



All-Party Parliamentary
Group for Diabetes



All-Party Parliamentary
Group on Heart Disease



All-Party Parliamentary
Kidney Group



All-Party Parliamentary
Group for Stroke



Tackling Cardiovascular Diseases: Priorities for the Outcomes Strategy

Contents

- 01_Foreword
- 02_Introduction
- 04_Prevention is better than cure
- 06_Person-centred treatment
- 08_Support to live with cardiovascular diseases
- 10_Conclusion and summary of recommendations
- 13_Annex



Foreword

Excellent progress has been made in tackling cardiovascular diseases over the last decade. But we cannot be complacent. Cardiovascular diseases are still the biggest killer in England, and can have a devastating effect on people's lives. The fact that we are living longer, and that our lifestyle choices are putting us at greater risk of developing these diseases, is threatening to destroy what we have already achieved. Add to this the major structural changes being made to the way healthcare is provided, and the current financial pressures, and it is clear that we need to do more if we are to sustain and improve progress.

The Government's announcement that it would be producing a new Cardiovascular Disease Outcomes Strategy recognised this, and was welcome acknowledgement of the important links between the various conditions.

The All-Party Parliamentary Groups on Heart Disease, Stroke, Kidney and Diabetes decided to come together to examine the key priorities for addressing cardiovascular diseases and to inform the development of this new Strategy. It is the first time we have come together in this way and reflects the need for more joined up policy making from the Government. We worked together with those that represent the voice of people living with these conditions and healthcare professionals – the real experts in tackling and living with cardiovascular diseases – to help ensure the Strategy will deliver the better outcomes that people deserve.

We would like to thank the members of the Cardio and Vascular Coalition who took the time to provide written submissions and those that came along to speak at and participate in the four Parliamentary meetings. These sessions were invaluable, thought provoking and constructive, giving us cause for both optimism and concern. Their contributions have formed the basis for our report.

We hope that those in the Department of Health working on the Outcomes Strategy find our report useful and take on board our recommendations.



Helen Jones MP, Chair,
All-Party Parliamentary Group for Stroke

Robert Buckland MP, Co-Chair,
All-Party Parliamentary Kidney Group

Madeleine Moon MP, Co-Chair,
All-Party Parliamentary Kidney Group

Chris Ruane MP, Chair,
All-Party Parliamentary Group on Heart Disease

Adrian Sanders MP, Chair,
All-Party Parliamentary Group for Diabetes

What are cardiovascular diseases?

Cardiovascular diseases include conditions that directly affect the heart, such as arrhythmias, cardiomyopathies and congenital heart disease and conditions that arise as a consequence of vascular disease, such as coronary heart disease, stroke, transient ischaemic attack, and peripheral vascular disease as well as conditions that can lead to, or result from, vascular disease including diabetes and chronic kidney disease.

Having one organ affected by vascular disease greatly increases the risk of it affecting another organ.



Introduction

The National Service Frameworks for coronary heart disease, diabetes and chronic kidney disease, the Stroke Strategy and NICE quality standards have all driven significant progress in tackling cardiovascular diseases in recent years:

- Premature deaths from coronary heart disease have fallen by more than 40% since 2000, and waiting times for heart surgery have been reduced.
- The number of people being diagnosed with chronic kidney disease at a late stage has decreased and since 2006 over 40% more people are on a register.¹
- There have been major advances in the quality of treatment available to many people with congenital heart disease, with around 80-85% surviving into adulthood.²

However, cardiovascular diseases are still the biggest killer in England, and stroke is the largest single cause of adult disability. Over 157,000 people died from cardiovascular diseases in 2008³ and around 300,000 are living with moderate to severe disability as a result of stroke.⁴ Up to 10% of the general population have significant kidney impairment and treatment of end stage kidney disease costs over £2 billion.⁵ There are 140,000 new diagnoses of diabetes each year and it is estimated that over five million people in the UK will have diabetes by 2025.⁶ Congenital heart disease affects one in every 133 babies born each year.⁷ There are a number of areas where improvements to treatment and care are needed, including:

- Management of heart failure and high blood pressure, diagnosis of atrial fibrillation, take up of cardiac rehabilitation and end of life care.
- Post-hospital and longer-term care for stroke survivors, and care for people arriving at hospital out of hours.
- Earlier diagnosis of chronic kidney disease, and testing of people living with kidney disease in their last year of life by GPs.
- Earlier diagnosis of Type 2 diabetes to prevent complications including stroke, kidney and heart disease, and improved care for people with Type 1 and Type 2 diabetes including more equal access to the diabetes care processes.
- Services for the increasing number of people surviving to adulthood with congenital heart disease.
- Wide variations in care across the country for all cardiovascular diseases.

In addition, an ageing population and the increasing prevalence of risk factors for cardiovascular diseases – in particular obesity – could start to erode the progress that has been made. There is also expected to be a large rise in the number of people with Type 2 diabetes. More, therefore, also needs to be done to prevent cardiovascular diseases by tackling the lifestyle factors which can lead to their development.

The Government announced in December 2011 that it would be developing a Cardiovascular Disease Outcomes Strategy. The All-Party Parliamentary Groups on Heart Disease, Stroke, Kidney and Diabetes, which all have an interest in this, agreed to work together to examine what the priorities for this Strategy should be.

*"We need to make sure that we end up with a Cardiovascular Outcomes Strategy that is not an end in itself but is a means to an end which is improving outcomes for patients and those at risk of cardiovascular disease."*⁸

Dr Mike Knapton, British Heart Foundation

Members of the Cardio and Vascular Coalition (CVC) – a group of 40 voluntary organisations with an interest in promoting and protecting cardiovascular health – and other interested organisations were invited to make written submissions addressing a number of questions in relation to prevention, risk assessment and early diagnosis, treatment, and living with cardiovascular diseases. The submissions received are included in the Annex of this report. They were supplemented by testimony from members of the CVC, representatives of the NHS, and patients, at four meetings hosted by the All-Party Parliamentary Groups. This evidence forms the basis of this report.

"[This lady] has Type 1 diabetes and was really badly looked after when she was a child, leading to kidney failure in her twenties... she had several heart attacks, I know she has had some strokes as well... her transplant failed after about a year. She is blind now and back on dialysis...her story is the reason that we need to have a Cardiovascular Disease Outcomes Strategy that looks after these people and does not let them get to that stage."

Fiona Loud, the Kidney Alliance

Prevention is better than cure

"This is the predicted increase in prevalence [in cardiovascular diseases as a result of lifestyle factors by 2050]... 44 % increase in coronary heart disease... 98% increase in diabetes... 23% increase in stroke... I think you can see the issues."

Dr Damian Jenkinson, Interim National Clinical Director for Stroke

The number of people at risk of developing cardiovascular diseases as a result of their lifestyle is high and set to increase. In 2010 only 25% of adults and 20% of children consumed the recommended five or more portions of fruit and vegetables a day, and there has been a significant increase in spending on items such as sugar and butter. Twenty per cent of people say they took walks of at least 20 minutes "less than once a year or never". Around 25% of adults and 16% of children were obese, and it is predicted that by 2050 47% of men and 36% of women could be obese.⁹ In 2009 21% of adults still reported smoking.¹⁰ Five thousand children a year are estimated to be born with congenital heart disease – which cannot be prevented.¹¹

Preventing people from developing cardiovascular diseases, including through the treatment of diabetes and diagnosing them earlier, will reduce the number of deaths from these diseases, and improve people's quality of life. It will also reduce the cost to the NHS of treating these diseases. It costs £14.4 billion a year to treat cardiovascular diseases in the UK.¹² There are also the wider costs to the economy such as lost working days and informal care that are estimated to be £16.3 billion a year.¹³ This is a real case of investing to save – although the Government must recognise that this is not a quick fix for the budget and that savings will only be realised in the longer term.

Leading from the top

"The difficulty is to persuade Governments to move the money from the back end [acute care], where there are quick and visible results, to the front end [prevention] where there are delays, but hugely bigger and more cost effective results."

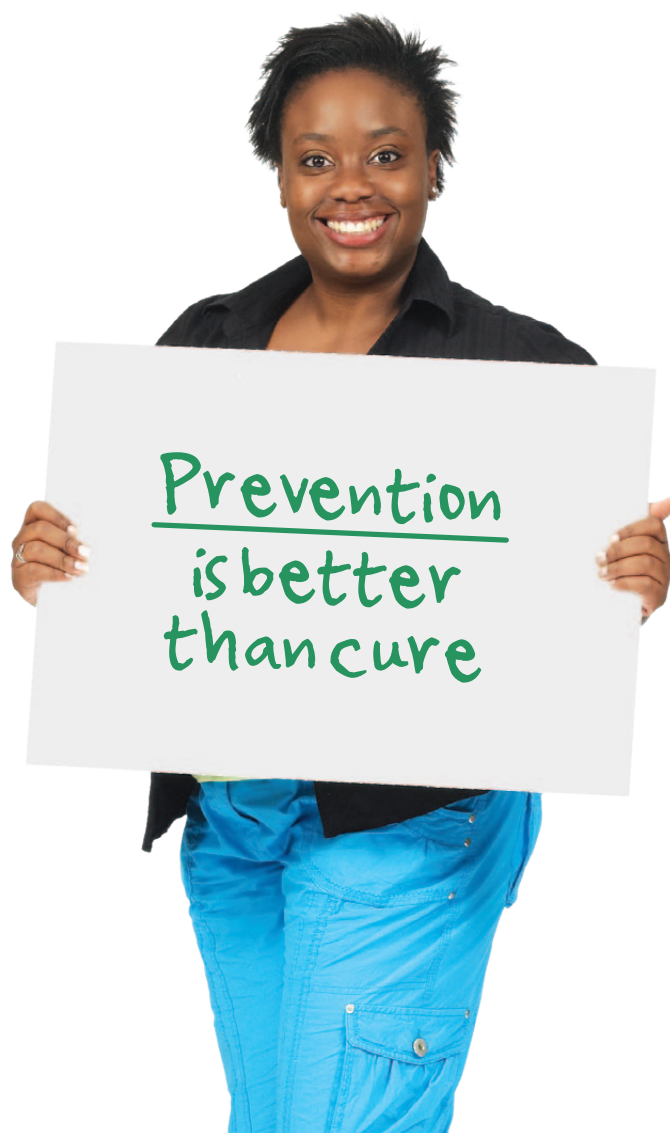
Lord Rea

CVC members felt that large scale health campaigns in other areas, such as behaviour change to prevent AIDS, and, more recently, recognising the symptoms of bowel cancer to increase early diagnosis, had been very successful. **The Outcomes Strategy should prioritise investment in campaigns to raise public awareness of the factors that can increase the risk of developing cardiovascular diseases and persuade people to make lifestyle choices that reduce this risk.**

"Now I speak to women on real issues and why we end up ill... It is to do with lifestyle you know."

Lynette Webbe, living with heart disease

However, CVC members were concerned that unhealthy behaviour was often the result of an unconscious decision prompted by, for example, unhealthy food and drink being advertised online. **The Outcomes Strategy should give further consideration to public health regulatory measures such as restrictions on the marketing of high fat, sugar and salt foods to children and the introduction of plain packaging for tobacco products.**



Checking it out

There are a significant number of people living with cardiovascular diseases, or the risk factors which lead to them, that do not know it. It is estimated that there are 850,000 people with Type 2 diabetes¹⁴ and up to 1.8 million with chronic kidney disease¹⁵ that remain undiagnosed.

There are some conditions, such as familial hypercholesterolaemia where a dedicated screening programme is needed,¹⁶ or atrial fibrillation where opportunistic pulse checks could be undertaken when people in the affected age groups are in contact with the health service.¹⁷ But for many people prevention, risk assessment and early diagnosis is best done as part of wider health check programmes such as the NHS Health Checks. Everyone between the age of 40 and 74 is eligible for an NHS Health Check every five years, which includes a number of simple tests to check for risk factors for heart and kidney disease, stroke and diabetes.

