drug treatment in adults

Statement 7. Drug treatment in children

Statement 8. Annual review

Key Findings from the RCP FH Audit

The clinical management in lipid clinics is of a good standard for individual patients who have been diagnosed with FH.

Current resources are inadequate to cope with the identification of the predicted additional FH cases UK wide.

There is a major lack of family “cascade” testing, whether carried out on the basis of lipid levels, or more effectively by a DNA diagnosis.

While there is good access to DNA diagnosis and funding for DNA testing in the Devolved Provinces, access and funding in England is poor.

There is a shortfall in child-focused services throughout the country, with only 26% of sites offering paediatric FH services.

FH Services in the North East in 2013

Gap Analysis

- No centralised disease register for Adult FH probands and families in North East
- No Specialist nurses in Adult or Paediatric FH Clinics
- No regional infrastructure for FH Family cascade testing available to support Clinics
- No access to DNA mutation testing for new FH probands
- No clinical management database software (e.g. PASS) available to FH Clinics
- Adult specialist lipid clinics shortage, particularly in the south of the Region
- Paediatric Lipid clinics not available in south of the Region
- FATS/NECVN Primary Care FH Guidelines not fully implemented in south of Region
- No access to LDL Apheresis

Northern CCG Forum

- 13 CCGs
 - North East SHA area plus Cumbria CCG
- Long history of collaboration across the area
 - E.g. Clinical Innovation Teams
- Strong and independently minded forum
- Academic Health Sciences Network
 - Co terminus
 - Need for CCG engagement

A Population Approach

- 3.1 million people
- 12,000 (5,000) people living with FH mutations
- Only 15% known
- Perhaps 100 preventable cardiac deaths per year
- CCGs agreed to risk share / population approach

Selling Idea To The CCGs

- Prevention
- Innovation
- Implementing NICE guidance
- Best practice
- Population
- The human touch

The North East FHG Consortium

- North East Cardiovascular Network LSAG (10 clinics)
- Northern CCG Forum (13 CCGs)
- Northern Regional Genetics Service (genotyping)
- NewGene Ltd (genotyping)
- Academic Health Sciences Network (AHSN) (genetics)
- City Hospitals Sunderland (CHS FT, nurses host Trust)
- Newcastle NIHR Diagnostic Evidence Co-operative (DEC)
- AstraZeneca Ltd (PASS software licences)

