Cardio & Vascular Coalition

Destination 2020

A plan for Cardiac and Vascular health

The voluntary sector vision for change
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Cardiac and vascular conditions – those affecting and related to the heart and blood vessels throughout the body, including heart attack, stroke, diabetes and chronic kidney disease – remain the number one cause of death and disability in the UK. Prevalence – and treatment costs – will only increase with our ageing population and rising incidence of risk factors such as obesity.

Driven by clinical leadership, adequate resourcing and a dedicated workforce, the National Service Framework (NSF) for Coronary Heart Disease (CHD) in England delivered dramatic progress in the fight against cardiovascular disease. In the decade since the framework was written, the NHS has been transformed. But emerging priorities such as the need to tackle inequalities and find local solutions to national challenges require us all to take stock and make plans fit for the future.

It is vital that the achievements of NSFs and strategies for CHD, stroke, diabetes, and kidney disease are sustained and built upon. A new approach for England is needed, covering the common elements of cardiac and vascular disease, which sets national standards for local implementation.

Destination 2020 outlines the key principles that should guide a new strategic government approach to cardiac and vascular conditions.

The Cardio & Vascular Coalition (CVC) is urging Government to commit to a proactive and co-ordinated plan that builds on the success of the current NSFs and initiatives.

The National Quality Board has been set up to act as a powerhouse for change and provide strategic oversight and leadership in quality across the NHS in England. The quest for quality, integration and transparent prioritisation lies at the heart of this document and it should prove invaluable to the board.

A new emphasis on the commonalities between CHD, stroke, diabetes and kidney disease is needed to achieve effective prevention, diagnosis and treatment. This should embrace patient involvement in the recognition and management of co-existent chronic diseases. Gaps in services – particularly prevention in children, congenital conditions, rehabilitation, end of life care and reducing inequalities – must be filled.

The charities, patient and professional organisations that make up the CVC have come together because we believe that we must not risk what we have gained to date by taking a piecemeal, project-based approach to combating the UK’s biggest killer.

By working in co-operation to a published strategy with clear goals, we can – within a generation – reduce our rate of cardiac and vascular disease to one of the lowest levels in Western Europe and provide cardiac and vascular patients with the integrated services they need and deserve.

Betty McBride
Chair, Cardio & Vascular Coalition
Executive summary

A new national strategic approach to cardiac and vascular health in England should be developed to sustain and build on the achievements of the 2000 National Service Framework (NSF) for Coronary Heart Disease (CHD) 10-year plan of action. It should work alongside current initiatives (such as NSFs and strategies for stroke, diabetes and kidney disease), address remaining gaps, meet new challenges and further improve the health of the nation.

We need to widen the scope of the original NSFs by incorporating better management of co-existing cardiac and vascular diseases (including conditions affecting the heart, stroke, Type 2 diabetes – and Type 1 where relevant – peripheral vascular disease, and chronic kidney disease), and their modifiable risk factors. Congenital conditions have not been considered in previous guidance, and will require attention in future planning.

Destination 2020 outlines the principles that should guide a new strategic government approach to cardiac and vascular conditions. It is not intended to describe the details of work programmes for specific areas of cardiac and vascular conditions. Nevertheless, it does draw attention to some areas where the need for action is critical.

Why develop a new strategic approach to cardiac and vascular health?

- Cardiac and vascular conditions are the major public health challenge of the next decade – particularly given the growing burden of acute and chronic conditions – and should be prioritised as such.

- Work within individual disease areas must be maintained so that there is no loss of momentum in the drive towards improved care.

- Targeted health strategies that set national standards work. A strategic approach will deliver further improvements and allocate the resources and funding needed to achieve them.

- Key gaps remain where further progress is needed, including cardiac and vascular disease prevention, congenital conditions, rehabilitation, emerging needs for acute and chronic conditions, and end of life care.

Ambitions should be to:

- Reduce the incidence of cardiac and vascular disease in England to one of the lowest levels in Western Europe, within a generation.

- Reduce inequalities in the prevalence and treatment of cardiac and vascular disease across gender and geographic, social, economic and ethnic groups.

- Achieve better integration of the patient pathway across health and social care.
These ambitions should be achieved by:

1. Standards of excellence
   Setting new standards of excellence in prevention, treatment and service provision with the adoption of the best evidence-based approaches.

2. A patient centred approach
   People with cardiac or vascular disease, together with their carers and family, should be centrally involved and empowered.

3. A new focus on prevention
   Co-ordinated evidence-based programmes should be prioritised to improve cardiac and vascular health in the long term, preventing disease and the progression of disease in people who already have cardiac and vascular conditions.

