Health Committee inquiry into the work of NICE:
Response from HEART UK – The Cholesterol Charity

HEART UK is the nation's cholesterol charity. HEART UK is responding on the role of NICE clinical guidelines in improving the quality of healthcare and the role of NICE Quality Standards in the new NHS architecture.

The role of NICE clinical guidelines in improving the quality of healthcare

HEART UK believes that NICE clinical guidelines present an opportunity to make genuine improvements in healthcare. The guidelines are based on the best available evidence for high quality treatment. However, in some instances, it is clear that NICE guidelines are not being implemented.

A case in point is the wholesale failure to implement the NICE Guidelines on Familial Hypercholesterolaemia (FH) in England (CG71), published in 2008. There are an estimated 120,000 people living with FH in the UK. Yet only 15-20% of these have been formally diagnosed. Children of an individual with FH have a 50 per cent chance of inheriting the condition. Left untreated, FH may lead to premature death from CVD. 50% of males with untreated FH will develop coronary heart disease (CHD) before the age of 50 (for females, 50% have CHD before age 60). 50% of untreated males will die before they are 60. These deaths are avoidable. Unlike many genetic conditions, FH can be diagnosed relatively easily and, with inexpensive treatment, people with FH can lead normal, healthy lives.

The NICE guideline recommends identifying cases of FH, using cholesterol measurements and genetic testing of families, by a method known as cascade screening. Referral to specialist lipid clinics is recommended for confirmation of the diagnosis, patient counselling and in order to initiate cascade screening.
The devolved countries each have a national directive or initiative specifically targeting FH, which has helped them achieve higher standards of care for their FH patients than for those in England.

Despite the NICE Guidelines, we know that little has been achieved in England. Indeed, in 2010, to better understand the extent to which the Guideline has been implemented in England, HEART UK conducted a study in which Freedom of Information requests were sent to Primary Care Trusts, asking about their progress to date. The study showed that little has been done to implement the Guideline in England. The findings demonstrate a lack of formal planning for FH and incomplete provision of clinical services and education about FH. There is a paucity of specialist services, including provisions for paediatric, obstetric, as well as adult patients. The NHS Health Checks programme recommends that people identified with total cholesterol > 7.5 mmol/L should be considered as a possible case of FH, with referral advised according to clinical guidelines. However, identification continues to take place on an ad hoc basis and the commissioning of FH services remains very limited.

Translating the NICE FH Guidelines into practice has not worked for a number of reasons, including:

- Issues associated with the localised commissioning structure have hampered the development of FH services and access to genetic testing
- Lack of clinical awareness and understanding of FH
- Lack of appropriate IT software that would aid the process of cascade screening and registering patient data
- Lack of lipid clinics to help treat people with complex lipid disorders
- Management/financial blocks to purchase an FH genetic test, as the test is considered by some to be a 'new development'.

A number of elements need to work effectively in unison in order for the NICE Guidelines on FH to be implemented. HEART UK believes that the FH Guidelines can most effectively be implemented with national leadership.

HEART UK recommends an England national programme should be established to improve the diagnosis and treatment of people with FH. In February 2012, HEART UK published a new report, *Saving lives, saving families: The health, social and economic advantages of treating Familial Hypercholesterolaemia*. (Download the report at: http://heartuk.org.uk/files/uploads/HUK_SavingLivesSavingFamilies_FHreport_Feb2012.pdf). The report includes new economic modelling that demonstrates the health and cost savings that can be made through improved identification and treatment of FH.

Key findings of the research include:

- High intensity treatment, compared to low intensity or no treatment, results in greater reduction of low density lipoprotein (LDL) cholesterol and major cardiovascular events, which translates into more quality adjusted life years and life years gained
- High intensity treatment will mean 101 cardiovascular deaths avoided per 1,000 FH patients (aged 30 to 85 years), when compared with no treatment
- The UK could save £378.7 million from cardiovascular events avoided if all (100 per cent) relatives of FH index cases are identified and treated optimally over a 55 year period, or £6.9m per year.

Examining the evidence and FH programmes in other countries, HEART UK suggests the following actions to help realise these improvements:

1. A national programme for FH in England under the NHS Commissioning Board or similar body. This is the best means of ensuring that access to FH services is available beyond the limited boundaries of a PCT or clinical commissioning group. A national programme should have ring-fenced funding and include the following:
    a. A dedicated network of involved professionals, including lipid clinics, primary care and genetic services
    b. Clear referral pathways at local level

    c. Employment of FH nurses to rollout the cascade screening process
    d. Measurement of outcomes as the programme is rolled out at local level
2. A UK-wide national patient register and database for FH to aid better cascade screening across the country
3. Improved capacity of lipid clinics to manage patients with possible or definite FH.
4. Increased education and training programmes that have been developed to nationally agreed standards and contain nationally agreed content.

A National programme for FH could emulate the work already taking place in Wales. Wales has established the FH All Wales Cascade Testing Service. This features a diagnostic service for FH combined with family cascade testing. The Wales service uses the NICE Guidelines on FH as the evidence base for its work. The Welsh Assembly is providing long-term funding for the project.

The service is multidisciplinary, and links with elements of current lipid clinic provision, clinical genetics, paediatrics and laboratory testing. The service is hosted by Cardiff and Vale Health Board and managed by the All Wales Medical Genetics Service with oversight from a multidisciplinary all Wales steering group.

A key benefit of the service is that it enables wider availability within Wales for referral to specialist lipid services and for genetic testing for FH. It provides a pathway to assist diagnosing FH for use in primary and secondary care and also sets out a system for family testing for FH. As a result, a Welsh national database of patients with FH is being developed. Based on experience from the Dutch testing programme, the service aims to identify 60 per cent of those affected in Wales over a 10-year period.

The Welsh experience demonstrates the value of national leadership to aid the implementation of the clinical gold standards contained in the NICE FH Guidelines. This leadership is critical for the implementation of the same Guidelines in England.

The role of NICE Quality Standards in the new NHS architecture, in particular the status of NICE guidelines in determination of commissioning priorities

Defining high standards of care for specific conditions presents another useful opportunity to demonstrate and encourage optimum care. HEART UK is pleased that a Quality Standard is being developed for FH. However, the implementation of that Quality Standard after it is completed remains to be seen.

For better detection and treatment of FH, a national programme is the best means of delivering improvements in patient outcomes. Localised commissioning structures cannot accommodate the long-term view required to realise the gains of cascade testing for FH.