However, CVC members raised concerns about the proportion of people that are eligible for the NHS checks that have been offered them, as well as the number that actually took up the offer. In 2011-12, 14% of those eligible were offered a check. However, there was significant variation across the country ranging from over 20% in some PCT areas to less than 3% in others, against a recommendation from the Department of Health that PCTs set themselves a target of 18%. Three PCTs had failed to offer any health checks at all. And only 51% of those that had been offered a health check actually took it up.¹⁸ Concerns were also expressed that the results of those health checks that were delivered were not being followed up and opportunities for early diagnosis and prevention were being missed.

"Clearly if health checks are being done we would like to make sure that some action is being taken and results aren't just left gathering dust in a drawer somewhere."

Dr Dermot Neely, Heart UK

CVC members were also concerned that the transfer of the programme to local authorities in April 2013 as part of their public health responsibilities could make the situation worse. Under the Public Health Outcomes Framework local authorities will report on take up of health checks by those eligible. We believe authorities could look to improve take up by taking health checks out into the community, rather than expecting the community to come to them. **Public Health England should track the number of health checks that are offered and taken up, including amongst those communities most at risk of developing cardiovascular diseases. Directors of Public Health should report on the actions that were taken as a result of health checks conducted in their annual report.**

Tackling health inequalities

"A lot of the generic literature... is focussed on UK diets and a lot of the dietary needs of different communities are quite different."

Raj Chandarana, Diabetes UK

Your socioeconomic and ethnic group influences how likely you are to develop cardiovascular diseases. For example Type 2 diabetes is six times more common in the South Asian community, and three times more common in the African and Afro-Caribbean community than in the White British community – we heard worrying indications that these communities are also less likely to be aware of diabetes.¹⁹ And heart disease is one third higher in men and around 50% higher in women in the most deprived social group than in the least deprived social group.²⁰ These inequalities are well documented, yet CVC members highlighted their persistence as a key concern. This must be a genuine priority for the Outcomes Strategy.

CVC members told us of some excellent work they were doing to raise awareness of cardiovascular diseases amongst those at highest risk.

- Diabetes UK's Community Champions programme trains community leaders to raise awareness and carry out assessments for diabetes in Black Asian and Minority Ethnic communities, for example by running events.
 - The British Heart Foundation's Hearty Lives programme which provides tailored interventions in areas where people are at highest risk of heart and circulatory disease – including health coaches in a former mining town and delivering heart health education for young families through children's centres.
-

The transfer of responsibility for public health to local authorities presents an opportunity to make real progress on this issue. Authorities should work closely with the voluntary and community sector to raise awareness and encourage behaviour change and risk assessment amongst communities at higher risk of developing cardiovascular diseases. **Local authorities should ensure those at high risk are offered health checks and follow up support as a priority. The action taken to reduce cardiovascular inequalities should be part of the annual report made by Directors of Public Health.**

CVC members also pointed to the continued existence of an unacceptable variation in diagnosis and treatment of cardiovascular conditions. Provision of diagnostics such as echocardiography (the study of the heart in motion using ultrasound), and hospital treatment for conditions such as heart failure, congenital heart disease and care for diabetes and stroke were frequently described as "patchy" or "variable in quality". **The Department of Health should publish an additional Atlas of Variation which sets out the differences in cardiovascular care across England, and the NHS Commissioning Board should use this to ensure consistent standards of care.**

Person-centred treatment

"People do not have health problems or social care problems, they have problems."

Chris Clark, the Stroke Association

CVC members were clear that access to specialist care – whether for a heart condition, kidney disease, stroke or diabetes – should be available at the right time and in the right place. For example, evidence shows that people with cardiac conditions other than acute myocardial infarction have better outcomes if they are managed in specialised cardiac care units rather than in generic wards.²¹ Similarly, people on stroke units have better outcomes than those admitted to and treated on general wards.²² But CVC members also recognised that the different specialities tend to work in isolation, and that they need to be better integrated to improve outcomes for people living with cardiovascular diseases.

"The cardiologists and nephrologists continued to disagree [about whether to do an operation] and I was in a dilemma over the next five years."

Alan Craig, living with kidney disease and heart disease, stroke survivor

CVC members also highlighted the poor reputation that both different parts of the NHS, and the different organisations involved in providing health and social care, have for working together effectively to meet people's needs. The people living with cardiovascular diseases that spoke to us highlighted the need for improved communications and collaboration between healthcare professionals. In a recent survey of stroke survivors in the UK nearly half of respondents said poor joint working between health and social care services had been a particular problem for them.²³

"I felt like the parcel in a pass the parcel game, being sent to three different hospitals"

Ann Frewer, stroke survivor

CVC members felt that achieving healthcare that integrated the different medical specialities and joined up with social care depended on ensuring that people, and not process, were at the centre of their treatment. The changes to the structure of the healthcare system made by the Health and Social Care Act 2012 are intended to achieve this, although members felt that it was still unclear how the new structure would play out in practice. The Outcomes Strategy must ensure that the intention of the 2012 Act becomes a reality for people with cardiovascular diseases.

Educating for integration

"If the person... has a stroke they come to see me. I need to bear in mind that this person is not only at risk of going on to have another stroke, but their heart attack risk is two to three times greater."

Dr Damian Jenkinson, Interim National Clinical Director for Stroke

GPs and community nurses, as well as specialists, will often deal with people with cardiovascular conditions who may have, or be at risk of developing, other conditions.



"As a GP I do tend to see patients with stroke or heart disease - and they tend to have one and possibly two or three other conditions."

Dr Mike Knapton, British Heart Foundation

These include, for example, rheumatoid arthritis and obstructive sleep apnoea, as well as other cardiovascular diseases. People with cardiovascular diseases are also at greater risk of developing mental health problems, and those with mental health problems are at greater risk of developing cardiovascular diseases. CVC members highlighted the importance of providing education and training for health care professionals to improve their knowledge of the various conditions, and ensure they understand what to do when they come across people with them. This will become increasingly important as GPs will lead the Clinical Commissioning Groups responsible for commissioning services for people living with cardiovascular conditions. **Health Education England and Local Education and Training Boards should ensure that health care professionals, particularly those in primary care, are equipped with the training that they need to support people living with cardiovascular and related conditions.**

Networking for success

"The results for us have been phenomenal. We were aiming for 10% of patients to be thrombolysed [given clot busting drugs, only suitable for some stroke patients], given that we were on 3.5% and nationally it was about 2%. The fact that we have now gone up to 14% is phenomenal."

Helen O'Kelly, Assistant Director for Stroke, South London Cardiac and Stroke Network

Clinical networks – where all of those involved in the pathway for a particular condition in a certain geographical area come together to work out exactly what should happen on that pathway and how – were considered by many CVC members to have been instrumental in delivering the progress made in recent years. Since the development of the London Stroke Strategy, over 95% of patients now arrive at a hyperacute stroke unit within 30 minutes of the emergency services being called, 95% have brain imaging within 24 hours, and 86% are seen by a physiotherapist within 72 hours.²⁴

Clinical networks should have a key role in implementation of the Outcomes Strategy. The Strategy should ensure there is adequate resourcing of these networks and encourage networks for the different cardiovascular diseases to work together to ensure that the pathways for the various conditions are better integrated.

Commissioning for integration

"There is more than one set of blood pressure targets [for different cardiovascular conditions] around the place. So no wonder healthcare professionals are confused, but what about the poor old patient at the end of it as well, what are they to do?"

Fiona Loud, the Kidney Alliance

The way that services are commissioned will be crucial to ensuring that they are integrated around the needs of patients. CVC members felt that commissioning should cover the whole of the pathway. Particular concerns were raised about the need for services to be commissioned across the interface between primary and secondary care and that post-hospital care – including palliative and end of life care – should form part of this commissioning. CVC members also highlighted the pivotal role that the new Health and Well Being Boards will have in ensuring that services are joined up across the NHS and local authorities. **Health and Wellbeing Boards should ensure that Clinical Commissioning Groups and others commission patient experience surveys to measure the extent to which integrated services are being provided – both within healthcare, and between healthcare and social services.**

CVC members were concerned that the way that GP practices and hospitals are paid does not encourage integrated services. In particular they raised issues about the Quality and Outcomes Framework – under which GP practices are paid for performance against a number of indicators – which has individual sets of indicators for the different cardiovascular conditions, and different targets for indicators such as blood pressure between the different conditions. CVC members suggested that the Quality and Outcomes Framework should reward GPs for achieving joint targets across conditions. Similar concerns were raised about tariffs, under which hospitals are paid a standardised price for different operations and procedures, rather than for the whole package of care provided to a patient. In some cases tariffs have varied markedly from one year to the next, making strategic planning difficult. **The Quality and Outcomes Framework and relevant tariffs should be reviewed to ensure that they properly incentivise provision of integrated services.**

Support to live with cardiovascular diseases

"When I started in cardiology back in the 1970s [people who had suffered] a heart attack... died of that. Nowadays... we're saving people. The burden of that saving, though, is survivorship with a damaged heart, and that's what we have to deal with. That's no bad thing, but we're changing the goalposts."

Dr James Beattie, Consultant Cardiologist

The progress made in reducing premature deaths from cardiovascular diseases has meant that there are now more people living with these diseases long term. Yet the consensus amongst CVC members was that post-hospital and longer-term care has some way to go to match the improvements made in hospital treatment that have driven this progress.

"[I was] sent home with a leaflet on brain haemorrhage... that was literally it, a leaflet and no stroke pathway or anything."

Inger Wallis, stroke survivor

A key concern raised by the people living with cardiovascular diseases that spoke to us was the lack of support available following discharge from hospital. A survey of stroke survivors in the UK found that 39% of respondents had not been offered an assessment of their needs beyond hospital. Of those who did receive an assessment 60% had not received a care plan setting out how these would be met. And of those who had a review of their needs after leaving hospital, 47% had only had one review when reviews are recommended after six weeks, six months and then annually.²⁵

The 'Year of Care' model has helped to drive successful care planning for people living with diabetes. This yearly care plan is agreed as a result of a discussion between the person with diabetes and their diabetes healthcare team outlining individual needs and setting targets. In the evaluation people reported an improved experience of care and real changes in self-care behaviour; professionals reported improved knowledge and skills, and greater job satisfaction, and practices reported better organisation and team work.²⁶

The need for a better transition between child and adult services for congenital heart disease, to ensure patients continue to receive the support they need, was also highlighted by members.

Psychological and social as well as physical support

"[Being discharged from hospital was] nothing more than a prison sentence for me, served in my own home, in more or less solitary confinement."

Ann Frewer, stroke survivor

People told us that as well as the physical problems associated with cardiovascular diseases, they also encountered both practical problems and emotional issues. For example, difficulties with mobility and lack of suitable public transport can mean they are unable to get out of the house. One of the biggest problems people experience as a result was loneliness, which is often compounded by a lack of understanding of what has happened to them. Addressing the emotional needs of people living with cardiovascular diseases is important: poor physical health increases the risk of people developing mental health problems, and poor mental health is also associated with an increased risk of disease. The ability to continue to work where possible was also considered important.

"Ultimately, I was shoehorned into early retirement."

Stuart White, living with heart disease, diabetes and chronic obstructive pulmonary disease

Some programmes of support already exist, although there are issues with both availability and take up. Early Supported Discharge for stroke survivors provides intensive rehabilitation at home, but is currently only available in 37% of areas.²⁷ Cardiac rehabilitation offers people living with heart disease physical, psychological and social support to help them manage their own condition – however it is not offered universally and only 43% of eligible people take part.²⁸ Take up could be improved by explaining the benefits of the programme to patients as well as providing choice as to where support is provided – some will prefer to have this support at home, whilst others will prefer a group environment in hospital or a community centre. **The Outcomes Strategy must increase the emphasis on longer-term support for people living with cardiovascular diseases, ensuring their psychological and social support needs, as well as their physical needs, are assessed, met and reviewed regularly.**

Palliative care

People living with cardiovascular diseases should also be supported to make decisions about their end of life care at an early stage, given the unpredictability of some diseases and the impact that stroke or dementia may have on their ability to communicate their wishes. Health professionals should be trained to understand and be confident in talking to patients about end of life care.²⁹ For example, specialist heart failure nurses have said that training in end of life skills would help to improve the experience of people with heart failure.³⁰ **The Outcomes Strategy should encourage the development of new models of palliative care for people living with cardiovascular diseases.**

Access to information

"The voluntary and community sector is an essential complement to the clinical services that are provided."

