

# What is Familial Hypercholesterolaemia (FH) and why Identify FH patients?

- FH is an inherited condition which leads to exceptionally high cholesterol levels often 2 – 4 x those of the general population
- It is estimated that one in 250 people may have FH in the UK, meaning at least 260,000 people in the UK may be living with this condition
- Without treatment, affected men will frequently develop symptoms of coronary heart disease before 40 years, and half will be symptomatic by the age of 50 years. In women a similar proportion are symptomatic by 60 years.
- The NICE FH Guideline (CG71) recommends genetic testing of relatives of individuals known to have FH which is the most effective strategy for early identification, leading to effective treatment through diet, lifestyle interventions and cholesterol lowering drugs.
- With early intervention and careful follow up to ensure concordance with treatment, the excess coronary heart disease risk and premature mortality associated with FH can be effectively reduced.

## There is a national focus on cholesterol and FH.....

- **Reducing the population LDL-cholesterol by 5% would prevent 64000 cases of CVD**
- **Reducing the population LDL-cholesterol by 1mmol/l has the potential to reduce CHD by 19%**
  - DoH CVD outcomes strategy – Better identification of very high risk families/individuals
  - Identified in Public Health England CVD prevention pathway
  - Identified in the long term plan – Increase detection over 5 years from 7% to 25%

## 10 year cardiovascular disease ambitions for England

### Atrial fibrillation (AF)



**85%**

of the expected number of **people with AF are detected by 2029**

**90%**

of patients with AF who are already known to be at high risk of a stroke **to be adequately anticoagulated by 2029**

### High blood pressure



**80%**

of the expected number of **people with high blood pressure are diagnosed by 2029**

**80%**

of the total number of people already diagnosed with high blood pressure are **treated to target as per NICE guidelines by 2029**

### High cholesterol



**75%**

of people aged **40 to 74 have received a formal validated CVD risk assessment and cholesterol reading** recorded on a primary care data system in the last five years by 2029

**45%**

of people aged **40 to 74 identified as having a 20% or greater 10-year risk** of developing CVD in primary care are **treated with statins by 2029**

**25%**

of people with **Familial Hypercholesterolaemia (FH) are diagnosed and treated** optimally according to the NICE FH Guideline by 2024

**The ambitions are underpinned by the need to do more to reduce health inequalities**

Reduce the gap significantly in amenable CVD deaths between the most and least deprived areas by 2029

# Aim of the FH project in the North East and North Cumbria

- The overall aim of the Academic Health Science Network for the North East and North Cumbria, in collaboration with Clinical Commissioning Groups, GP Practices, NECS, PRIMIS, AMGEN and SANOFI is to implement targeted FH risk assessment and medication review at a Primary Care level.
- Reduce the excess coronary heart disease risk and premature mortality associated with FH by developing a pathway covering the following key areas:
  - Identify patients at high-risk
  - Evaluate medications
  - Education and treatment
- Increase the utilization of the genetic screening programme across the AHSN footprint through proactive patient identification. Currently identified 387 index cases and 431 relatives through cascade testing. Total diagnosed in North East and North Cumbria = 818
- Improve the patient experience by providing more specialist care within primary care and ensure better utilisation and more appropriate referrals to the specialist service within secondary care

# Results of the PILOT so far.....

Registered population	No of pts identified by the tool as very high risk of FH	Red	Amber (DLS 3&4)	Green (DLS 5+)
45123	303	122	155	26

**Red** = Excluded due to secondary causes  
**Amber** = DLS 3&4, further data required  
**Green** = DLS 5+ Will be invited to clinic

# Next steps

- Roll out to DDES and Darlington CCG – identifying and testing where necessary of green patients
- Continue in pilot practice to identify most efficient ways of screening the amber patients.
- Case study to capture learns and successes so far
- Exploring options to capture data – i.e. flagging in GP systems
- Education around capturing family history

# Summary

- Identifies high risk patients and potentially prevents CVS events
- Puts you ahead of the curve in relation to the long term plan
- Improves patient experience by providing a specialist service within primary care.
- Free and simple to implement

# Any questions.....