4. Effective commissioning
   Commissioning should include awareness of, and incentives for, service development and implementation based on the needs of local populations – joined up across services where appropriate. Measurable standards should be set and regularly audited.

5. Research
   The strong research heritage of the NHS should be built upon, by providing resources and support for research that strengthens the evidence base for improving cardiac and vascular health.

6. Addressing specific areas of need
   Key areas where more progress is required, or that were outside the remit of the existing NSFs, should be addressed.

The CVC is a unique collaboration of voluntary and professional organisations with an interest in cardiac and vascular health. The CVC represents the voice of both patients and professional bodies, who are the experts on living with, and tackling, cardiac and vascular disease.

Reports that underpin Destination 2020 and detailed information on the priorities of member organisations are available on the CVC website: www.cardiovascularcoalition.org.uk

This report is focused on England, although the CVC hopes that it will inspire further progress in cardiac and vascular conditions in other nations of the UK.
Why develop a new strategic approach to cardiac and vascular health?

National strategies drive service and health improvements

The NSF for CHD – and the additional arrhythmias chapter (2005) – led the way as one of the first national plans developed to take a root and branch approach to improving the prevention, treatment and care of people with a particular condition. It set out a 10-year plan for action to prevent coronary heart disease, improve the quality of life for people with CHD, and save more lives.

The success of the NSF for CHD, and of the ongoing strategies for diabetes, stroke and kidney disease, demonstrates that having national plans with clear lines of accountability is a highly effective way to drive improvements in services and in health. They provide staff with goals, direct funding to areas of need, and provide clear standards of care to inform the public what they should expect.

A progress report on the NSF for CHD in 2007 estimated that this approach was saving more than 22,000 lives per year (DH, 2007a). Key achievements included:

• The target of reducing deaths from cardiovascular disease for people under 75 years of age by 40% was met five years early.

• The number of people suffering a heart attack who received thrombolysis within 60 minutes of a call for help increased from 24% of patients in early 2001 to almost 70 per cent in 2007.

• Waiting times for heart surgery dropped dramatically, from more than 5,500 people waiting more than three months for heart surgery in 2000 to none in 2007.

In asking for a new transparent and strategic approach for cardiac and vascular diseases, we draw comparisons with a voluntary sector campaign to update the 10-year NHS Cancer Plan (DH, 2000). Concerns that the Cancer Plan needed updating to take account of major NHS structural changes led a collaboration of 34 cancer charities to draft recommendations for an updated plan (Cancer Campaigning Group, 2007).

In its first year the Cancer Reform Strategy (2007) has delivered innovation and an increased focus on prevention. National Cancer Director, Professor Mike Richards, wrote, “...considerable and significant progress has been made, and [that] we are well positioned for further progress next year” (Allberry, 2008).

The CVC believes there is a similar case for a renewal of the strategic approach to cardiac and vascular disease. This will ensure there is no loss of momentum in progress achieved and will re-invigorate services and programmes already set up to deliver improved prevention and care.
What are cardiac and vascular diseases?

For the purposes of this document, cardiac and vascular diseases are conditions affecting the heart and blood vessels throughout the body. They include heart attack, arrhythmias, stroke, transient ischaemic attack, peripheral vascular disease, congenital heart disease, and conditions predisposing to vascular disease including diabetes and chronic kidney disease.

Cardiac and vascular disease remains a priority

The premature death rate may be falling, but cardiac and vascular conditions remain the leading cause of death in the UK. Heart disease, stroke, kidney disease and diabetes currently affect the lives of over four million people in England, cause 170,000 deaths a year, and are responsible for one fifth of all hospital admissions (DH, 2008a).

The prevalence of cardiac and vascular disease will increase as the population ages, as risk factors increase, and as more people survive premature cardiac and vascular events. Acute and chronic conditions such as heart failure, stroke, heart valve disease, heart block and atrial fibrillation are set to rise. This extra burden needs to be planned for.

The major risk factors for cardiac and vascular diseases, such as smoking, abnormal blood lipid values and hypertension, are increasingly better prevented or treated but there is room for improvement. Hypertension affects a third of the adult population, and evidence demonstrates that blood pressure is not being controlled to recommended levels in a significant number of these people (Craig & Shelton, 2007). Some risk factors, particularly obesity and lack of physical activity, are increasing (Lyralzopoulos, 2006). On current trends, 60% of males and 50% of females will be obese by 2050 (Foresight, 2007). If unchecked, it is predicted that this will lead to a massive increase in diabetes, with the current trend indicating that more than four million people in the UK will have the condition by 2025 (Diabetes UK website). This will result in a large increase in the number of patients requiring medication to prevent cardiac and vascular events.