Tom Greenwood, the Stroke Association

Some people living with cardiovascular diseases told us that they had received little by way of information from healthcare professionals, and had needed to be proactive in finding information and help to manage their condition. They had also experienced difficulties with information about their condition not being passed onto other healthcare professionals, meaning they had to repeat their medical histories. Online tools, such as Renal Patient View, which provide information to people on their condition as well as giving them access to data on their diagnosis, treatment and latest test results, which they can share with others, has helped to fill these gaps. Where possible, information should be integrated, for example, covering why maintaining a healthy diet, or stopping smoking is important across all cardiovascular diseases, rather than providing separate leaflets on these issues for different conditions.

"I was literally desperate to meet up with people who had had the same experience because, believe me, now I live in a different world to you. I do."

Inger Wallis, stroke survivor

People were not always aware of the advice and support provided by the voluntary sector, including the organisations providing specialist information to children, families and adults living with congenital heart conditions. **The Outcomes Strategy should ensure information signposts patients to the support available from the voluntary and community sector.**



Conclusion

"The Outcomes Strategy will need to recognise that today's heart patient could be tomorrow's stroke victim. Cardiovascular diseases don't wait in line – all too often people are living with more than one condition and this can have a devastating impact on people's lives."

Betty McBride, Chair of the Cardio and Vascular Coalition

If the Strategy is to deliver lasting improvements in prevention and supporting people living with cardiovascular diseases, then we need robust measures of success. While reporting against the existing outcome frameworks for the NHS, public health and social care and the forthcoming outcome framework for commissioning will provide some indication of progress, this cannot be relied upon alone.

CVC members highlighted the importance of clinical audit in measuring progress and improving outcomes. However, there were some concerns about Health Trust's willingness to participate and about audit databases being difficult for patients to access. **The Outcomes Strategy must ensure continued investment and the highest participation in clinical audit.**

There should also be cross-Government oversight of implementation of the Outcomes Strategy.

CVC members felt this would be valuable in ensuring that policies and programmes on the wide range of areas that impact on cardiovascular health are joined up between different Government departments.



Summary of recommendations

- Clinical networks should have a key role in implementation of the Outcomes Strategy. The Strategy should ensure there is adequate resourcing of these networks and encourage networks for the different cardiovascular diseases to work together to ensure that the pathways for the various conditions are better integrated.
- Health and Wellbeing Boards should ensure that Clinical Commissioning Groups and others commission patient experience surveys to measure the extent to which integrated services are being provided – both within healthcare, and between healthcare and social services.
- The Quality and Outcomes Framework and relevant tariffs should be reviewed to ensure that they properly incentivise provision of integrated services.
- The Department of Health should publish an additional Atlas of Variation which sets out the differences in cardiovascular care across England, and the NHS Commissioning Board should use this to ensure consistent standards of care.
- Health Education England and Local Education and Training Boards should ensure that health care professionals, particularly those in primary care, are equipped with the training that they need to support people living with cardiovascular and related conditions.
- The Outcomes Strategy must increase the emphasis on longer-term support for people living with cardiovascular diseases, ensuring their psychological and social support needs, as well as their physical needs, are assessed, met and reviewed regularly.
- The Outcomes Strategy should encourage the development of new models of palliative care for people living with cardiovascular diseases.
- The Outcomes Strategy should prioritise investment in campaigns to raise public awareness of the factors that can increase the risk of developing cardiovascular diseases and persuade people to make lifestyle choices that reduce this risk.
- The Outcomes Strategy should give further consideration to public health regulatory measures such as restrictions on the marketing of high fat, sugar and salt foods to children and the introduction of plain packaging for tobacco products.
- Public Health England should track the number of health checks that are offered and taken up, including amongst those communities most at risk of developing cardiovascular diseases. Directors of Public Health should report on the actions that were taken as a result of health checks conducted in their annual report.
- Local authorities should ensure those at high risk are offered health checks and follow up support as a priority. The action taken to reduce cardiovascular inequalities should be part of the annual report made by Directors of Public Health.
- The Outcomes Strategy should ensure information signposts patients to the support available from the voluntary and community sector.
- The Outcomes Strategy must ensure continued investment and the highest participation in clinical audit.
- There should be cross-Government oversight of implementation of the Outcomes Strategy.

Members of the Cardio and Vascular Coalition, and other interested organisations, have made detailed submissions which outline other key points they feel should be included in the Outcomes Strategy. These are included at the Annex.

References

- ¹ All statistics from evidence provided by Dr Damian Jenkinson, Interim National Clinical Director for Stroke to the All-Party Groups, 16 May 2012.
- ² Written submission from the Children's Heart Federation.
- ³ Coronary Heart Disease Statistics, 2010 edition, British Heart Foundation.
- ⁴ Written submission from the Stroke Association.
- ⁵ Written submission from the Kidney Alliance.
- ⁶ Written submission from Diabetes UK.
- ⁷ Written submission from the Children's Heart Federation.
- ⁸ All quotes taken from meetings held in Parliament by the All-Party Groups.
- ⁹ All figures from Statistics on obesity, physical activity and diet: England 2012, the NHS Information Centre.
- ¹⁰ Statistics on Smoking: England, 2011, The NHS Information Centre.
- ¹¹ Written submission from The Children's Heart Federation.
- ¹² Coronary Heart Disease Statistics, 2010 edition, British Heart Foundation.
- ¹³ Coronary Heart Disease Statistics, 2010 edition, British Heart Foundation.
- ¹⁴ Written submission from Diabetes UK.
- ¹⁵ Oral evidence given by Dr Damian Jenkinson to the All-Party Groups, 16 May 2012.
- ¹⁶ Written submissions from Heart UK and the British Heart Foundation.
- ¹⁷ Written submissions from the Stroke Association and the British Heart Foundation.
- ¹⁸ All statistics from the Department of Health NHS Health Checks, Number of eligible people that have been offered and received NHS Health Checks.
- ¹⁹ Oral evidence provided by Raj Chandarana, Diabetes UK to the All-Party Groups, 22 May.
- ²⁰ Diabetes and the disadvantaged: reducing health inequalities in the UK, 2006, All-Party Parliamentary Group for Diabetes and Diabetes UK.
- ²¹ Written submission from the British Heart Foundation.
- ²² Written submission from the Stroke Association.
- ²³ Written submission from the Stroke Association.
- ²⁴ All figures from evidence provided by Helen O'Kelly, Assistant Director for Stroke, South London Cardiac and Stroke Network, to the All-Party Groups, 23 May 2012.
- ²⁵ All statistics from the written submission from the Stroke Association.
- ²⁶ Written submission from Diabetes UK.
- ²⁷ Written submission from the Stroke Association.
- ²⁸ Written submission from the British Heart Foundation.
- ²⁹ Written submission from the National Council for Palliative Care.
- ³⁰ Oral evidence provided by Dr Mike Knapton, Associate Medical Director, British Heart Foundation to the All-Party Groups, 16 May.



Annex Contents

15__	Arrhythmia Alliance
16__	Blood Pressure Association
17__	British Association for Cardiovascular Prevention and Rehabilitation
19__	British Heart Foundation
23__	British Lung Foundation
26__	British Society of Echocardiography
31__	British Society for Heart Failure
33__	Children's Heart Federation
36__	Diabetes UK
42__	Education for Health
44__	Genetic Alliance UK
45__	Grown up Congenital Heart Disease
47__	Heart of Mersey
50__	Heart UK
52__	Kidney Alliance
56__	Kidney Research UK
60__	Little Hearts Matter
61__	Mental Health Foundation
64__	National Council for Palliative Care
68__	National Heart Forum
71__	National Rheumatoid Arthritis Society
72__	Stroke Association
76__	Tiny Tickers

Submission from the

Arrhythmia Alliance



Arrhythmia Alliance would like to offer the following statement in recognition of the valuable work needed to shape the Cardio and Vascular Disease Outcomes Strategy:

Arrhythmias, including atrial fibrillation, sudden cardiac death and unexplained loss of consciousness must be a priority on the CVD Strategy policy as arrhythmias is the number one cause of death in the UK killing more than 100,000 people each year from SCA. Unexplained loss of consciousness and syncope is frequently misdiagnosed with up to 30% of adults diagnosed with epilepsy when in fact many have an underlying, potentially fatal, arrhythmia. AF is the leading cause of stroke and heart failure. We must therefore strive to improve diagnosis and access to appropriate treatment for all those suffering with cardiac arrhythmias.

www.heartrhythmcharity.org.uk

Blood Pressure Association



1. What is your vision for the outcomes strategy? What conditions should be covered by the outcomes strategy? Where do we need to focus efforts in the coming decade and what is the balance between prevention and treatment? What needs to be sustained and what has been overlooked?

Our vision is to see prevention of cardiovascular disease as being the biggest priority. We'd like to see a much greater emphasis on prevention. Blood pressure, Cholesterol, Diabetes and Atrial Fibrillation control are key to reducing Cardiovascular disease. With particular focus on blood pressure– high blood pressure is responsible for 60% of strokes and 40% heart attacks as well as a risk factor for kidney disease and dementia amongst others. It's essential that we move towards prevention. Stroke has the biggest financial cost and also has a huge cost to society.

We also need to ensure people who have been diagnosed with high blood pressure have it under control. We need to identify the 5 million people in the UK with high blood pressure, but don't know it (as it has no symptoms). More money invested in prevention will mean far less money will need to be spent on treatment.

2. Who needs to do what to achieve the ambitions for reducing cardiovascular diseases and improving treatment for people with inherited heart disease? What is the role of national government, the NHS Commissioning Board, Public Health England, local directors of public health and clinical commissioning groups?

A national framework for prevention with key targets for the NHS Commissioning Board (and clinical commissioning groups) needs to be established. This needs to look at blood pressure, cholesterol and atrial fibrillation. Key priorities for blood pressure are:

- Ensure those who have been diagnosed with hypertension have their blood pressure controlled, this could mean relevant compliance programmes are put in place and local services are also offered where necessary, for example, weight loss.
- People with high blood pressure and who do not know it are identified and offered free blood pressure checks. This can take place through a number of avenues, work place testing, NHS health checks, community testing etc and can tie in with local government public health services.
- Ensure salt targets are put in place for post 2012, current salt reduction targets are due to expire at the end of this year. No announcement has yet been made on whether this is likely to continue. Reducing salt consumption at a national level is one of the cheapest and most successful public health interventions.
- Technology that can help with diagnosis/ compliance needs to be used, for example clinically validated blood pressure monitors, smart phones to help with drug compliance, exercise etc.

3. How will we know whether progress is being made on these ambitions? What should be measured and how?

A series of key targets and measures need to be set for each condition. With the use of regional data, local targets and measures can then be used to ensure progress is being made and the right things are being measured.

4. A key challenge is the need to properly re-frame cardiovascular diseases as long term conditions, how can we ensure that people get the support that they need to live well and manage their health?

Patient journeys and pathways need to be drawn from the prevention stage and intervention stages identified using the most appropriate tools available. This will also allow a systematic review of resources and will mean different interventions and tools can be evaluated.

British Association for Cardiovascular Prevention and Rehabilitation



BACPR Standards and Core Components for Cardiovascular Disease Prevention and Rehabilitation (2nd Edition)

On behalf of the British Association for Cardiovascular Prevention and Rehabilitation (BACPR), we are delighted to announce our new standards and core components. These can be readily downloaded at www.bacpr.com/resources/15E_BACPR_Standards_FINAL.pdf.

