



CVD Prevention

Health
Innovation
East Midlands



Driving Innovation and
Improvement in CVD Care



June 2024

Familial Hypercholesterolaemia: Useful Resources

The purpose of this document is to signpost primary care professionals to existing informative and credible resources on familial hypercholesterolaemia (FH). The resources listed have not been developed or accredited by Health Innovation East Midlands, but rather, have been selected by the Health Innovation CVD Delivery Team as 'useful' resources.

FH is an inherited CVD condition that is passed down through families and causes very high cholesterol levels, from which the body struggles to remove the excess 'bad' cholesterol. It is one of the most common inherited conditions that affects about 1 in every 200 – 250 people. It's estimated that more than 270,000 people in the UK have it, but most don't know they do. If one parent has the condition, there's a 50 per cent (1 in 2) chance that it will be passed on to any of their children. People with FH are at high risk of getting heart and circulatory disease at an early age if it's not treated.

Primary care plays a key role in helping to identify and treat people with FH before it causes a CVD event. If you would like to know how Health Innovation East Midlands can support you, as a health care professional, or your wider practice / PCN, to know more about FH and / or work with you to improve detection and treatment of FH, please contact us at healthinnovation-em@nottingham.ac.uk.

What is FH

- [Heart UK Publication - 'What is FH' video](#)
- [BHF Publication - Familial Hypercholesterolaemia: Your quick guide](#)

How to recognise FH

- [Heart UK Publications - videos](#)
 - An introduction to FH, including how to identify and treat it
 - Awareness of FH and the challenges in identifying it
 - The clinical relevance of diagnosing FH
 - How to take a mouth swab for DNA collection

Guidelines – FH and wider lipid management

- [Heart UK / Health Innovation Network \(formerly AHSN\) AAC Pathway](#)
- [NICE CG71 - Familial hypercholesterolaemia: identification and management](#)
- [NICE NG238 - cardiovascular disease: risk assessment and reduction, including lipid modification](#)



Genetic Testing & FH

The East Genomic Laboratory Hub geography covers the East Midlands. Please find links below to their FH guidance and referral pathways (please note that the referral pathway is an additional pathway that can be used by primary care as an alternative to their ICB pathway. This was setup to support / alleviate the volumes going into secondary care in 2023. Patients must have an East Midlands postcode to be referred for genetic testing via this route).

- [NHS East Genomics: FH Information Zone](#)
- [NHS East Genomics: FH Genetic testing pathway](#)

FH Education Sessions & Training

- [Heart UK Publication - A Focus on Familial Hypercholesterolaemia \(FH\) video](#)
- [Health Innovation East – East Anglian CV Seminar Series: FH Identification – March 2023](#)
- [Health Innovation North East North Cumbria - Improving population health FH video](#)
- [Heart UK Publication: Wider cholesterol, including FH, education series: The Tackling Cholesterol Together New Education Programme](#)

Publications & Leaflets – (patient facing)

- [Heart UK publications - click here to access the below resources](#)

Adults (18+)

- Familial Hypercholesterolaemia adults
- Living with FH – stay active
- Living with FH – food chart
- Living with FH – eat healthy

Children & Young People

- My family, FH & me 0-7 yrs
- FH & me 7-11 yrs
- Getting to grips with FH 11-18 yrs

Resources with meaningful patient stories

- [BHF - Life with Familial Hypercholesterolemia \(patient facing\)](#)
- [Health Innovation East \(formally East AHSN\) – Mark's story, October 2022 – Hear Mark's story and experience about being diagnosed and living with FH](#)

Please note any clinical opinions / views shared here remain those of the clinician/s and are not necessarily those of Health Innovation East Midlands.

Any case studies, links or other information (not directly produced by HIEM) is for the purpose of sharing useful information and available resources. The HIEM does not declare or promote this information as 'best practice'.

Readers are advised to follow the latest national and local clinical guidelines for their area.

Clinical advice and guidelines change – please take note that this material has been published in June 2024, and any guidance shared or discussed may be superseded in the future.