The number of people requiring kidney dialysis is set to double by 2014 to over 45,000, but growth in the prevalence of cardiovascular disease and diabetes could increase this number further.

National programmes, such as the Vascular Risk Assessment Programme, the Abdominal Aortic Aneurysm Screening Programme for men over the age of 65 and cascade screening for genetically determined conditions, will identify new patients requiring appropriate interventions and treatment to reduce their risk.

These changes pose a major challenge for future services. A strategic approach is needed to prioritise and implement measures to plan for them. Investment now to prevent premature chronic illness will lead to savings in the future.
Why should cardiac and vascular conditions be considered together?

An overarching plan is needed to comprehensively tackle cardiac and vascular diseases together, as the major public health issue of the next decade.

The cardiovascular system consists of a complex network of blood vessels feeding every organ and tissue in the body, with the heart as its central ‘pump’. Diseases that affect blood vessels tend to share common risk factors, for example, smoking, diet, high cholesterol and blood pressure, and lack of physical activity. Having one cardiac or vascular disease commonly predisposes people to another. For example, people with diabetes or kidney disease are at much greater risk of developing heart disease, and the predominant cause of death to those with kidney disease is cardiovascular disease (John et al, 2004). Their shared risk factors, related pathology, and possible co-morbidities support the development of a consistent approach to the management of cardiac and vascular conditions.

This approach dovetails with the work already underway by the Department of Health and National Clinical Directors for heart disease and stroke, diabetes, and kidney disease to address shared issues including prevention, early detection and risk management.

In line with the *NHS Constitution* (DH, 2009), the new approach should recommend measures that encourage the NHS to work “across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population.”
What are our ambitions for a new strategic approach?

Reduce the incidence of cardiac and vascular diseases in England to one of the lowest levels in Western Europe within a generation

The UK death rate for CHD has been decreasing for decades. However, the death rate for CHD for men under 64 years is higher in the UK (44 deaths per 100,000 population) than in comparable Western European countries (17 deaths per 100,000 population in France; 25 in Spain; 40 for the EU as a whole) (Allender et al, 2008a). For women, the age-standardised death rate for CHD is 11 per 100,000 population for the UK, compared with three for France, four for Spain, and ten for the EU. France has the lowest CHD death rate in Western Europe for both men and women (Ibid).

Age-standardised death rates from stroke for men aged under 64 are nine per 100,000 for the UK, compared with seven for France. Comparable figures for women are seven deaths per 100,000 for the UK, compared to four in both France and Spain. Switzerland has the lowest rate in Western Europe for men, at five stroke deaths per 100,000 and three deaths per 100,000 for women under 64 (Ibid).

Alongside these differences in premature death rates, there is some evidence to suggest that many other EU member states perform better than the UK in their provision of heart health care. The Euro Consumer Heart Index (July 2008) provides a ranking of European national cardiovascular healthcare systems across key areas. This study ranked the UK ninth out of EU member states, just after Slovakia (Bjornberg & Yazbeck, 2008).

CVC members believe that a strategic approach to cardiac and vascular policy is needed in order to reduce levels of premature death to one of the lowest levels in Western Europe.

Reduce inequalities in the prevalence and treatment of cardiac and vascular disease

The burden of cardiac and vascular disease falls disproportionately on people living in disadvantaged circumstances and on particular ethnic groups (DH, 2008a).

The prevalence of coronary heart disease in men in England increases markedly with deprivation, with the rate being one-third higher among men in the most deprived group compared with the least deprived group. This difference is even greater in women, where those in the most deprived group have a rate of heart disease at least 50% greater than the least deprived group. Similar patterns are seen in the prevalence of stroke. Complications of diabetes such as heart disease, stroke and kidney damage are three and a half times higher in lower socioeconomic groups (All Party Parliamentary Group for Diabetes, 2006).

Ethnic origin also impacts on cardiac and vascular disease risk for certain conditions:

• People of African and African-Caribbean descent are at significantly higher risk of hypertension (Williams et al, 2004).
• Type 2 diabetes is up to six times more common in people of South Asian descent and up to three times more common in those of African and African-Caribbean descent. It is also more common in people of Chinese descent and other non-Caucasian groups (DH, 2001).

• South Asian and African-Caribbean people have three to five times greater risk of progression of chronic kidney disease than other ethnic groups. Complications of diabetes and hypertension are largely responsible for this increased risk, again highlighting the important links between these conditions (Kidney Research UK website).