The second edition of the BACPR Standards and Core Components for Cardiovascular Disease Prevention and Rehabilitation replaces the previous guidelines published in 2007. Seven core standards and seven core components are set out which aim to improve uptake and quality of rehabilitation programmes nationwide. Patients, healthcare professionals and commissioners should expect the following from high quality cardiac rehabilitation services:

1. The delivery of seven core components employing an evidence-based approach.
2. An integrated multidisciplinary team consisting of qualified and competent practitioners, led by a clinical coordinator
3. Identification, referral and recruitment of eligible patient populations.
4. Early initial assessment of individual patient needs in each of the core components, ongoing assessment and reassessment upon programme completion.
5. Early provision of a cardiac rehabilitation programme, with a defined pathway of care, which meets the core components and is aligned with patient preference and choice.
6. Registration and submission of data to the National Audit for Cardiac Rehabilitation.
7. Establishment of a business case including a cardiac rehabilitation budget which meets the full service cost.

Cardiac rehabilitation is one of the most clinically and cost-effective therapeutic interventions in cardiovascular disease management (Figure 1). Cardiac rehabilitation is effective in improving the cost effective use of NHS resources. However, to realise these benefits it must be delivered in accordance with the associated evidence-base. Of concern audit data suggests that provision in the UK remains incomplete.

Figure 1: The benefits of cardiac rehabilitation Cardiac rehabilitation:

1. Reduces:
 - All cause mortality by 11-26% ^{1 2 3 4}
 - Cardiac mortality by 26-36% ^{1 2 3 4}
 - Morbidity ^{4 5}
 - Unplanned admissions by 28-56% ^{6 7}
2. Improves:
 - Quality of life ⁸
 - Functional capacity ⁸
3. Supports:
 - Early return to work ⁸
 - The development of self-management skills ⁸

Our new standards and core components continue to call for: referral of all eligible patients by cardiologists and/or specialist cardiovascular health care physicians to a prevention and rehabilitation programme as a standard (not optional) policy that is held in the same regard as the prescribing of cardioprotective medications; the provision of comprehensive integrated cardiovascular prevention and rehabilitation programmes to be properly funded as a cost-effective means and obligatory element to any modern cardiology or vascular health care service; and tighter control of service audit (e.g. through NACR), not only to ensure these standards and core components are being met but to demonstrate that improved practice, clinical effectiveness and health outcomes have been achieved

The BACPR now begins work in communicating these standards and core components through publication in an appropriate scientific journal and a textbook to guide delivery of programmes to meet the standards. We also begin important work towards supporting the implementation of these standards and core components by: developing a performance indicators' tool; providing resources for service development e.g. tool-kits for business case development, exemplary assessment frameworks and mechanisms for effective knowledge transfer and training; and developing competency frameworks that are fully supported by high quality education and training programmes and research where required.

We hope this information is useful to the discussions and would be most grateful for notification of future meeting dates to bacpr@bcs.com.

We'd be most grateful for your support in communicating these revised standards throughout the APPG. Thanking you in advance for supporting us in our overall aim: "To promote excellence in cardiovascular disease prevention and rehabilitation".

References

- ¹ Heran et al. Exercise-based cardiac rehabilitation for coronary heart disease. Cochrane Database of Systematic Reviews 2011, Issue 7. Art. No: CD001800. DOI: 10.1002/14651858.CD001800.pub2.
- ² Taylor on behalf of the 2011 Cochrane Review Authors. The RAMIT trial: its results in the context of 2012 Cochrane review. *Heart* 2012; 98: 672-3.
- ³ Taylor et al. Exercise-based rehabilitation for patients with coronary heart disease: systematic review and meta-analysis of randomized controlled trials. *Am J Med* 2004; 116(10):682-697.
- ⁴ Lawler et al. Efficacy of exercise-based cardiac rehabilitation post-myocardial infarction: A systematic review and meta-analysis of randomized controlled trials. *Am Heart J* Oct 2011; 162: 571-584.
- ⁵ Clark et al. Meta-Analysis: Secondary Prevention Programs for Patients with Coronary Artery Disease. *Ann Intern Med* 2005; 143(9): 659-672.
- ⁶ Lam et al. The effect of a comprehensive cardiac rehabilitation program on 60-day hospital readmissions after an acute myocardial infarction. *J Am Coll Cardiol* 2011; 57:597, doi:10.1016/S0735-1097(11)60597-4.
- ⁷ Davies et al. Exercise training for systolic heart failure: Cochrane systematic review and meta-analysis. *Eur J Heart Fail* 2010; 12(7): 706-715.
- ⁸ Yohannes et al. The long-term benefits of cardiac rehabilitation on depression, anxiety, physical activity and quality of life. *Journal of Clinical Nursing* 2010; 19(19-20):2806-2813.



1. What is your vision for the outcomes strategy? Where do we need to focus efforts in the coming decade and what is the balance between prevention and treatment? What needs to be sustained and what has been overlooked?

The BHF warmly welcomes the development of a cardiovascular disease outcomes strategy. We have long called for a renewed strategic approach to tackling cardiovascular disease in England.¹ The National Service Framework for Coronary Heart Disease delivered a step change in the treatment and care of heart patients in England and the new strategy should build on this foundation.

We recognise that the new strategy sits in an emerging context of outcome frameworks, NICE guidelines and quality standards, regulatory arrangements from the Care Quality Commission and Monitor and new structures to join up health players at the local level. It is vital that the cardiovascular disease outcomes strategy adds to the value of this emerging architecture, is more than the sum of these parts, and is viewed as a means to an end rather than an end in itself.

The NHS, and wider public sector, is facing an unprecedented financial situation. This is likely to bring changes to the way that services are delivered and more emphasis on prevention than chronic disease management could reduce the economic burden of disease in the long term. An important function for the strategy will be ensuring that optimum standards of care are delivered to all people living with cardiovascular disease, wherever they live in England.

Outcome: Preventing people from dying prematurely

- Prevention – there has been good progress in reducing people's chances of an early death from cardiovascular disease in recent years. But these improvements have not benefitted everyone equally and so it will be important for the strategy to focus on tackling health inequalities, especially closing the gap between affluent and deprived groups and amongst different ethnic groups. This may require dedicated interventions in particular parts of the country or for particular parts of the population. The BHF is taking such an approach through our flagship Hearty Lives programme, which is investing £11million in local areas where people are at a higher than average risk of heart and circulatory disease. We are working in partnership with local authorities and health trusts to develop programmes that meet local needs. As one programme does not fit the needs of all communities, we are supporting tailored interventions in each locality. These include health coaches in a former mining town, psychological support for heart patients, supporting employers to set up workplace health programmes and delivering heart health education for young families via children's centres.²
- Early diagnosis – the strategy should address widespread underdiagnosis for a range of cardiovascular conditions including hypertension³ and atrial fibrillation – over 15,500 strokes every year are attributable to undiagnosed atrial fibrillation. While some people might be identified through NHS Health Checks, the strategy should also consider other measures including encouraging opportunistic pulse checks whenever people from relevant age groups are in touch with the health service and whether data held by GP practices could be better utilised.
- Primary angioplasty – the most recent data shows that 82% of heart attack patients in England received the gold standard treatment of primary angioplasty.⁴ The strategy should sustain this progress, including through investment in staffing and cardiac catheter laboratories.

- Out-of-hospital cardiac arrests – survival rates for out of hospital cardiac arrests remain poor in the UK with between two and twelve per cent of people surviving to be discharged from hospital depending on where the arrest takes place.⁵ The strategy should commit to cross government action to give everyone the best possible chance of survival. This could include training more people in CPR, recording and increasing the number of automatic defibrillators in public places, investment in community first responders and ensuring the quickest possible ambulance response times.
- Inherited cardiac conditions – the strategy should ensure appropriate investment in identifying people living with undiagnosed inherited conditions. In particular, a national familial hypercholesterolemia cascade screening programme would effectively identify people living with this potentially fatal condition. The need for such a programme was recognised by NICE in 2008 but this has yet to be implemented fully.⁶
- End of life care – historically, there has been less investment and understanding of the end of life care needs of people with long term conditions other than cancer, including heart failure patients. Despite therapeutic advances, which enable many people to live full lives for many years, heart failure is a progressive clinical syndrome that causes death. Although not all patients will require specialist end of life care, many do require general palliative and supportive care when living with heart failure. The strategy should ensure adequate provision of heart failure specialist nurses, who play a vital role in supporting people living with heart failure, including helping to identify when patients are approaching end of life and avoiding hospital admissions. The strategy should also look to develop new models of best practice for palliative care for long term conditions other than cancer. The BHF is working in partnership with Marie Curie Cancer Care and NHS Greater Glasgow and Clyde on a five year programme to improve quality of, and access to, palliative care for people with advanced heart failure. The aim is to develop pioneering models of care which can be replicated by others in different parts of the UK.⁹

Outcome:

Enhancing quality of life for people with long-term conditions

- Cardiac rehabilitation – the BHF has long championed cardiac rehabilitation, a programme that offers lifestyle advice and support to people with established coronary heart disease to help them manage their own condition. It improves quality of life by helping people to live with their heart condition and to prevent a further major heart event. However, the latest available figures show that only 43% of heart patients in England took part in cardiac rehabilitation.⁷ In addition, particular sections of the population, including women and people from ethnic minority backgrounds, are under-represented in existing programmes. The new strategy should ensure that all heart patients who are suitable and wish to take part are offered access to a properly resourced cardiac rehabilitation programme.

Outcome:

Ensuring that people have a positive experience of care

- Cardiac care units – people with cardiac conditions other than acute myocardial infarction need to be managed in specialised cardiac care units rather than generic wards to maximise outcomes. The strategy should ensure all hospitals admitting acute patients have an appropriately sized, staffed and equipped cardiac care unit, where high risk patients with a primary cardiac diagnosis should be managed.⁸
- Integrated care – there is a consensus that services need to be designed around patients rather than around systems and that people should have all their physical, psychological, health and social care needs met. The strategy should support the development of commissioning and service provision models that attempt to make this policy ambition a reality. The BHF has recently invited applications for models that deliver integrated care for people living with cardiovascular disease. Despite issuing clear guidelines, the applications that came back demonstrated that there is widespread misunderstanding and confusion about what integrated care really means in practice.

- Specialist nursing – the value of specialist nursing has been proved through the BHF's sustained investment in developing healthcare professionals. Between April 2009 and March 2011, BHF nurses reported that they were responsible for avoiding 19,555 unplanned hospital admissions. This has saved the NHS in the region of £34.5million. The strategy should ensure that all heart patients have access to a specialist nurse when they need one. Where specialist nurses are in post, they need the resources and capacity to train other healthcare professionals in their locality to meet the needs of heart patients in the community.

2. Who needs to do what to achieve the ambitions for reducing cardiovascular diseases? What is the role of national government, the NHS Commissioning Board, Public Health England, local directors of public health and clinical commissioning groups?

At the national level:

- The Department of Health needs to work with other government departments as many of the measures needed to address inequalities and improve prevention require action outside of the health arena. The strategy should be governed by a cross ministerial advisory group in the same way as has been established for the mental health strategy.¹⁰
- The Department of Health review of clinical networks and senates should ensure consistent provision of high quality cardiac support across the country. The networks played a vital leadership role in development and implementation of the National Service Framework for Coronary Heart Disease and should play a similar role for implementation of the outcomes strategy.¹¹
- The NHS Commissioning Board should produce an annual report on implementation of the strategy, including identifying and working to address any unacceptable variations in practice. The Board should also scrutinise the extent to which cardiovascular disease is prioritised at a local level according to prevalence in the local area.
- Public Health England should establish and maintain a repository of proven approaches to preventing cardiovascular disease, including supporting diverse communities and engaging with lower socio-economic groups.
- The Centre for Workforce Intelligence and Health Education England should ensure that the 2013 review of the cardiology workforce takes into account the staff needed to deliver the outcomes strategy.¹²

At the local level:

- Clinical commissioning groups will need to commission a range of services to meet the outcomes in the strategy including primary care, ambulance services and diagnostics. As well as commissioning ambulance services, they should consider a broader range of provision to increase survival following cardiac arrest including provision of emergency life support training, defibrillators in relevant public places and the creation of a network of community first responders.
- Clinical commissioning groups should also ensure that they are commissioning integrated service provision for people living with cardiovascular disease, meeting physical and mental health needs and joining up health and social care.
- Directors of Public Health should include details in their annual report of how they have used NHS health checks to inform the supply and demand of appropriate services including smoking cessation and weight management interventions. They should also report on how they are seeking to engage with the wider population about their cardiovascular health and how they have used local authority powers to further public health.¹³
- Health and wellbeing boards should ensure that joint strategic needs assessments take into account prevalence of cardiovascular disease in the local area and genuinely inform commissioning decisions. An analysis that we conducted in 2010 found that only half of joint strategic needs assessments identified heart disease as a priority for the area, even though over 80% of strategic commissioning plans identified heart disease as a priority.¹⁴
- Ambulance trusts should raise awareness of the importance of seeking emergency help when experiencing chest pains, ensure they are meeting required response times following suspected myocardial infarction and co-ordinate community resuscitation work.