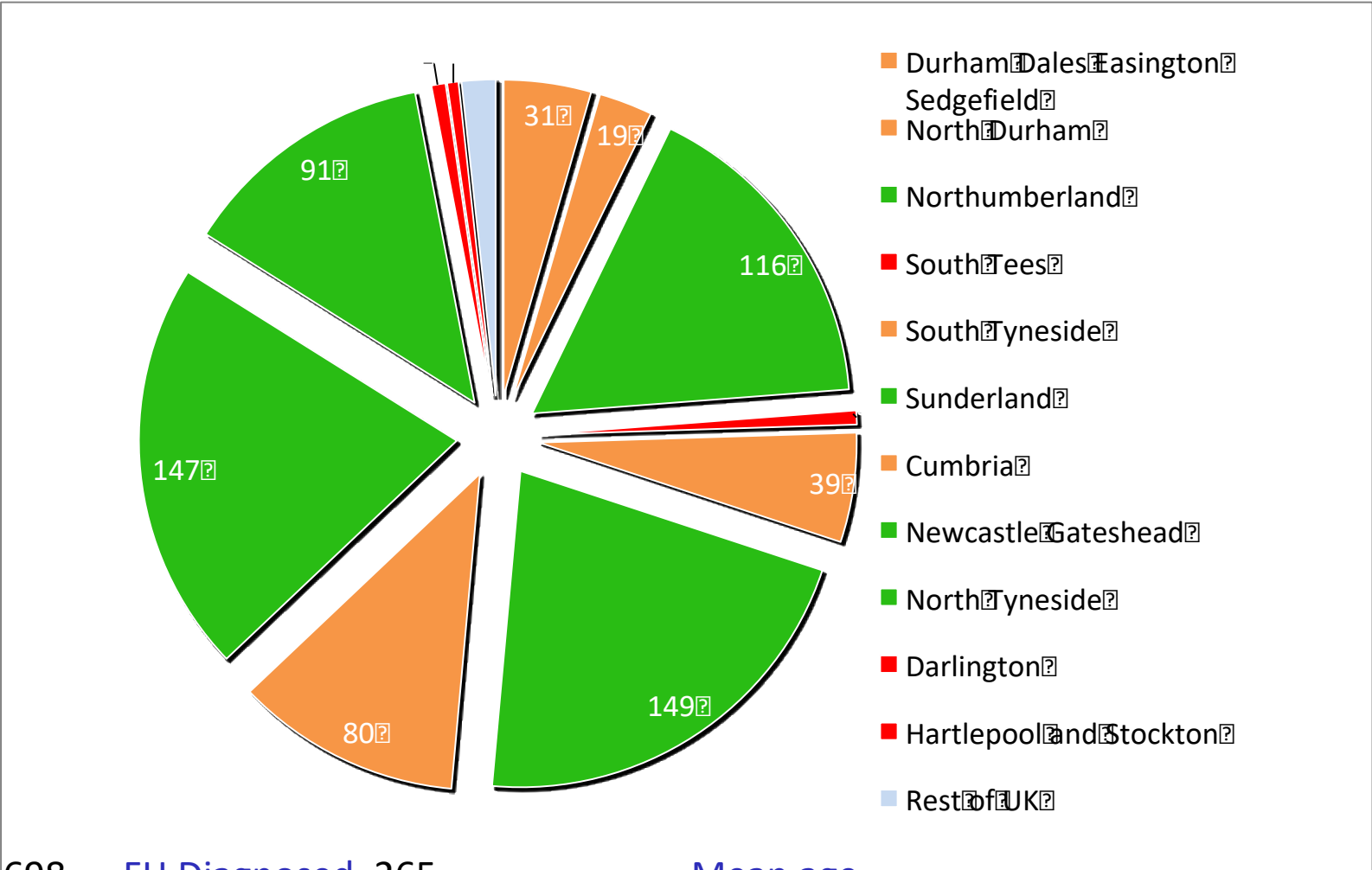
British Heart Foundation Support for FHG Nurses



Chapter Two

A Partial Success

NECVN FH Genetic Testing Activity 2014-16



Total FH Tests 698	FH Diagnosed 265	Mean age
Proband Tests 414	Proband Mut+ 129 (31.2%)	52 yrs
Cascade Tests 284	Cascade Mut+ 136 (47.9%)	35 yrs