Alongside evidence of regional variations in mortality and morbidity (Allender et al, 2008b), there is compelling evidence showing regional variations in access to care.

• The CVC-commissioned report *Access to Cardiac Care in England* (Oxford Healthcare Associates, 2009 [in press]) highlights clear geographical inequity in access to cardiac interventions both within the four countries of the UK, and within each country at the regional level. For example, it demonstrates a clear regional variation in access to revascularisation, suggesting that for example, patients in the north east and north west are at a clear disadvantage to patients in London and the south east.

Combating inequalities should be at the core of cardiac and vascular planning:

• Measures should be adopted to ensure that the level of cardiac and vascular disease deaths in all local authority areas is reduced to the current level in south east England, or below.

• Dedicated services, awareness raising campaigns and research in particular groups known to suffer disproportionately from cardiac and vascular disease are needed.

• Diversity impact assessment frameworks should be applied to all care pathways to benefit disadvantaged groups.

• People with more severe mental illness such as schizophrenia and bipolar disorder are twice as likely to die from coronary heart disease as the general population (DH, 2006a) – the cardiac and vascular needs of this group should be addressed.

• Inequalities should be monitored using group data in primary care and other large databases, capturing data on outcomes as well as prevalence. The Connecting for Health programme could be a useful mechanism to help deliver this.

• The extent to which inequalities are addressed should be a key success measure for the next decade and all new initiatives should be subject to full equality impact assessments.
Achieve better integration of the patient pathway across health and social care

Current organisational arrangements break the patient pathway – an individual’s journey through illness and care – into separate parts, often with poor co-ordination between them. The professionals involved may have different employers, objectives and IT systems. Measures are needed to enable services to work together more effectively.

Integration across provider organisations has been greatly strengthened by the development of networks for heart disease, stroke, diabetes and kidney disease. These are working well in some areas, but are lacking in others. Further development of networks requires adequate resources, agreed protocols, and a successful multidisciplinary approach. The creation of the Care Quality Commission is timely, and it should have an interest in this process.

Patients should receive seamless and appropriate care that begins with prevention of the onset of symptoms and encompasses treatment, rehabilitation, social, and palliative care as required:

• Services should be better co-ordinated across primary, secondary and tertiary care in the NHS, by encouraging further development of integrated care organisations, including cardiac, diabetes, kidney and stroke networks.

• Measures should be introduced to improve the co-ordination of services across different sectors, such as the NHS and social services.

• Good care planning should involve working in partnership to identify and meet individual priorities to deliver an agreed care plan.

• A patient held record card could be re-introduced to record diagnosis, significant test results, emergency treatment received and secondary prevention measures undertaken, including rehabilitation and targets for treatment.

• Treatment tariffs should ideally reflect the whole package of care rather than the individual components.

• Hospital discharge should be co-ordinated more efficiently to provide for the needs of patients and carers immediately on discharge. This needs to match rapid patient turnover in hospitals. Patients and carers should be involved in discharge planning.
How to achieve these ambitions

1. Standards of excellence

A major strength of cardiac and vascular disease medicine is the strong evidence base that guides best practice. Evidence-based best practice should be promoted by:

• Setting national minimum standards of care.
• Encouraging clinical leadership to translate evidence into practice.
• Rapid implementation of new and existing evidence-based guidelines at the local level.
• Supporting prompt evaluation of new evidence by the National Institute of Health and Clinical Excellence, as proposed by the *NHS Next Steps Review* (Darzi, 2008).
• Measures to encourage wide sharing of evidence for effective interventions, making use of emerging channels such as the NHS Evidence portal.

We need measures and incentives to ensure that recommendations are implemented locally. To achieve this, national and local audits and registries in cardiac and vascular diseases should be strengthened and integrated analysis developed. For example, the Myocardial Ischaemia National Audit Programme (MINAP) is a high quality and effective part of the National Audit Service. It is crucial that secure funding is provided to support this programme, and other registries for cardiac and vascular disease. Additionally, new funding to allow the development of programmes to audit other aspects of services, such as atrial fibrillation, is required.

The delivery of excellent care requires well-trained professionals who receive ongoing training to keep their knowledge and skills up-to-date as innovations are introduced.

2. A patient centred approach

The person with cardiac or vascular disease should be placed at the centre of service and treatments, together with their carers and family, in line with the new vision for the NHS (Darzi, 2008). The aim should be to develop true partnerships between people with long-term conditions and the professionals and volunteers who care for them, underpinned by care plans, encouragement of self management where appropriate, and better patient information.

• It should be clear to patients and carers how their views have been taken into account and are making a difference to planning and provision.