3. How will we know we are making progress on these ambitions? What should we measure and how?

- Tackling health inequalities should be the key barometer for the outcomes strategy and all progress should be assessed against the extent to which it is closing the heart health gap between affluent and deprived groups and between different ethnic groups.
- Preventing and tackling cardiovascular disease should be seen as part of all the domains in the NHS Outcomes Framework. The current indicators place cardiovascular disease largely in domain 1 on preventing people from dying prematurely. The strategy should consider the other domains as outlined in response to question 1 above.
- The Public Health Outcomes Framework includes an indicator on take up of NHS Health Checks. This should measure broader risk assessment and follow up with the local population rather than only focusing on a process that only some people will engage with. The framework also includes measures on smoking cessation, overweight adults and children and physical inactivity – consideration should be given to regulatory approaches that may help to make progress in these areas including restrictions on marketing of high fat, sugar and salt foods and the introduction of plain packaging for tobacco. History shows us that public health benefits from timely, evidence-based legislation.

- The Commissioning Outcomes Framework includes a number of measures on tackling cardiovascular disease but these lack consistency. The framework should be revised following publication of the strategy to give clinical commissioning groups a sense of priority and scale for the proposed indicators on ambulance response times, quality of life for people with long term conditions, cardiac rehabilitation, episodes of ill health, patient experience and end of life care.
- The strategy should ensure ongoing investment in established clinical audits on heart failure, acute coronary syndromes, hypertension, congenital heart disease, cardiac surgery and other areas.¹⁵ The existing audit of cardiac rehabilitation, funded by the British Heart Foundation, should be funded by clinical commissioning groups as they are required to report on provision of cardiac rehabilitation in the Commissioning Outcomes Framework. The new requirement on ambulance trusts to collect data on survival rates from out of hospital cardiac arrests should be used to assess the frequency of effective interventions such as CPR.
- In order to identify and address geographical inequalities, consideration should be given to publication of a Cardiovascular Atlas of Variation.¹⁶ If such a publication were produced, support should be provided to those working in local areas where there is a higher prevalence of disease or poorer outcomes for people living with cardiovascular conditions.
- The forthcoming core set of quality indicators should include a focus on tackling cardiovascular disease. A recent analysis of existing quality accounts conducted by the BHF found that only 12% of providers prioritised cardiac arrest, heart attack or heart failure services as an area for improvement in 2010/11, compared with 19% for stroke and 34% for venous thromboembolism. In addition only 2% of providers had prioritised the experience of cardiovascular patients as an area for improvement in 2010/11.
- The strategy should include measurement of patient experience of the interventions and services that are put in place to support people living with cardiovascular disease.

5. How will voluntary organisations be contributing to meeting these ambitions?

The BHF will be making a number of contributions to help ensure the ambitions for the new strategy are realised:

- We are the single biggest independent funder of cardiovascular research in the UK, identifying new areas of science and supporting the best researchers from the UK and abroad. In particular, we are seeking to spend £50million on regenerative medicine which could transform the lives of people living with heart failure.¹⁷
- We support over 750 cardiac specialist healthcare professionals across the UK and have pioneered a number of innovations in cardiac care. We are currently investing in models of delivering integrated cardiovascular care.
- We are helping to tackle heart health inequalities by working in partnership with local authorities and health trusts to develop innovative ways to support people at high risk of developing premature heart disease.¹⁸
- We give voice and support to heart patients and carers through our Heart Voices patient involvement programme,¹⁹ our online community,²⁰ campaigning for change,²¹ our helpline²² and heart support groups.²³

References

- ¹ Cardio and Vascular Coalition (2009) Destination 2020: A Plan for Cardiac and Vascular Health.
- ² <http://www.bhf.org.uk/heart-health/how-we-help/in-your-area/hearty-lives.aspx>.
- ³ NHS Rightcare (2011) NHS Atlas of Variation 2011.
- ⁴ NICOR (2011) Myocardial Ischaemia National Audit Project: Tenth Public Report.
- ⁵ Perkins GD, Cooke MW. Variability in cardiac arrest survival: the NHS Ambulance Service Quality Indicators. *Emerg Med J* 2012 29 doi: 10.1136/emered-2011-200758. Available at: <http://emj.hiwire.org/content/29/1/3.full.pdf>.
- ⁶ National Institute for Health and Clinical Excellence (2008) Identification and management of familial hypercholesterolaemia.
- ⁷ BHF (2011) National Audit of Cardiac Rehabilitation Annual Statistical Report 2011.
- ⁸ British Cardiovascular Society (2011) From Coronary Care Unit to Acute Cardiac Care Unit – the evolving role of specialist cardiac care.
- ⁹ <http://www.bhf.org.uk/default.aspx?page=12961>.
- ¹⁰ DH (2011) No health without mental health: a cross-government mental health outcomes strategy for people of all ages.
- ¹¹ Ipsos Mori (2010) Coronary Heart Disease National Service Framework: An Evaluative Review Among Key Stakeholders.
- ¹² Centre for Workforce Intelligence (2011) Cardiology medical fact sheet and summary sheet.
- ¹³ This could include a range of measures such as restrictions on the number of outlets selling high fat, sugar and salt food or improvements to make it easier for people to walk and cycle. The National Heart Forum have produced a toolkit of how local authority powers could be used – <http://www.healthyplaces.org.uk/>.
- ¹⁴ BHF (2010) Heart Health on the Commissioning Agenda: A Document Review.
- ¹⁵ <http://www.ic.nhs.uk/services/national-clinical-audit-support-programme-ncasp/heart-disease>.
- ¹⁶ <http://www.rightcare.nhs.uk/index.php/atlas/our-proposed-programme/>.
- ¹⁷ <http://www.bhf.org.uk/research/mending-broken-hearts/the-science.aspx>.
- ¹⁸ <http://www.bhf.org.uk/heart-health/how-we-help/in-your-area/hearty-lives.aspx>.
- ¹⁹ <http://www.bhf.org.uk/heart-health/how-we-help/training/hearty-voices.aspx>.
- ²⁰ <http://community.bhf.org.uk/>.
- ²¹ <http://www.bhf.org.uk/get-involved/campaigning.aspx>.
- ²² <http://www.bhf.org.uk/heart-health/how-we-can-help/support/heart-helpline.aspx>.
- ²³ <http://www.bhf.org.uk/heart-health/how-we-help/support/heart-support-groups.aspx>.



The importance of early intervention in obstructive sleep apnoea

Background

- Obstructive sleep apnoea (OSA) is a condition in which a person experiences repeated episodes of apnoea (stopping breathing) because of a narrowing or closure of the airway in the upper throat (pharynx) during sleep.
- The most common signs of OSA are snoring and interrupted breathing while asleep, and excessive sleepiness when awake. OSA places a considerable strain on the body, and is associated with a number of serious health problems, including cardiovascular disease.
- OSA is a common condition. It is estimated that at least 4% of men and 2% of women have symptomatic OSA. Figures from 2008 suggest that around one million people in England may have symptomatic OSA.¹
- Although OSA can affect men, women and children of all ages, OSA is more prevalent in certain risk groups. Major risk factors for developing OSA are obesity, increasing age and being male.² The number of people affected may rise due to more people being overweight and obese.
- Treatment is simple and cost-effective. The recommended treatment for moderate to severe OSA is continuous positive airway pressure (CPAP), although a variety of other treatment options are also available, particularly for obese patients and those with milder OSA.

OSA and cardiovascular disease

- Untreated OSA makes an important contribution to cardiovascular risk, including of arrhythmias, stroke and coronary heart disease. Research has shown that people with OSA have higher blood pressure than matched controls; and epidemiological studies have shown OSA to be an independent risk factor for hypertension, even when confounding demographic and lifestyle factors are excluded.³
- Death from cardiovascular disease is accordingly higher in people with severe OSA, and the mortality rate increases with the severity of OSA. In one large cohort study, cardiovascular disease accounted for 42% of all deaths in those with OSA, compared to 26% of matched controls.⁴ Men with severe OSA have a 58% higher adjusted risk of incident heart failure than men without OSA.⁵
- Inversely, OSA prevalence is higher amongst patients with cardiovascular conditions. Between 30% and 57% of patients with Coronary Artery Disease have also been found to have OSA.⁶
- OSA is associated with type 2 diabetes. OSA is common amongst people with type 2 diabetes, and data suggest that OSA is independently associated with alterations in glucose metabolism which places patients at increased risk of development of type 2 diabetes.⁷

Benefits of early intervention

- Continuous positive airway pressure (CPAP) is recommended by NICE for treatment of moderate and severe OSA, as it leads to more quality-of-life years and lower costs than non-treatment.⁸
- Effective treatment of OSA is accompanied by a reduction in blood pressure, although data vary across severity grades. CPAP treatment has been shown to have a significant effect on mean arterial blood pressure in those with severe OSA.⁹
- Accordingly, CPAP treatment is associated with a reduction in cardiovascular risk. Effective treatment can serve as primary prevention and secondary prevention of adverse cardiovascular outcomes. It is estimated that treatment with CPAP reduces the 10-year incidence of myocardial infarction by 49%, and the 10-year risk of stroke by 31%.¹⁰
- Improved diagnosis and treatment of OSA can therefore contribute significantly to reducing cardiovascular morbidity and mortality.
- Successful treatment brings wider societal benefits, including an often transformative impact on quality of life for patients and families; significantly decreased risk of occupational and road traffic accidents; increased work productivity; and reduced longterm healthcare costs. Patients with untreated OSA are heavy users of healthcare services, and have been estimated to incur health costs of approximately double those of the general population.¹¹

Obstacles to early diagnosis and treatment

- In spite of OSA being common, identifiable and treatable, knowledge of the condition is often limited and diagnosis rates remain low. It is estimated that between 80% and 90% of cases are undiagnosed.¹² Low diagnosis and treatment rates come at considerable health and economic cost.
- Obstacles to diagnosis include a lack of public awareness and self-referrals; a lack of knowledge amongst primary care practitioners of symptoms, risk factors and screening techniques; and regional discrepancies in availability of specialist diagnostic sleep services.
- In view of present low diagnosis rates and the existence of distinct risk groups for OSA, more needs to be done to screen those at greatest risk.

Recommended priorities for the Cardiovascular Disease Outcomes Strategy

What is your vision for the outcomes strategy?

- We welcome the principle underlying the strategy of a joined-up approach to cardiovascular diseases across multiple condition areas and areas of care. The strategy should be at the forefront of the shift from single-disease frameworks to patient-centred models of care, better able to cope with multimorbidity.¹³ It is essential that this extends to improving outcomes for those with single or multiple morbidities that place them at risk of developing cardiovascular disease.
- The strategy must provide new impetus to identify relevant risk groups and reduce eventual likelihood of vascular events. This should include recognition of the importance of early detection and intervention in less well-known conditions, such as OSA, that are closely linked with high blood pressure and multiplication of vascular risk.