Chapter Three

Going South
With
General Practice

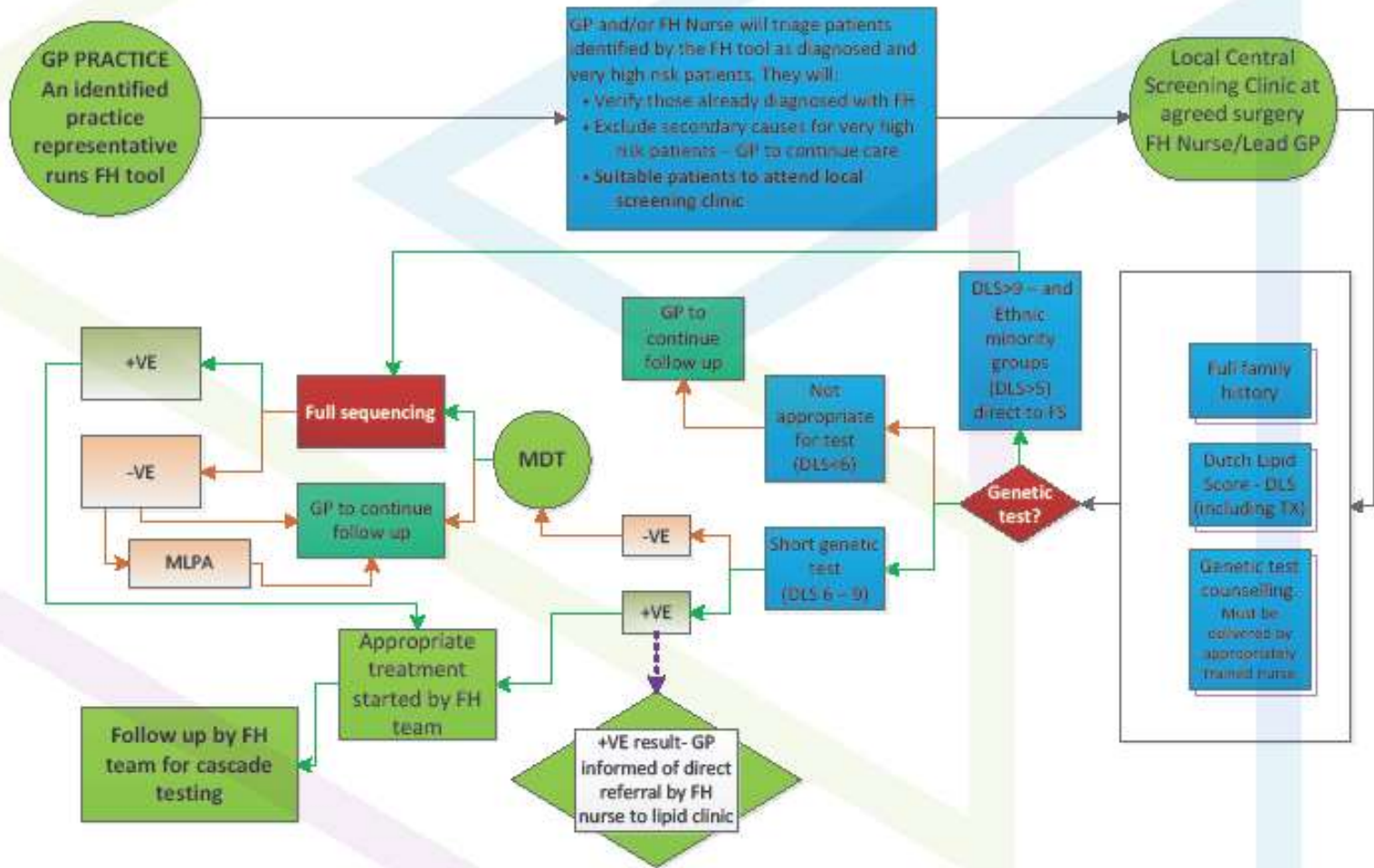
The Challenge

- Growing activity in the south of the patch
- Starting with GP registers and the data we hold on individuals
- Engaging with GP practices and CCGs
- Facilitating case finding

Key Steps

- AHSN
 - Created and hosts the broader collaboration
 - Amgen and Sanofi have joined the group
- FH Tool
 - Dr Nadeem Qureshi, Nottingham University
 - FAMCAT
 - PRIMIS
- Developing the pathway

FH Pathway (September 2018)



FAMCAT

- Extract from GP system
- PRIMIS (Grasp-AF, Grasp-HF)
- Ranks register by risk
- Example (Cruddas Park Surgery)
 - 66 High risk
 - Rule of thirds
 - Secondary (alcohol, diabetes)
 - Known to lipid service
 - Worth reviewing

Durham story

- Dr Mike Hackett pioneered use of FAMCAT locally, including group consultations
- Started work to apply FAMCAT across DDES
- Nursing team presentation later
- We aim to triage from our registers a target population to test.
- What rate of positives will we find?
 - Earlier experience (Chapter 1) was 35%
 - Can we achieve the same?
 - Even 25% would be very good

Chapter Four

- Lots still to do to increase rates of case finding and subsequent cascade testing
- But....
- Child-Parent FH screening in Primary Care David Wald et al, NEJM 2016
- For every 1000 children screened 8 positive (4 + 4 parents)