• Patient outcomes should be measured, rather than focusing only on processes. Methods to capture patient experience should be included in implementation.

*Greater involvement of third sector organisations*

Third sector organisations representing patients with cardiac and vascular conditions and those around them should be encouraged to play a greater role in ensuring their needs are addressed in policies and services.
Measures to improve compliance with treatment and patient empowerment

Many patients with cardiac and vascular conditions need to take treatment on a long-term basis to reduce their risk of further events or complications. Patients need effective education about their condition, how their treatment works and why they need to undergo it. Evidence suggests this type of education is sometimes lacking. For example, research commissioned by the Stroke Association found that only 46% of stroke survivors questioned said they had been given information about preventing a further stroke (Stroke Association, 2006). The NHS Constitution makes patient information a right, and information prescriptions for people with long-term cardiac and vascular conditions should help in guiding people to relevant and reliable sources of information about their health and care.

• Systems should be developed to further involve patients in decision-making and to improve understanding of and concordance with treatment. This should include communicating care plans to patients and carers both orally and in an appropriate written form.

• Effective use should be made of existing public and patient forums, such as Local Involvement Networks (LINks), the Expert Patient Programme, local support groups, and the emerging Expert Carer Programme – Caring with Confidence.

Carers

Carers play a crucial role in the ongoing care, rehabilitation and recovery of patients. The Government has already demonstrated its support for carers, with its New Deal for Carers, and its follow-up, Carers at the heart of 21st century families and communities (DH, 2008b). However, a recent survey commissioned by the CVC showed that only 5% of carers had had a formal assessment of their needs for support (Hutton et al, 2008).

• Carers’ needs should be assessed and included in the planning of a patient’s package of care.

3. A new focus on prevention

Prevention is any activity that reduces the prospect of medical problems in the future. There are two main types of prevention:

• Primary prevention reduces risk in apparently healthy people.

• Secondary prevention targets patients with recognised cardiac and vascular conditions.

Prevention measures are ultimately the most effective way to reduce illness and prevent premature deaths, and should be at the heart of future planning for cardiac and vascular conditions. Outcomes should be evaluated – particularly for the high risk population. This will allow more reliable estimates of future demand for acute and chronic services.

Many prevention measures are effective across a number of different cardiac and vascular conditions, yet services sometimes focus on the immediate problem presented by a patient and do not look at their other risk factors. For example, a recent study showed that only one-third of people admitted to hospital with an acute stroke were discharged on a lipid-lowering drug even though it is likely that far more would benefit from this treatment (Bourke et al, 2006).
Comprehensive cardiac and vascular risk assessment and prevention measures should be encouraged, with particular emphasis on making further progress in smoking prevention and cessation and reducing obesity. Anecdotal evidence suggests that funding is often limited and short term. Resources must be provided to put these measures in place over the long term.

• Commissioners should be given training and support to help them deliver evidence-based prevention and health promotion programmes, and better understand how to act on local need. A recent King’s Fund report found that although commissioners have become more skilled at assessing population needs in recent years, they have less expertise in translating this information into service provision (Boyce et al, 2008).

• Incentive schemes should be developed to encourage healthcare professionals to implement prevention measures.

• Social marketing programmes should be delivered nationally and locally to inform populations about risks, prevention measures and services available to support behaviour change.

**Obesity**

The UK has a high rate of obesity (body mass index > 30kg/m2) compared with the rest of Europe. In 2005, nearly one in four (24%) UK adults were classified as obese (Craig & Mitchell, 2006) and the Foresight project predicts that this will increase to more than half by 2050. The proportion of cardiac and vascular disease, including Type 2 diabetes, stroke and kidney disease attributable to obesity will also increase substantially.

Future planning for cardiac and vascular health should support and link with programmes, such as Change4Life, to tackle the rising trend in obesity.

**Tobacco control**

Smoking remains a major cause of cardiac and vascular morbidity and mortality. Efforts to lower smoking have made a major contribution to reducing rates of these conditions. Nearly half (48%) of the decline in deaths due to coronary heart disease in England and Wales between 1981 and 2000 is attributed to reductions in risk factors, most notably smoking (Allender et al, 2008b). However, rates remain high, and even the most optimistic estimates suggest there will still be at least five million smokers in the UK in 10-12 years time (DH, 2008c). A new comprehensive tobacco control strategy is required to build on progress made in reducing health inequalities, and the burden of disease caused by smoking.