- The strategy must bring together the various quality improvement mechanisms already in place, including the stroke strategy, the NHS and Public Health Outcomes Frameworks, and NICE Quality Standards, to facilitate coherent implementation for commissioners and service planners. A Quality Standard for Sleep-disordered breathing (of which OSA will be a major component) has been referred to NICE for development.

Who needs to do what to achieve the ambitions for reducing cardiovascular diseases?

Nationally:

- There should be OSA representation on national and regional implementation and review boards for the strategy. The British Lung Foundation (BLF) has a wide network of OSA patient contacts and medical advisors with specialist knowledge of sleep medicine, and is ideally placed to support this work.
- The strategy will need to operate in conjunction with future and pre-existing public health initiatives and local public health bodies to address obesity and smoking levels and reduce health inequalities in these areas.

In primary care:

- The strategy should further work that is being done to improve early diagnosis of hypertension in primary care. This may involve specific tasking of, and investment in, primary care nurse teams.
- Routine preliminary screening for core OSA symptoms should be considered in primary care for those presenting with hypertension and type 2 diabetes. Assessment of cardiovascular risk and target organ damage is currently recommended in the NICE clinical guideline for management of hypertension.¹⁴ The type 2 diabetes guideline recommends annual assessment of cardiovascular risk, screening for renal disease and target and intervention levels in the context of regular blood pressure monitoring.¹⁵ Neither mentions OSA. Preliminary screening of core symptoms of OSA for referral to specialist diagnosis can be carried out swiftly and cheaply in primary care through case history and assessment of daytime sleepiness levels.

How will we know we are making progress on these ambitions?

- It is essential that the ambitions outlined in the strategy are supported by data collection to drive and support implementation. The Department of Health should produce an annual report on implementation of the strategy. This should include analysis of progress and regional variations in early detection and diagnosis rates.
- There is currently a paucity of data on OSA referrals, diagnosis and treatment. The BLF is asking the Government to undertake national OSA audits to assess standards of OSA service provision and identify variations, enabling commissioners and service planners to provide targeted services. This would contribute to the ongoing review process of the strategy, alongside established clinical audits for cardiovascular disease. In addition, there should be standardised data systems, used across all specialist sleep services, to provide data on the numbers of patients receiving OSA treatment.

- Early and accurate OSA diagnosis and treatment will make a contribution to the indicators in the NHS Outcomes Framework relating to cardiovascular disease, notably those in domain 1: preventing people from dying prematurely.
- OSA screening and specialist referrals should be introduced into local and national Quality and Outcomes Frameworks (QOF). This would both allow for more accurate data on the number of referrals being made from primary care, and provide an immediate financial incentive for an early intervention that will reduce costs and improve outcomes in the long term.

How will voluntary organisations be contributing to meeting these ambitions?

The BLF is leading a major campaign to raise awareness of OSA and improve diagnosis and treatment. Objectives include increasing awareness amongst health care professionals (especially in primary care) and the public; helping to find those with undiagnosed OSA and improve their quality of life; establishing OSA as a strategic priority within government; and encouraging improvements to services. More specifically, the following initiatives can contribute both to meeting the ambitions of the strategy and to supporting its implementation.

Information and awareness:

- The BLF is producing a range of information resources for the general public, and for OSA patients, sleep clinics and primary care providers, both online and in hard copy.
- In the next year, the BLF will deliver pilot OSA awareness campaigns and events in targeted geographical areas. The BLF already runs highly successful knowledge and awareness campaigns for COPD, which are bought in from the BLF by commissioners for their local areas.

Expert knowledge and advice:

- Work is being undertaken to analyse potential gaps and variations in sleep service provision across the UK.
- The BLF convenes an OSA advisory group to provide expert guidance on a range of strategic and technical issues. Membership includes specialist sleep physicians, respiratory nurses, technicians, patients and carers.

Representing patients and their families:

- The BLF will lead a UK-wide patient survey to find out what patients think about the services they receive, and what they would like to see improved.
- The BLF has experience in bringing together patient focus groups, and currently convenes a COPD patients' group, at the request of the Department of Health, which provides advice on issues relating to respiratory conditions, including the implementation of the outcomes strategy for COPD and asthma in England.
- The BLF is developing resources to support patient and lay representatives on local and regional health and commissioning boards.

Further information

For further information on any of the above, please contact Malcolm Reid at Malcolm.Reid@blf-uk.org or on 0207 688 5588.

References

- ¹ CPAP for the treatment of OSAHS: Costing templates and report. NICE, Implementing NICE guidance, 2008.
- ² Continuous positive airway pressure for the treatment of obstructive sleep apnoea/hypopnoea syndrome. NICE technology appraisal guidance 139, 2010.
- ³ Management of Obstructive Sleep Apnoea/Hypopnoea Syndrome in Adults: A national clinical guideline. Scottish Intercollegiate Guidelines Network, 2003.
- ⁴ Young, Finn, Peppard, Szklo-Coxe, Austin, Nieto, Stubbs and Hla. "Sleep Disordered Breathing and Mortality: Eighteen-Year Follow-up of the Wisconsin Sleep Cohort". *Sleep* 2008; 31(8):1071-8.
- ⁵ Gottlieb, Yenokyan, Newman, O'Connor, Punjabi, Quan, Redline, Resnick, Tong, Diener-West and Shahar. "Prospective study of OSA and incident coronary heart disease and heart failure: The Sleep Heart Health Study". *Circulation* 2010; 122(4):352-60.
- ⁶ Lee, Nagubadi, Kryger and Mokhlesi. "Epidemiology of Obstructive Sleep Apnoea: a population-based perspective". *Expert Rev Respir Med.* 2008; 2(3): 349-364.
- ⁷ Lee, Nagubadi, Kryger and Mokhlesi. "Epidemiology of Obstructive Sleep Apnoea: a population-based perspective". *Expert Rev Respir Med.* 2008; 2(3): 349-364; Downey, Obstructive Sleep Apnoea. Medscape reference, 2011.
- ⁸ Continuous positive airway pressure for the treatment of obstructive sleep apnoea/hypopnoea syndrome. NICE technology appraisal guidance 139, 2010.
- ⁹ Continuous positive airway pressure for the treatment of obstructive sleep apnoea/hypopnoea syndrome. NICE technology appraisal guidance 139, 2010.
- ¹⁰ Pietzsch, Garner, Cipriano and Linehan. "An integrated health-economic analysis of diagnostic and therapeutic strategies in the treatment of moderate to severe OSA". *Sleep* 2011;34(6):695-709.
- ¹¹ Management of Obstructive Sleep Apnoea/Hypopnoea Syndrome in Adults: A national clinical guideline. Scottish Intercollegiate Guidelines Network, 2003.
- ¹² One of a million? British Lung Foundation, 2012.
- ¹³ Cf. Barnett, Mercer, Norbury, Watt, Wyke and Guthrie. "Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study". *Lancet*, 2012.
- ¹⁴ Hypertension: Clinical management of primary hypertension in adults. NICE clinical guideline 127, 2011.
- ¹⁵ National Collaborating Centre for Chronic Conditions. Type 2 diabetes: national clinical guideline for management in primary and secondary care (update). Royal College of Physicians, 2008.

British Society of Echocardiography



1. Introduction to Echocardiography

Echocardiography is a non invasive test that provides comprehensive information about the structure and function of the heart using ultrasound. First developed in the late 1950s, the technique was popularised during the 1970s because of its ability to see the heart moving in real time. By the 1980s echocardiography was part of routine cardiovascular practice and has remained central to the investigational strategies of cardiologists ever since.

Echo uses a number of different modes to interrogate the heart. Initial scanners used m-mode (or motion mode) which was able to scan only at one point allowing an idea of the heart structures in motion but only in a single scan line. The introduction of sector scanning allowed much larger areas of the heart to be interrogated and its motion observed. This was the first form of scanning which produced an image which actually looked like a heart in motion. Spectral Doppler and colour allowed the quantification of blood flow and with it the function of heart valves. All these elements, as well as advanced techniques such as tissue Doppler and most recently 3 dimensional echo, are deployed in every study to ensure a comprehensive assessment of the heart.

Not just an Echo!

Transthoracic Echo (TTE). Here the scan is conducted using an ultrasound probe located on the chest wall. The majority of echocardiography is performed in this manner.

Transoesophageal Echo (TOE). The scan is conducted in a semi invasive way (like upper gastrointestinal endoscopy), with a probe in both the stomach and oesophagus. This is a specialised technique performed in hospital when adequate views can not be obtained by TTE.

Stress Echocardiography. This scan is performed on the heart under resting and stress conditions to observe its response. The stress can be either in the form of drugs or exercise. The usual purposes of the test are either to investigate angina or to look for myocardial viability (areas of heart muscle which do not work but might if blood flow were restored). Increasingly, heart muscle and valvular heart disease are also reasons to undergo stress echo.

Contrast Echocardiography. This divides into two main types; Micro-bubble transpulmonary contrast allows very clear visual appreciation of the heart chambers. It can be used where images are unclear using conventional techniques or during stress echo. This technique is under utilised when compared to guidelines. Agitated saline contrast echo does not cross the lungs and is therefore used to look for concealed shunts from the right to the left side of the heart. This is particularly relevant in the investigation of unexplained stroke.

Point of Care Echocardiography for Emergency Indications. A number of heavily protocol driven schemes for the assessment of the shocked patient have been developed. These are an invaluable adjunct to initial resuscitation but do not supplant the need for subsequent TTE.

What does an Echo tell us?

The Echo examination will give a large amount of data on heart function across a range of heart diseases from the very rare to the very common. Below are outlined some key areas where the Echo provides vital clinical information:

Left Ventricular Performance

The assessment of heart function and particularly left ventricular function is a key parameter in assessing prognosis and likely response to treatment in a range of cardiovascular diseases including heart failure due to ischaemic heart disease, cardiomyopathy and cancer chemotherapy.

Echocardiography can measure the thickness of the heart walls, identify any areas of heart attack related scarring and measure the proportionate amount of blood the heart can pump on each heart beat – the Ejection Fraction. The Ejection Fraction, a parameter that is key for decision making in heart failure patients, is most usually obtained from echocardiogram. This parameter is central to identifying people with heart failure in the heart failure clinic.¹ It guides the need for additional prognosis improving treatments after a heart attack, and decision making about whether to implant cardiac devices such as defibrillators.² Serial measurements of ejection fraction guide Herceptin therapy in women with breast cancer³ and the application of this technique enters a myriad of different treatment decisions. But heart failure is not always associated with a reduced ejection fraction and echocardiography can also aid in the assessment of cardiac relaxation which is implicated in many of these cases.

Advanced techniques in Echo can be useful in the early assessment of inherited heart muscle disease, even in hearts that look ostensibly normal to the eye. Echo assessment is also part of the work up for establishing the risk of sudden cardiac death in competitive athletes.

Valvular Function

Echo has a unique aptitude for examining heart valve structure and function. All four valves can be readily visualised by TTE or TOE. This is vital for the evaluation of both chronic heart valve disease such as aortic stenosis or rheumatic heart disease and acute diseases such as bacterial endocarditis. Most of the information required to plan treatment and follow up can be gleaned from echocardiography.

Structural Heart Disease

To have normal cardiac structures is vital for health but congenital abnormalities are relatively common (1/100 pregnancies). Echocardiography performed either before birth, in childhood or as an adult can establish whether structural abnormalities that required intervention are present.

2. The British Society of Echocardiography

The British Society of Echocardiography is the UK's national professional society and was established twenty one years ago to promote excellence in echocardiography. It is an independent charitable organisation with a membership comprising of clinical scientists and doctors undertaking echocardiography. The current membership is around 2500 practitioners.⁴ The scope of activity is outlined below.

Individual Accreditation

Individual accreditation is a voluntary process which practitioners may undergo to demonstrate that they have achieved a basic level of competence. Although voluntary it is increasingly seen as the badge of ability which employers look to. It is mirrored, but not identical to, other schemes offered by the European Association of Echocardiography and the American Society of Echocardiography. The process consists of a written examination, a log book of 250 cases and a number of marked video cases. Individual accreditation is offered in TTE, TOE, Community echocardiography and soon Intensive Care Echocardiography.

