**Cardiovascular Outcomes Strategy: HEART UK response**

**1. We want to bring all CVD services up to the standard of the best. Are you aware of examples of good practice in cardiovascular service delivery that could be replicated?**

In 2011, HEART UK produced a new report, *Cholesterol and a healthier nation: Shared responsibility for better public health*. The report examined the rollout of NHS Health Checks in England, and features some innovative examples of rolling out CVD prevention programmes in different settings, including walking clubs, men's health projects, health checks in religious venues, and GP-referred exercise programmes.

Download the *Cholesterol and a healthier nation* report at: http://heartuk.org.uk/files/uploads/documents/2011_12_HeartUK_CholesterolHealthReport2011_FINAL.pdf

HEART UK is currently developing an online library designed to showcase good practice in the local delivery of cardiovascular prevention programmes. The library will invite organisations to submit information online, with the aim of cataloguing projects by theme – for example, target populations. HEART UK hopes that the resource will be utilised to replicate programmes that have delivered high quality outcomes.

**2. In your experience, in terms of preventing, treating or managing CVD, what doesn't work well at present and why?**

At present in England, there is a policy commitment to innovation, efficiency and prevention. However, this policy does not always translate into practice.

For HEART UK, a case in point is the wholesale failure to implement the NICE Guidelines on Familial Hypercholesterolaemia (FH) in England.

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.

In 2008, NICE published a clinical guideline for the Identification and Management of FH (CG71). The 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 have 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'.

Recommendations to address these problems are given in response to Question 3.

**3. What action is needed to reduce the number of people dying prematurely from CVD? Please provide information about the extend to which your suggestions are likely to impact on the number of people dying?**

An England national programme should be established to improve the diagnosis and treatment of people with Familial Hypercholesterolaemia (FH). The actions and impact of those actions are outlined in HEART UK's response to this question.

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 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. These programmes would aim to improve primary care awareness of FH and local care pathways for lipid management. This would also facilitate much of the long-term care and review of FH patients to be appropriately carried out in primary care.

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.

In Wales they have successfully adapted the Dutch FH cascade testing software, PASS. This system has been shown to work effectively in Wales (see Haralambos K et al. Evaluation of cascade testing software for familial hypercholesterolaemia – The Wales pilot project , at http://medicine.cf.ac.uk/news/wales-fh-cascade-testing-service-implementation-dedicated-ca/)

For more information on the Wales project, see the HEART UK FH Report: http://heartuk.org.uk/files/uploads/HUK_SavingLivesSavingFamilies_FHreport_Feb2012.pdf Also see the All Wales Medical Genetics Service (FH Service) site: www.FHwales.co.uk

**4. What more needs to be done to improve patients' and carers' quality of life? Please provide evidence (qualitative and quantitative) where you can about how your proposal improves quality of life.**

**5. What more needs to be done to improve patient and carers experiences of treatment and care? Again, please provide evidence to support your proposal.**

Awareness needs to be raised about rarer CVD conditions in primary care to help improve their diagnosis and treatment. HEART UK's discussions with patients reveal that many believe that primary care awareness of Familial Hypercholesterolaemia needs to be improved.

**6. Bearing in mind there are no new resources available to deliver this outcomes strategy, what do you think is the best way of delivering the proposals you have made for improving CVD outcomes? For example, changing tariff arrangements, empowering patients and carers to have greater control over their care and management, improving benchmarking data or other things?**

Key measures to improve CVD outcomes include the need to:

1. Target people at risk - ensure that the NHS Health Checks programme is widely implemented *and* reaches people most at risk of a heart attack or stroke.

2. Strengthen Local Authority capability on public health - Ensure that local authorities have the resources, skills and capability to undertake their new public health responsibilities.
3. Share best practice - Best practice on health checks should be shared across PCTs/CCGs and local authorities should share examples of good public health promotion.

At present, the NHS Health Checks programme is being delivered effectively in some places, though not in others.

HEART UK believes that the NHS Health Checks, if universally pursued throughout England, engage the public in health prevention by:

- Identifying potential risk factors for CVD
- Providing individuals with information to reduce their risk of CVD through lifestyle changes
- Reducing their risk of CVD through treatment where necessary.

HEART UK sent Freedom of Information requests to 152 Primary Care Trusts (PCTs) across England in September 2011 to collect information about the local provision and implementation of NHS Health Checks. The charity received 111 responses, a response rate of 73 per cent, and information received revealed that the NHS Health Checks programme has had a patchy start.

Results included:

- Encouragingly, four out of the five regions with the highest death rates for coronary heart disease were among the top five regions for providing Health Checks. This shows that these regions recognise the benefits of the programme, and are working hard to make sure that patients are accessing the service
- Only 15 of those PCTs surveyed are providing the Health Checks in places other than GP surgeries or pharmacies. This is despite the fact that this programme should be improving access to services for hard to reach groups
- Nine of the PCTs who responded to the survey had not delivered a single Health Check.