**Healthier environments**

Evidence suggests that individual advice on healthy behaviours is more effective when supported by a social and physical environment that promotes health. More emphasis is needed at the national and local level on developing health-promoting environments. Health and health inequality impact assessments should be included in all areas of government and local policy, in order to promote and support healthier lifestyles.

Legislative and regulatory measures are needed to help support people make healthier choices and tackle inequalities. Alongside a new tobacco control strategy, these might include: mandatory front-of-pack food labelling; a ban on TV advertising of high fat, sugar and fat foods before 9pm; and requirements for manufacturers to reduce salt and saturated fat content in foods.
Building on the Vascular Risk Assessment Programme

The CVC welcomes the roll out of the Vascular Risk Assessment Programme (VRA), to identify many of the major risk factors for cardiac and vascular diseases, and suggests that this should form part of a wider focus on prevention.

Although it is a national policy, implementation of the VRA will be decided at a local level ‘delivered in different ways to suit the needs of local populations.’ (DH, 2008c). Local needs should be systematically assessed and used to inform implementation, so that health inequalities are not inadvertently increased.

Plans and resources must be put in place to meet the needs of the large number of people identified by the VRA who will require follow-up. This may include help on understanding risk factors and assistance to change lifestyles, and treatment to reduce risk.

4. Effective commissioning

Measures should ensure commissioning supports the provision of the resources, services and staffing required to implement a new government plan. Major differences in the provision of services for people with cardiac and vascular diseases should be overcome by developing national minimum standards. There should be systematic assessment of risk and application of evidence-based guidelines for all patients.

The World Class Commissioning Programme (WCCP) aims to reduce inequalities between the areas of worst health and the overall population (DH, 2007b). The WCCP should be fully implemented. Use of the Health Inequalities Intervention Tool (London Health Observatory website) should be encouraged to help Primary Care Trusts (PCTs) and their partners narrow the life expectancy gap and reduce health inequalities.

Taking account of the local population’s needs to ensure equitable access may be particularly relevant for high technology procedures such as ablation for atrial fibrillation and emergency treatments such as primary Percutaneous Coronary Intervention (PCI) for heart attack.

Incentives should be available for the registration of all patients with cardiac and vascular conditions and with major risk factors such as hypertension, family history and raised cholesterol, and for implementing measures to reduce risk. Some of these are already achieved in GP Quality and Outcomes Framework (QOF) indicators, but could be extended to include all relevant risk factors and evidence-based measures with a clear outcome benefit. To enable improved information sharing, data protection protocols should be reconsidered.

5. Research

Research has a vital role in improving standards – with the potential to provide novel approaches to prevention and treatment and achieve step changes in the quality of care. Research is required to explore epidemiological trends in cardiac and vascular diseases, to develop and assess the impact of new treatments and interventions, to scrutinise evidence-based policies, and to determine the impact of prevention programmes.
In many ways, the NHS is an ideal organisation for research, caring for large numbers of people in the same service, using similar management approaches and shared guidelines. Our strong heritage in cardiac and vascular research should be built upon, and the best use made of the very rich sources of information collected in NHS databases, while ensuring patient confidentiality and the highest levels of governance. Connecting for Health may help facilitate research, although this programme has yet to deliver its full potential.

There is growing concern among health professionals and patient organisations about the process of research in the NHS. CVC members report that NHS research has been stifled by an increased bureaucratic burden. Ways of streamlining research approval processes should be explored.

- Measures should be introduced to maintain and strengthen the UK as a world leader in clinical trials in cardiac and vascular diseases, conducted by both NHS and non-NHS research bodies.

- The establishment of the UK Clinical Research Network and topic specific networks, such as those for stroke, kidney disease, and diabetes, are helpful first steps in improving research in the NHS. A dedicated cardiac and vascular disease research network should be established, alongside condition specific networks.

- Primary care should be included in research and development programmes and incentives should be introduced to actively encourage PCTs to take on responsibility for supporting research. There should also be incentives for GPs to participate in research.

6. Addressing specific areas of need

Measures are required to address key areas where targets have not yet been met or were outside the remit of the existing NSFs. Priorities for further work in cardiac and vascular conditions include:

- Prevention in children
- Congenital conditions
- Emerging needs for acute conditions
- Emerging needs for chronic conditions
- Rehabilitation
- End of life care

**Prevention in children**

Following standards set in the Children’s National Service Framework, measures specifically devoted to improving children’s long-term cardiac and vascular health are required.

The growing emphasis on prevention, early risk detection and treatment based on current risk factors and genetic testing for conditions such as channelopathies (conditions that affect the movement of ions through cell membranes) and familial hypercholesterolemia (inherited high cholesterol) means that there will be a greater need for child specific services to deal expertly with young people.
• Future planning should include prevention and specialised services for children and young people with cardiac and vascular conditions. This should extend the standards set in the Diabetes and Renal NSFs.

