



## Implementing the NICE Familial Hypercholesterolemia Guideline in England

**BMA House, London, 25 January 2010**

### **Facilitated session: Summary**

During this interactive session, participants were asked to discuss key themes relating to implementation of the NICE FH Guideline. Participants then fed back the outcomes of those discussions to the broader group.

#### **Three key themes were considered:**

1. Commissioning
2. Collaborative working
3. Detection, interventions and support

This paper summarises those discussions, which highlighted the complexity of commissioning FH services, and the need for champions and change to enable us to overcome the barriers to commissioning services in line with the NICE Guideline. Participants indicated that a large number of partners could potentially be involved in helping identify and treat people with FH, and many useful suggestions were given to improve interventions for FH. Key issues to emerge are outlined below.

#### **1. Commissioning**

- In commissioning, groups to approach – SHAs, specialist commissioners, PCTs, PBC, lipid clinic (trusts, hospital), primary care, cardiac networks, Care Quality Commissioner, genetic centre (regional)
- Barriers include lack of national model
- Identification in primary care key is key, as is provision of lipid clinics
- Cost of DNA analysis for cascade screening an issue, plus lab budgets
- National tariff – how is it funded? Family trees – who does it?
- Key elements to consider for new FH service include: capacity issues, costs/benefit analysis, quality standards, health improvements, three year PCT plan
- Current arrangements: opportunistic, special interest, ad hoc, currently no cascading currently, lipid clinics or cardiology led, variable knowledge, secondary care based
- Improvements should be made in: **financial** (funding of genetics, costings for different models and costs benefit analysis, pros and cons of different models, tariff); **clinical** (development of specific FH clinics, dieticians involved) and **educational** (formal educational programme, primary and secondary care, client/family education)
- Question to consider: who is responsible for paying for out of borough tests? Consider reciprocal arrangements? Look at doing across a larger area?

**Key elements for business case:**

- Numbers – potentials/prevalence
- Needs assessment
- Cost benefit realisation – what could you save; cost of set up, benefits, cost of not doing, comparisons against other services
- Options – present options appraised and cost; model ie geographical model (macro/micro delivery)
- Drivers and levers – NHS Health Checks; NICE Guideline
- Who? Clinical networks and/or specialised commissioning. Need to include public and laboratories (all stakeholders)

**2. Collaborative working**

Participants identified a broad range of groups, organisations and clinicians who could/should be involved in the development of screening and treatment/care for people with FH. This demonstrates the (often untapped) opportunities to consider and pick up the possibility of FH. Collaborative working on FH could involve:

**Organisations:**

- HEART UK/Family Support Centres
- PCT commissioners
- Hospital trusts
- Department of Health
- Royal Colleges
- SHAs
- BHF

**Networks:**

- Lipid forums needed to link like minded from all backgrounds
- Cardiovascular networks – including genetics
- Genetic networks

**Professionals:**

- GPs
- Practice nurses and receptions
- Dieticians
- Community CVD screening
- Specialist nurses (with special training from genetics nurses)
- Opticians – pick up corneal arcus and xanthelasma
- Lipidologists
- Genetic services (if available)
- Genetic counsellors
- Community pharmacists
- Endocrinologists
- Diabetologists/metabolic physicians
- Cardiologists/cardiac clinics
- Vascular surgeons
- Paediatricians
- Chemical pathology
- Cardiac rehab nurses
- Stroke (clinics)
- Dermatology
- Hepatology

- Biochemistry labs
- Public health
- Nephrology
- Plastic surgeons

**Patients:**

- The family – patient support groups

**Other:**

- Software/screening database

**Linkages and awareness among these groups can be enhanced through:**

- Guidance and good treatment protocols
- Communication – lipid forums
- Good leadership
- Multidisciplinary representation on lipid forums
- FH nurse links to help communicate results to different parts of the country
- Education for commissioners
- Other education – use of guidelines, public health protocols, pop up boxes on screen in clinical software
- Workplace screening – occupational health
- Education for OH teams
- Children can be used as the drivers/leverage (for action) – families motivated to do things for the children, eg ‘cholesterol parties’
- Triage scheme?
- Link between primary and secondary care could be improved with ‘lead person’ in practices (amalgamations of small practices)

**3. Detection, interventions and support**

**To improve detection and interventions, there is a need for:**

- Development of (further) guidelines
- Education of staff
- Build in rewards for identifying FH – QOF points?

**Identification of people with FH is achieved through:**

- Family history of premature CHD
- LDL cholesterol
- Genetic test
- Cascade testing not widely available (patchy use of biochemical cascade testing)
- Identification in primary care – vascular checks, Healthy Hearts, opportunistic screening, well patient clinics, Simon Broome criteria for FH, clinical signs (eg, tendon xanthoma, not seen often, so not many certain what they look like); and in secondary care – database, following MI, blood test, genetic testing, CMT

**How can we identify the FH in one in 500 people?**

- Remove barriers: logistics, manpower, skill mix, funding
- Increase genetic testing
- Education – awareness of FH as a condition (primary and secondary care)
- IT database – national or comprehensive linking of local database
- Identify young/first infarcts under 60 females, under 50 males – consider FH
- Primary care education – exclude secondary causes for raised cholesterol and other hyperlipidaemia (FCH)

- NHS Health Checks
- CVD Prevention Guidelines – local across networks

#### **How readily available is cascade testing in England?**

- Specialist lipid and cardiac clinics know about testing
- Regular lipid and cardiac clinics don't know about cascade testing?
- Depends on availability – eg, paediatric lipid clinics
- Depends on GPs' willingness to refer to genetics
- Geographic limitations re where do relatives live?

#### **How might we ensure that family members with suspected FH are more effectively tested?**

- Using genetic test not routinely available in England
- Family member testing – integrated approach, national database, good networking
- Involving and educating the family – family support activities, take to community
- Media and political attention
- Patient forums
- Family friendly lipid clinics/organisation of clinics – done in working hours, so reorganise in family friendly way
- Raise awareness of FH – eg, scriptwriters writing for television soaps.

#### **What interventions are currently offered for people with FH?**

- Lifestyle interventions (smoking, diet, physical activity, alcohol), cardiovascular and treatment
- Statin and other lipid lowering drugs
- Other medication
- Genetic counselling
- LDL apheresis
- Liver transplant? Cardiac stress test?
- Support through website information – eg, HEART UK, BHF

#### **How might these be improved?**

- Increased accessibility to LDL apheresis
- Don't go for 'cheap and cheerful' statin – use high potent statin
- Access to other lipid lowering agents
- FH nurse to support family, give time to discuss all matters
- Pre-genetic counselling
- Patient forums/groups
- Patient leaflets

#### **Other considerations:**

- Genetic testing – long turnaround time for results, implications for family, costly, 'dysfunctional family' has implications for full cascade test of relatives.