The results of the study feature in HEART UK's *Cholesterol and a healthier nation* report: http://heartuk.org.uk/files/uploads/documents/2011_12_HeartUK_CholesterolHealthReport2011_FINAL.pdf

The Health Checks programme may realise its potential to improve health outcomes through pursuit of the following key recommendations:

1. Where PCTs are not already doing so, consideration should be given to where the NHS Health Checks programme can be provided to reach society's most at-risk groups

2. PCTs to audit local CVD services to consider how local initiatives can be joined-up with local NHS Health Check services

3. The Government must ensure that the NHS Commissioning Board oversees the continued delivery of the NHS Health Checks programme and monitors local implementation rigorously

4. The Department of Health and the new NHS Commissioning Board should devise a system for sharing best practice across PCTs to help with the roll out of the NHS Health Checks programme

5. Targets for delivering the NHS Health Checks programme should continue to be specified in the NHS Operating Framework until the programme is fully rolled out across England

6. NICE should review QOF indicators for secondary prevention of CHD and ensure that all existing targets reflect best practice guidelines and are ambitious enough to help individuals achieve the best possible outcomes.

7. The Government and Royal Colleges should consider how best to support GPs and other healthcare professionals to provide lifestyle advice and support to patients

8. Local authorities should consider adopting innovative best practice examples for promoting public health locally.

With respect to better detecting and treating familial hypercholesterolaemia (FH), as indicated in previous responses, 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.

The Netherlands has had a national FH screening programme since 1994. In the Netherlands, large-scale genetic testing for FH in high-risk families has proved to be feasible and cost effective. (See Wonderling, D. et al (2004) Cost-effectiveness analysis of the genetic screening program for Familial Hypercholesterolaemia in the Netherlands. *Seminars in Vascular Medicine*, 4 (1): 97-104).

**7. Can you give any examples in preventing, treating or managing CVD where it would be better to stop or change practice because that practice is not delivering the results expected? For example, because it is out of date or a different approach has been found to be more clinically and cost effective.**

**8. Do you know of any developments in prevention, diagnosis, treatment or management that will impact on the way in which CVD services need to be commissioned or delivered over the next decade?**

As indicated above, HEART UK believes that a national programme for Familial Hypercholesterolaemia (FH) should be commissioned. It should be managed at the national level, but rolled out locally.

**9. As we work to improve CVD outcomes, what do you think are the main inequalities and how can we make sure that we continue to try and tackle them?**

Health inequalities may be due to range of factors, encompassing the wider or social determinants of health, access to health services, and health outcomes linked to lifestyle. Therefore, health inequalities in the prevention and treatment of CVD can be reduced through broader, joined-up policies that also seek to address these factors. The Public Health Outcomes Framework can play a positive role in reducing inequalities if the second outcome is realised – namely, "Reduced differences in life expectancy and healthy life expectancy between communities."

Poor health literacy has also been associated with poorer health outcomes (see, for example, http://www.bmj.com/content/344/bmj.e1602). Improvements in health literacy and greater population-wide understanding of prevention measures would help alleviate health inequalities. Innovative and effective patient tools and health promotion measures could be better incorporated into clinical practice and public health campaigns respectively.

HEART UK is currently preparing a new report that will examine CVD inequalities. The report will set out the extent of inequalities in CVD across the UK and recommend policy solutions to help alleviate those inequalities. HEART UK intends to seek the views of public health leaders to help guide those recommendations. A health inequalities map will be developed alongside the report to identify those parts of the UK where CVD outcomes are the worst.

Inequalities may also persist in CVD between different countries of the UK because of differences in policy and service provision. In the case of familial hypercholesterolaemia (FH), other parts of the UK are faring better than England. This is due in part to the FH programmes and/or clinical standards that have been established to address the condition in Scotland, Wales and Northern Ireland. With no national FH programme in England, health inequalities will soon emerge for those with the condition living in different countries of the UK.

Health inequalities persist between regions and individuals healthcare facilities. The Quality and Outcomes (QOF) Framework may be a useful means of helping to tackle these inequalities. This is illustrated by recent proposed changes to QOF. In early 2012, HEART UK submitted a response to proposed changes to QOF indicators.
One proposed indicator is:
"Secondary prevention of CHD: the percentage of patients with an MI within the preceding 15 months with a record of a referral to a cardiac rehabilitation programme (Indicator 4)

- The percentage of patients with an MI within the preceding 15 months with a record of a referral to a cardiac rehabilitation programme."

HEART UK supports the inclusion of referral to a cardiac rehabilitation programme as an indicator within QOF. However, the charity feels that NICE could expand this to

include uptake. It would be useful if the indicator includes the percentage of referred patients *attending* a cardiac rehabilitation programme.

The National Service Framework (NSF) for Coronary Heart Disease (CHD) recommends that 85% of patients should attend cardiac rehabilitation. However, this figure is not always met, and there is great regional and hospital variation in uptake.

A recent audit by HEART UK examined the offer and uptake of cardiac rehabilitation across England - see
http://heartuk.org.uk/files/uploads/documents/2012_16Jan_After_the_event.pdf

The audit found that more than 95% of providers offer cardiac rehabilitation to those who have had a heart attack. However, among audit respondents the percentage of patients who accepted invitations to cardiac rehabilitation ranged from 36.7% to 99.8%. The reasons for poor uptake include lack of engagement, lack of effective referral, scarcity of service provision and practical reasons.

HEART UK suggests that adding a measure to QOF to ensure greater *uptake* would help reduce the inequalities that persist in cardiac rehabilitation.

**10. Any other comments?**