• Childhood prevention strategies aimed at tackling smoking, increasing physical activity and improving diets are needed.

• Children, young people and families should receive high quality cardiac and vascular services that are co-ordinated around their individual and family needs and take account of their views, as set out in the NSF for Children.

**Congenital conditions**

Congenital heart disease (CoHD) is a defect in the structure of the heart and primary blood vessels which is present from birth. Congenital conditions are different from acquired cardiac and vascular diseases, as they are present at birth and require different treatment. The number of people affected by congenital conditions is small compared to most other cardiac and vascular conditions. However, this group of patients was not included in the CHD NSF and needs to be included in future planning.

CVC member charities report that services for CoHD patients are patchy. As a consequence, there is variability in patient outcomes, with specialist services difficult to access in some parts of the country. Care planning processes need to ensure patients have access to treatment in age appropriate, well staffed, specialist centres throughout the course of their life.

**Children**

CoHD is the commonest birth defect, affecting approximately one baby in every 133 (or 5,000 babies every year in the UK). About half of these have major and life-threatening structural heart defects, requiring surgery and life-long follow-up. Congenital conditions should be addressed specifically, because although some general measures, such as provision of excellent treatment, will apply, there are also specific needs that should be met. The majority (85%) of babies with CoHD are born to women with no identifiable risk factors, which makes the case for whole population screening of pregnant women.

• A national policy/pathway to improve the diagnosis and management of CoHD is needed.

• Services for congenital cardiac and vascular conditions should be commissioned nationally.

• The audit of variations in outcomes in the management of CoHD should be strengthened and measures taken where required to match the outcomes achieved in the best performing centres.

• Charities working in this area would like to see more specialist training for healthcare professionals working with children with congenital heart and vascular diseases.

• Routine antenatal ultrasound screening should include examination of the fetal heart for major congenital anomalies. National standards for screening should be introduced and audited to reduce current variations.
Grown up congenital heart disease patients

80-85% of people born with CoHD now survive to adulthood, with an annual increase of 2,500 young adults (Somerville, 2002). Evidence suggests that some adults are still being treated by paediatricians due to the lack of specialist adult services, while others are seen in local adult cardiology centres where there are varying levels of expertise in treating congenital conditions (Somerville 2002).

- A national structure should be developed for grown up congenital heart disease (GUCH) patients, providing properly resourced and staffed specialist care in geographically appropriate centres. These centres and their locations should take into account demand and critical mass, implementing the centre structure defined in the NHS GUCH Guide (DH, 2006b).

- GUCH patients have a high prevalence of complex rhythm problems, so centres for these patients must have ready access to sub-specialists with experience of managing these problems.

Emerging needs for acute conditions

The growth in the prevalence of vascular disease due to the ageing population will be accompanied by an increase in acute events such as heart attack, unstable angina, stroke, malignant arrhythmias and acute heart failure. This must be planned for, since many of these patients will be older and likely to have complex vascular disease requiring a greater degree of supportive care and longer hospital stays than is currently the case. For example, one of the biggest pressures to be faced in the next ten years will be the demand for intensive therapy unit beds.

- Strategic planning should drive the use of evidence-based treatments, protocols and interventions that have already transformed the expected outcomes of many acute cardiac and vascular conditions.

- Where recommended standards from previous guidance have not been achieved, the reasons for this should be explored and improvement measures put in place.

- The NSF for CHD called for patients with suspected cardiac arrest to receive trained help, including use of a defibrillator, within eight minutes of calling for help. This has not been achieved in most locations and must be urgently addressed.

- As demand for services increase and technologies improve, scanning and diagnostic facilities will need to be reviewed.

- Equitable and timely access to medical interventions is needed - for example, primary PCI for ST segment elevation myocardial infarction, rapid imaging and appropriate reperfusion therapy for stroke and vascular access for dialysis. Improved pre-hospital care and diagnosis will be key in meeting these objectives.

Heart disease in pregnancy is an area where substantial progress is required. Heart disease is the commonest cause of death in pregnant women in the UK and maternal death from heart disease is rising. Sub-standard care was a factor in a third of all maternal cardiac deaths, according to a recent enquiry (Lewis, 2007).

- Specialised pregnancy services should be available for mothers with cardiac conditions.
Emerging needs for chronic conditions

The ageing population, combined with more people surviving acute events, will greatly increase the demand for long-term treatment and care. The greatest impact is seen in those affected by long term coronary and peripheral vascular disease. These patients are severely limited or incapacitated - for example, by cardiac and limb pain, and heart failure. Heart valve disease and chronic kidney disease will also become more prevalent in an ageing population.