Departmental Accreditation⁵

Departmental accreditation was launched as a voluntary process by which departments could benchmark their processes against agreed national minimum standards. Advanced accreditation is available for departments that perform above and beyond this level. With the strong assistance and support of the British Heart Foundation, the departmental accreditation process has gained popularity and there are currently around 30 accredited departments with more in the process of accrediting. Departmental accreditation, as part of its remit, incorporates clear standards for quality assurance, which have been lacking from many departments historically. The BSE has been working with the IQIPS team to harmonise the departmental accreditation process with the forthcoming cardiovascular physiological accreditation process being hosted by the Royal College of Physicians.⁶

Education

BSE offers a wide range of educational activities, including producing nationally relevant guidelines and protocols, organising a range of online activity and hosting a number of major national meetings.

3. Vision for the outcomes strategy

Where do we need to focus efforts in the coming decade and what is the balance between prevention and treatment? What needs to be sustained and what has been overlooked?

The last twenty years have seen a startling advance in these areas, with a steadily declining age adjusted mortality and the blossoming of both disease prevention and disease modifying treatment strategies. The National Services Framework⁷ represented a comprehensive plan to reduce the risks posed by coronary heart disease from population interventions to revascularisation and rehabilitation. Chapters six and eight incorporate the areas of heart failure and arrhythmia /sudden cardiac death. These documents were responsible for a revolution in the shape of care, but are now between seven and twelve years old. New paradigms and technologies are not necessarily represented in these statements.

Where do Echo and other imaging modalities sit in a contemporary outcomes strategy for heart disease, stroke, kidney and diabetes?

Coronary Heart Disease – Investigation and Treatment

Access to fast accurate diagnosis is a cornerstone of successful treatment for coronary heart disease. The NSF for stable angina developed the concept of the rapid access chest pain clinic. The main weakness of this approach was the central role of the exercise treadmill ECG, which has great limitations of accuracy especially in high and low risk populations.

NICE guideline number CG94 promoted a new paradigm using both new and existing technologies to obtain more accurate diagnosis in patients presenting with chest pain.⁸ This embraces multi-modality, patient focussed approach to investigation, with low risk patients undergo cardiac CT scanning to look for coronary calcium and/or narrowed coronary vessels using CT angiography.

Intermediate risk patients undergo a test that looks more at the consequences of narrowed arteries on heart function or blood flow, either a stress echocardiogram, a nuclear perfusion scan or an MRI perfusion scan. High risk patients go straight to coronary angiography. This approach remains aspirational, because many areas of the country have neither the equipment nor the trained personnel to deliver the guideline in full.

Equitable roll out of this guidance will require a considerable amount of planning, co-ordination and investment across all the modalities including stress echocardiography. Furthermore, the outcomes of non invasive cardiac assessments are difficult to define because a negative test will not be corroborated except by the absence of a cardiac event.

A national process to define the accuracy of cardiac testing against hard clinical outcomes, using a NICOR / MINAP approach, will be required to ensure equality of standards are matched between institutions.

Heart Failure

Heart failure is becoming more common. As the population ages and the treatment of acute cardiac diseases improves, the number of patients with the long term results of coronary heart disease, hypertension and cardiomyopathies, increases.

Advances in treatment over the last two decades have transformed heart failure from a malignant condition with a very poor prognosis, to a chronic disease that can be managed allowing many sufferers to live a long and fruitful life. The key is early diagnosis with rapid institution of prognostic therapies.

The comprehensive approach to heart failure investigation and treatment laid out in the NSF chapter 6⁶ was further modified and developed in the recent NICE guideline.¹

The central role is making a positive diagnosis of left ventricular systolic dysfunction in order to target well validated prognostic therapies at those in whom they have proven benefit is developed.

The NICE guidance introduces the use of Brain Natriuretic Peptide (BNP) as the initial test with echocardiography reserved for those with significantly increased blood levels. This approach is designed to increase the number of people diagnosed and reduce the number of unnecessary echoes performed, as well as providing valuable prognostic data.

The result, in practice, of this change has been steady increase in the requirement for echocardiography. This is because an echo was previously a difficult study to organise for GPs, requiring a traditional hospital referral model. A BNP however is available to primary care physicians without the requirement for referral and therefore inevitably used more freely. Because the investigation lacks specificity the number of echoes has risen since the guideline was published.⁹

In order to deliver echocardiography to meet the NICE guidance a greater investment will be required in infrastructure and suitably qualified staff to undertake the scanning. Heart failure investigation is frequently performed in the community and a focus on quality standards and strategic service planning is required to ensure equitable access to high quality validated services.

Heart Valve Disease

Heart valve disease is greatly under appreciated compared to other areas of cardiology. Moderate to severe valvular heart disease is seen in between 11 and 15% of people over the age of seventy five.¹⁰ Given that the population continues to age rapidly, the over 75's are now a very important demographic group and yet the numbers undergoing valve replacement or valve follow up are only a fraction of this figure and many patients still present with end stage, symptomatic disease.

Improved surgical and new interventional options for these diseases have been developed over the last decade. Interventions on the aortic valve have proven prognostic benefit in non surgical candidates.¹¹ The range and diversity of treatment options is set to expand over the next decade and this will be a significant challenge for healthcare policy.

The management of valvular heart disease has been historically haphazard. A strategy for community diagnosis of valvular heart disease (systematic auscultation) backed up by echocardiography is almost certainly required. Community screening echocardiography is already under evaluation by the Oxvalve study,¹² and should this demonstrate significant benefit, then the consequences for the organisation of services will be huge. Networks, or integrative strategies, to join up the care of patients with valve disease, from detection, through surveillance to intervention and post intervention care are required. Specific valve clinics, often led by clinical scientists undertaking echocardiography have been demonstrated to be safe and improve adherence to guidelines.^{13,14} The British Heart Valve Society is producing a guideline for the organisation of valvular heart disease services.¹⁵

As echocardiography is central to diagnosis, monitoring and interventional planning, developments in valvular heart disease will need to be mirrored by developments in echocardiography.

Inherited Cardiomyopathy

The importance of inheritance in heart muscle disease and its genetic basis is increasingly understood.¹⁶ Guidelines for the screening of relatives of patients with hypertrophic, dilated and arrhythmogenic right ventricular cardiomyopathy, require a well developed echocardiography service operating within a structured clinical service which can offer help and support to family members affected.

Adult Congenital Heart Disease

More patients with childhood heart disease are surviving to live full adult lives. This places a significant burden on echocardiography services which have to adapt to treat this new population. Not only that, the importance of heritability requires an aggressive approach to prenatal diagnosis when women with congenital heart disease fall pregnant.

Commissioning guidelines have been published which give structure to the future of adult congenital services. Echocardiography is central to the evaluation of these patients and while the population remains relatively small it is expanding; as the degree of expertise required is high and this is an area where advanced ongoing training is required.¹⁷

Stroke

While primary prevention of stroke is addressed by risk factor modification and the use of appropriate anticoagulation in appropriate patients, echocardiography is vital in the care of patients with stroke and transient ischaemic attacks for the prevention of further events.

A standard Echocardiogram is frequently appropriate to rule out important potential cardiac sources of blood clots such as the left ventricle, it is in the area of unexplained stroke that echo will be most required in future. Such patients are usually screened for a patent foramen ovale (PFO; a breach in the membrane between the right and left atria) which can be closed using percutaneous techniques. While at present a randomised trial to confirm the effectiveness of these techniques lacking, if the ongoing studies prove positive then it is likely the demand for such tests will increase significantly.

The current focus on stroke prevention is greatly to be welcomed. The role of echocardiography in establishing the causes of emboli needs to form part of structural planning for stroke prevention services.

Athlete Screening

Around 12 young people per week in the UK die suddenly from cardiac disease. Schemes in Italy using ECG as the primary triage tool have shown dramatic reductions in the rate of these catastrophic events.¹⁸ Schemes in the UK using clinical history taking, auscultation, ECG analysis and backed up by echocardiography are provided, often in the charitable sector.¹⁹ The sudden death of a young athlete is a disaster not just for the immediate family but for the whole wider community. A nationally approved strategy for the prevention of these, often unnecessary, deaths is long overdue.

This is an area where government, charitable groups and local primary care commissioners need to act in partnership to establish a deliver a nationally accepted policy.

Cancer

The advent of Trastuzamb treatment for HER2 positive breast cancer heralded a new era of cardiac screening for patients undergoing cancer therapy. The number of cancer targeted drugs that can cause reductions in heart function is increasing all the time.

Because of the requirement for ongoing surveillance it has been estimated that this could result in a >1% increase in the numbers of echoes performed in the UK.³ Rigorous standards for both the provision and quality of echocardiography need to be factored into plans to role out new cardio toxic anti cancer drug treatment.

4. Who needs to do what to achieve the ambitions for reducing cardiovascular diseases?

What is the role of national government, the NHS Commissioning Board, Public Health England, local directors of public health and clinical commissioning groups?

Development of Services to Meet these Requirements

In order to deliver the ambitions outlined above, as well as the many areas not covered, certain key areas need to be considered:

Demand for Echocardiography

It is recognised that there is an under provision of echocardiography. The most recent NHS Atlas of Variation indicated that while the number of echoes has increased to an average figure of 20 / 1000, the estimated number required by international comparison is in the region of 35–45 / 1000.⁹ It is clear that a significant investment in both infrastructure and manpower is required to meet these needs.

Governmental Actions

Government sets the tone for the health service. It is important that national health strategy identifies and recognises the need for high quality cardiac investigations including echocardiography in order realise better care. It is particularly important that quality is the key driver to national commissioning and particularly any qualified provider activity. Strong support for national quality standards, as promoted in the IQIPS process is essential.

Appropriate tariff setting is vital. The 2012 tariff saw a 20% reduction in tariff making many community services uneconomical. This perversely drives patients towards more expensive and unnecessary hospital based care.

For echocardiography workforce planning is central. There is already a national shortfall of qualified echocardiographers. Recent years have seen an upheaval in the training of clinical scientists with the introduction of modernising scientific careers.²⁰ While this offers a clear career trajectory, the number of places available across cardiology in general, leave aside echocardiography, are very small judged against workforce requirements. The BHF has supported a large number of trainees across the country which has enhanced the workforce in recent years, as well as supporting ongoing training.

Scientific careers are increasingly structured and the emergence of the consultant sonographer who undertakes specialist clinical roles is increasingly recognised as a welcome development.

A strategy of workforce planning exercise is overdue.

NHS Commissioning Board

NHS commissioning and specialist commissioning will need to have a strong input into the provision of multimodality cardiovascular imaging. This is a rapidly developing field and advances in other modalities such as cardiovascular MRI and cardiac CT scanning are now delivering very real patient benefits. A strong commissioning strategy to equalise access to these investigations is urgently required. Likewise the integration of investigation pathways as exemplified by the NICE CG 95 will be increasingly required for efficient use of resources.

Public Health Services

The implication of the changing population, the age matched mortality reductions from myocardial infarction and cancer need to be modelled on a national and local level. The emergence of new high prevalent disease such as aortic stenosis and atrial fibrillation, as a result of increased longevity, need to be accounted for. Furthermore the shift from acute to chronic disease status for most cardiovascular disease will present new challenges.

Clinical Commissioning Groups

The procurement of cardiovascular services needs to incorporate an integrative approach in particular the local agreement of integrative investigational pathways with the free flow of information between sectors is vital. For investigational medicine the free availability of data through appropriate IT solutions is a vital component of local commissioning and one that has worked very successfully in echocardiography in some areas.

Structuring Echocardiography

With the increased focus on community diagnostics and the changing structures inside hospitals, a reworking of traditional echo departments is also required. The BSE and the echocardiography community in general have embraced the diversification of echo with the growth of community services. Likewise the use of other personnel such as emergency clinicians to provide investigations at the point of care is being developed.

