

Child Parent Screening Service (CPSS) for Familial Hypercholesterolaemia (FH)
Opportunity to participate in the implementation of a new clinical pathway that supports the NHS Long Term Plan ambition to reduce cardiovascular disease

We are seeking G.P. Practices to take part in an exciting England wide project supported by NHSE and the Academic Health Science Network.

The NHS Long Term Plan (LTP) aims to identify 25% of individuals with heterozygous FH (increasing from the current 4-7%) by 2025. This relies on two approaches, each will be underpinned by Genomic Medicine testing accessed directly from primary care:

1. Searching of Primary Care records
2. Implementation of an innovative Child-Parent Screening Service (CPSS)

By taking part in the implementation of this clinical pathway you would be contributing towards achieving the goals set out in the LTP to increase the diagnosis and treatment of FH and reduce the number of deaths from CVD.

The combined Accelerated Access Collaborative (AAC) and the Academic Health Science Network (AHSN) Lipid Management and Familial Hypercholesterolaemia Programme aims to support the NHS LTP ambition by implementing the processes to identify FH using a combination of primary care adult screening across all 15 AHSNs and child-parent screening service, (CPSS), initially in a 24 month pilot across 7 AHSNs.

Benefits to Practices who join the CPSS pilot:

Free training and support of all staff involved will be available and the point of care analyser we are using is widely available but if necessary, this and the supporting consumables, (capillary tubes and lancets), will be provided to the practices taking part in this programme. On submission of monthly/quarterly screening data to the AHSN by the practice, a nominal incentive payment will be made for each child screened.

What are the benefits of diagnosing FH in children and how is it done?:

CPSS offers an equitable approach to FH identification and can detect up to 90% of affected people. By testing a child at the 1 year immunisation visit using a Point of Care (POC) heel prick capillary test, total cholesterol can be measured and in those children with a reading >95 percentile, genetic testing undertaken. Evidence shows that this is the age when cholesterol measurement discriminates best between individuals with and without FH; screening newborns or adults is less effective.

If the child receives a diagnosis of FH, at least one of the parents will also be positive, and will be identified by the practice by cholesterol measurement and genetic testing. Siblings and second degree relatives can then also be counselled, screened and treated as necessary. This will be undertaken by the FH nurse in the secondary care lipid service. One study found that for every 1000 children screened, 8 people (4 children and 4 adults) were identified as having FH and could begin potentially lifesaving medication and/or lifestyle and dietary changes. CPSS is currently the best model for FH detection and also offers a population – wide, low cost solution to the management of what can be a devastating condition.

Next steps:

If you would like to understand more about what is involved please contact Clare Evans at West of England AHSN on clare.evans14@nhs.net.