- Strategic planning should continue to drive the use of evidence-based treatments for chronic conditions of cardiac and vascular origin, improve care in the community and provide better support for carers.

- Equitable and timely access to medical interventions that have the capacity to reduce mortality, improve quality of life and reduce hospital admissions such as re-synchronisation therapy for heart failure, should be facilitated.

Rehabilitation

Rehabilitation – measures to ensure sustained recovery and improvements in health and wellbeing – can enable significant improvements and reduce disability in the lives of people who have had a heart attack or stroke. Rehabilitation is widely agreed to be an area where more progress is needed.

The NSF for CHD promised that cardiac rehabilitation would be available to 85% of heart patients by 2002, but a recent National Audit of Cardiac Rehabilitation warned that around 60% of eligible patients are denied the chance of taking part and that many programmes are unable to meet minimum clinical standards. Around 55% of cardiac programmes are significantly under resourced, and as a result patients face a lottery in the degree of support they receive, even if they are referred for cardiac rehabilitation. Research commissioned by the Stroke Association found that only 37% of stroke patients were given information on physiotherapy services in their area, and only 17% received information on local speech and language services (Stroke Association, 2006). Some groups, such as ethnic groups, are under-represented in rehabilitation programmes.

The CVC is calling for substantial investment in rehabilitation for patients with cardiac and vascular conditions. Rehabilitation programmes should be comprehensive, not focusing simply on exercise regimes, but also addressing risk factor management, secondary prevention, psychological, family and social issues. They should be delivered in a culturally sensitive manner.

Services providing rehabilitation should be better co-ordinated across different sectors, by encouraging the development of integrated care organisations and networks.

Future planning should draw on past experience, setting out ‘what excellence looks like’ and providing the resources needed to achieve high quality rehabilitation to all patients who need it.

- Every patient with cardiac and vascular disease who is suitable and wishes to take part should be assessed for rehabilitation and offered a programme suitable to their needs.

- Rehabilitation should be given dedicated core funding to establish high quality programmes in an equitable way.
• An appropriate, dedicated tariff for cardiac rehabilitation should be established to ensure that it is properly funded, since it has historically been excluded from the tariff mechanism.

• Common minimum standards for rehabilitation should be agreed and monitored. For example, cardiac rehabilitation programmes should meet the core minimum standards set out by the British Association for Cardiac Rehabilitation (BACR, 2007) and participate in the annual National Audit of Cardiac Rehabilitation.

End of life care
Cardiac and vascular patients receive less specialist palliative and supportive care compared with other conditions, most notably cancer. This is despite the fact that the mortality and disability associated with some cardiac and vascular diseases, such as severe heart failure (Stewart et al, 2001), exceed that of most common cancers.

Surveys suggest that, given the opportunity and right support, most people would prefer to die at home. Many people with cardiac and vascular disease die in acute hospitals, which means that access to quality end of life care must be available in these settings. There must also be further consideration of alternative models of care in other settings to support people with cardiac and vascular disease in the final stages of life.

Recommendations on end of life care must aim to reduce the current inequitable provision of palliative and supportive care. This includes meeting the needs of minority groups.

The End of Life Care Strategy (DH, 2008d) aims to improve care for people approaching the end of life whatever their diagnosis and wherever they are, including enabling more people to be cared for and die at home if they wish.

• People with cardiac and vascular conditions should receive high-quality, well-planned and co-ordinated end of life care and support, meeting the criteria promised by the End of Life Care Strategy.

• The end of life care needs of those with cardiac and vascular conditions should be jointly assessed by providers and commissioners, with services tailored to meet those needs.

**Destination 2020** is the synthesis of the work of the 41 members of the alliance. Reports that underpin **Destination 2020** and detailed information on the priorities of member organisations, are available on the CVC website: www.cardiovascularcoalition.org.uk
References


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Department of Health (2006b) A commissioning guide for services for young people and adults with congenital heart disease (GUCH).


Department of Health (2008c) Consultation on the future of tobacco control.

Department of Health (2008d) End of Life Care Strategy: Promoting high quality care for all adults at the end of life.


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The Cardio and Vascular Coalition (CVC) is a national coalition of 41 voluntary organisations with an interest in promoting and protecting cardiac and vascular health in England. The CVC is committed to working with and influencing central and local government, health and social care commissioners, service planners and policy makers to ensure that cardiac and vascular health is high on their agendas.