

# NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

## QUALITY STANDARD SCOPE

### **1 Quality standard title**

Familial hypercholesterolaemia

### **2 Quality standards**

NICE quality standards are a set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the prevention and treatment of different diseases and conditions.

NICE quality standards are derived from the best available evidence, such as NICE guidance and other evidence sources accredited by NHS Evidence. They are developed independently by NICE, in collaboration with the NHS, social care professionals, and their partners and service users, and address clinical and cost effectiveness, patient safety and patient experience.

This work is intended to help the NHS focus on delivering the best possible outcomes for patients.

The quality standard development process is described in detail on the NICE website (see section 5, 'Further information').

### **3 This standard**

This scope defines what the standard will (and will not) examine. It is based on the referral from the Department of Health and has been drafted following the first meeting of the Topic Expert Group.

The areas that will be addressed by the standard are described in the following sections.

### **3.1**      ***Population***

#### **3.1.1**      **Groups that will be covered**

- a)      Adults, children and young people with a clinical or molecular diagnosis of familial hypercholesterolaemia.
- b)      No patient subgroups have been identified as needing specific consideration.

#### **3.1.2**      **Groups that will not be covered**

- a)      People with secondary hyperlipidaemia and inherited lipid disorders other than familial hypercholesterolaemia.

### **3.2**      ***Healthcare settings***

- a)      Primary, secondary and tertiary care settings.

### **3.3**      ***Areas of care***

The areas of care of a patient's pathway used to inform the development of the quality statements are set out in section 3.3.1. During the development of the standard the Topic Expert Group will decide which of these areas are suitable for quality statements and measures. The draft quality statements and measures will be the subject of a public consultation. The content of the quality standard statements may change during the process and may differ after consultation with stakeholders.

#### **3.3.1**      **Areas of care that will be considered**

- a)      Diagnosis, including diagnosis in children and molecular testing.
- b)      Referral to specialist services and referral back to primary care.
- c)      Cascade testing.
- d)      Access to LDL-lowering apheresis.
- e)      Information for people with familial hypercholesterolaemia and their families on risks (including familial risks and cascade testing).

- f) Annual review, including review of drug treatment.

### **3.3.2 Areas of care that will not be considered**

- a) Liver transplantation.

### **3.4 Economic aspects**

The Topic Expert Group will take into account both clinical and cost effectiveness when prioritising the quality statements to be included in the quality standard. The economic evidence will be considered, and the cost and commissioning impact of implementing the quality standard will be assessed.

### **3.5 Timing**

The development of the quality standard will begin in October 2012.

## **4 Key development sources**

Relevant NICE guidance (published and in development) will be used to develop the quality standard. If available, other NHS Evidence accredited sources will also be used.

### **4.1 Published sources**

- [Identification and management of familial hypercholesterolaemia](#). NICE clinical guideline 71 (2008) (The [review decision](#) for this guideline was made in 2011 and the recommendation was not to update the guideline at this time).
- [Elucigene FH20 and LIPOchip for the diagnosis of familial hypercholesterolaemia](#). NICE diagnostic guidance 2 (2011).
- [Lipid modification: cardiovascular risk assessment and the modification of blood lipids for the primary and secondary prevention of cardiovascular disease](#). NICE clinical guideline 67 (2008) (This guideline is currently being updated).

## **4.2 Related NICE quality standards**

### **4.2.1 Published standards**

- [Patient experience in adult NHS services](#). NICE quality standard (2012).

### **4.2.2 Standards referred to the core library but not yet in development**

- Lipid modification
- Risk assessment of modifiable cardiovascular risk factors
- Secondary prevention of myocardial infarction and cardiac rehabilitation
- Obesity (adults)
- Childhood obesity
- Smoking cessation
- Physical activity
- Medicines adherence

## **4.3 Key policy documents and national audits**

Relevant national audits and policy documents will be used to inform the development of the quality standard.

- Royal College of Physicians (2010) [National Audit of the Management of Familial Hypercholesterolaemia 2010](#)
- Royal College of Physicians (2010) [National Clinical Audit of the Management of Familial Hypercholesterolaemia Pilot 2009](#)
- NHS Wales (2009) [Cardiac Disease National Service Framework for Wales](#)
- Department of Health (2004) [National service framework for children, young people and maternity services: core standards](#)
- Department of Health (2000) [Coronary heart disease: national service framework for coronary heart disease - modern standards and service models](#)

## **5 Further information**

Information on the quality standard development process is provided in:

- 'Developing NICE quality standards: interim process guide'.

This is available from the NICE website

([www.nice.org.uk/aboutnice/qualitystandards](http://www.nice.org.uk/aboutnice/qualitystandards)). Information on the progress of

the quality standard is also available from the NICE website

([www.nice.org.uk](http://www.nice.org.uk)).