Limited scans to screen for common heart disease are not acceptable because although they may save money they risk a loss of detail which may lead to missed or wrong diagnoses.

Maintaining Quality in Echocardiography

It is far less important where an Echo is performed than that is performed to an appropriate standard. The BSE continues to promote both individual and departmental accreditation as a benchmark or appropriate standards working with the IQIPS process towards full reciprocity.

5. How will we know we are making progress on these ambitions? What should we measure and how?

National Level Audit

Measuring the outcome of invasive or surgical procedures has become part of routine quality assurance activities for the NHS. As yet national level outcome audit has not been attempted. Variations in the quality of investigations are every bit as important because they inform decisions over treatment strategies. The BSE has already piloted a national approach to quality assurance and will be producing a pilot program to evaluate variations in ischaemia testing by stress echocardiography. A national level NICOR /MINAP program of outcome audit in non invasive cardiac imaging should be considered.

Processes for national accreditations, such as BSE departmental accreditation, have within them quality standards and requirements. A central driver for departments to become accredited with either the BSE or IQIIPS and an active target for accredited departments could be considered.

Local Level

Interventional procedures and certain diseases are actively counted at a local and national level. In order to address the lack of equity of access across the country and to allow appropriate local Commissioning, cardiac networks should report the range and volume of cardiac investigational work. Networks should also be responsible for evaluating the quality of local services particularly when they are not covered by a recognised national accreditation process.

6. How will voluntary organisations be contributing to meeting these ambitions?

The BSE is a voluntary organisation which promotes and represents echocardiography and echocardiographers in the UK.

The BSE provides a widely respected accreditation process for individual sonographers and, in partnership with the BHF, promoted a process of departmental accreditation in order to drive up quality standards.

The BSE has an active process of regularly developing national guidelines incorporating advances in medical knowledge and technological development. Working with its partners at the British Heart Foundation, the British Cardiovascular Society (and its imaging council), the Association for Cardiothoracic Anaesthetists, the Intensive Care Society and the Society for Acute Medicine, the BSE is working to promote efficient and proper use of echocardiography.

Key points

- Echo is central to the investigation of most cardiovascular diseases.
- Provision of echocardiography should rise from current levels to 35-40 / 10,000.
- Progress on NSF target areas should be maintained, but a more broad based range of cardiac diseases should be incorporated.
- Diversification in echo is welcome provided it is linked to clear established quality standards.
- Accreditation entrenches a focus on quality.
- Multidisciplinary working across multimodality cardiac imaging will provide the best investigational strategy for patients.
- National audit structures for non invasive cardiac imaging matched against outcome should be considered.

- Tariff should reflect national objectives to provide high quality services close to home.
- The BSE is a willing partner in improving the lot of today's and tomorrow's patients by promoting high quality echocardiography.

References

- ¹ NICE Clinical Guideline (CG108) Chronic heart failure: Management of chronic heart failure in adults in primary and secondary care. 2010.
- ² NICE technology appraisal guidance 95 Implantable cardioverter defibrillators for arrhythmias. 2006.
- ³ The Council of the British Society of Echocardiography. The evaluation of left ventricular function for patients being considered or receiving Trastuzumab (Herceptin) therapy 2006.
- ⁴ <http://www.bsecho.org>.
- ⁵ www.acredityourdepartment.org.
- ⁶ <http://www.rcplondon.ac.uk/projects/iqips>.
- ⁷ National Services Framework for Coronary Heart Disease. 2000
- ⁸ NICE Clinical Guideline (CG95) Chest pain of recent onset. Assessment and diagnosis of recent onset chest pain or discomfort or suspected cardiac origin. 2010.
- ⁹ The NHS Atlas of Variation in Healthcare. RightCare. 2011.
- ¹⁰ Nkomo VT, Gardin JM, Skelton TN, Gottdiener JS, Scott CG, Enriquez-Sarano M. Burden of valvular heart diseases: A population-based study. *Lancet* ;368:1005-1011.
- ¹¹ Leon MB, Smith CR, Mack M, Miller DC, Moses JW, Svensson LG, Tuzcu EM, Webb JG, Fontana GP, Makkar RR, Brown DL, Block PC, Guyton RA, Pichard AD, Bavaria JE, Herrmann HC, Douglas PS, Petersen JL, Akin JJ, Anderson WN, Wang D, Pocock S; PARTNER Trial Investigators. Transcatheter aortic-valve implantation for aortic stenosis in patients who cannot undergo surgery *N Engl J Med*. 2010 Oct 21;3.
- ¹² www.oxvalve.nhs.uk.
- ¹³ Taggu W, Topham A, Hart L, Carr-White G, Sulke N, Patel NR, Lloyd G. A cardiac sonographer led follow up clinic for heart valve disease. *Int J Cardiol* 2009, Feb 20;132(2):240-3.
- ¹⁴ Chambers JB, Lloyd GW, Rimington HM, Parkin D, Hayes AM, Baldick-Apps G, Topham A. Multidisciplinary valve clinics with devolved surveillance: A two-year audit *British Journal of Cardiology*;18:231-2.
- ¹⁵ www.bhvs.org.
- ¹⁶ Factfile: Inherited cardiovascular disease. British Heart Foundation 2009.
- ¹⁷ Designation of Specialist Service Providers for Grown-Ups with Congenital Heart Disease (GUCH)/Adults with Congenital Heart Disease (ACHD). www.specialisedservices.nhs.uk.
- ¹⁸ Corrado D, Basso C, Schiavon M, Thiene G. Screening for hypertrophic cardiomyopathy in young athletes. *N Engl J Med* 1998, Aug 6;339(6):364-9.
- ¹⁹ www.c-r-y.org.uk.
- ²⁰ Modernising Scientific Careers. The UK way forward. Department of Health.

British Society for Heart Failure



Addressing gaps in heart failure services for patients

Despite massive improvements in the prevention, diagnosis and treatment of many aspects of coronary artery disease since the publication and implementation of the NSF for Coronary Heart Disease, there is a crisis in the care of patients who develop heart failure in the UK. Yet transforming care for this group would deliver a substantial reduction in mortality alongside improvement in the quality of life, with opportunities to address some of the health inequalities that persist across different social deprivation rating groups into 2012. These strategies, vide infra, will also improve patient experience whilst delivering longer healthy life. Importantly the required changes to health care delivery are largely about priorities, and the reorganisation of existing cardiovascular care, rather than high cost interventions. This should mean, in the current financial climate that improvements are eminently deliverable – but the extent to which existing delivery of services, and perceptions need to be changed should not be underestimated.

Recent transformation of Stroke and MI care are exemplars of how conventional practice can be re-organised to improve acute care: there are helpful lessons to be learnt from these models, including some exemplars which might be emulated in heart failure, and others which should prompt a different approach.

The CVD strategy document refers to coronary artery disease and then other types of cardiovascular disease including heart failure, but this is to ignore the continuum between the two and the chronicity of coronary artery disease (CAD). Whilst some causes of heart failure are unrelated to CAD, over 50% of heart failure in the UK is a direct consequence of CAD. Indeed follow up of hospital patients who have sustained a heart attack shows that 80% of the subsequent deaths involve patients who have had an episode of heart failure.¹ For many other patients with HF there is common causality, and so potential for greater prevention (diabetes, obesity, hypertension, smoking and alcohol to name a few). Yet, whilst there has been considerable, often charitable, investment to support those with chronic heart failure, largely delivered by specialist HF nurse care within the community, there has been little recognition of, or investment in, the delivery of heart failure care within the acute sector.

Data from over 80,000 patients admitted to hospital with acute heart failure, collected through the National Heart Failure Audit, describe a bleak picture with a high inpatient mortality, and seemingly higher than elsewhere in Europe. Consistent themes have emerged in the annual reports since the audit was first established in 2007, including considerable variation in mortality, within hospitals depending upon where, and by whom, these patients are cared for, and between hospitals, in both instances reflecting variations in the overall quality of care.² Subsequent outcomes including early readmission, symptom control and mortality at 12 months are also predicated by care during the index admission. Patients are more likely to survive where care has been delivered by a specialist team in cardiology wards, more likely to have had a robust diagnosis (through echocardiography), more likely to be discharged on fundamental disease modifying drugs which each determine outcomes at 12 months, and more likely to have on-going cardiology and HF team involvement when home. These also predict a better outcome including fewer re-admissions and better quality of life. Establishing high quality care with a consistent approach to all heart failure admissions would by conservative estimates likely save thousands of lives annually, with the same strategy reducing the revolving door pattern of early readmission which has been so costly for both patients and the NHS. Essential key features of care:

- Early recognition and diagnosis of heart failure on admission to hospital (natriuretic peptides, echocardiography and identification by cardiology led multidisciplinary HF service).
- Care in an integrated HF unit (alongside an active outreach service) by the cardiology led HF team.
- Stabilisation and prescribing of key drugs and at adequate levels prior to discharge.
- Adequate discharge planning to include cardiology and community follow up in a timely fashion, with provision for rehabilitation, self-management, up-titration and palliation, complex pacing and other interventions as indicated.

Importantly this quality of care should be available, and can be readily made available in every acute trust obviating the need for transfer to more costly tertiary centres, except for the few who require specific interventions. Thus the proposed re-organisation of inpatient HF care emulates the changes seen in MI and stroke, in that the delivery of acute care needs fundamental re-organisation within the acute trusts, but differs in that the majority of acute phase care should be delivered in the local hospital, closer to the patients home and with lower cost implications. Encouragingly the National HF Audit suggests that this can be delivered without longer lengths of stay.

Many aspects of in-hospital diagnosis and treatment reflect the changes which have already been described in detail in the 2010 NICE Chronic HF guidance³ where there has been similar emphasis on an early accurate diagnosis invoking natriuretic peptides, echocardiography and cardiology assessment within specific timescales for people who present to their general practitioner with possible new heart failure, and thereafter involvement of the multidisciplinary team working closely across health care domains. The 2011 NICE Quality Standards⁴ reflect these key priorities and it is anticipated that the forthcoming COF/QOF HF document, due to be published in 2013, will be similarly consistent.

At this juncture HF care is worryingly variable both in primary care, the community and in the acute trusts – with implementation of the recent NICE guidance and the related NICE Quality Standards this should change. Commissioned outcomes for HF need to ensure the totality of the HF service is delivered and in this respect there are lessons to be learnt from recent commissioning of acute stroke care where arguably the acute stroke units have been more successfully delivered than the aftercare. To date in HF much of the acute care has been ignored, but we must be sure that in now addressing the acute care, which would be expected to save thousands of lives every year, we do not ignore and lose the established patterns of excellent after-care that exists within some if not all local communities. If the totality of HF services were commissioned as a complete bundle of care, rather than the piecemeal commissioning of the component parts, this might be avoided.

Much of the community care to date has been delivered by specialist HF nurses, and worryingly in parallel with rhetoric to “increase care closer to home”, in recent years and months there has been an absolute reduction in community based specialist HF nursing staff, alongside a tendency to replace specialist HF nurses with colleagues who have no expertise in HF, and where benefit is unproven.

Heart failure care is complex and often challenging, and patients with HF are vulnerable to great changes in their condition swinging from one end of the disease spectrum to the other very quickly. A well established HF team operating across primary and secondary care is fundamental to stabilising these patients, carefully titrating their drugs, identifying worrying changes and referring to other team members be that for more complex hospital care, rehabilitation or palliative care (both areas which are underprovided for), and or other services, all in a timely fashion. The role of the HF nurse specialist is well established,^{5,6} cost effective and has an important role both within and without the acute hospitals, as an essential part of the HF team. In 2008 it was suggested that there should be one heart failure nurse per 100,000 of the population, to be effective.⁷ This has yet to be achieved and may explain why some HF nurse specialists are sadly driven to being selective in the HF patients they support, and why not all HF patients have access to this input. In order to deliver the HF care that will both save lives and improve the well being of an especially vulnerable patient group investment is required in specialist staff, both Cardiologists, Nurses, and others.

References

- ¹ Tarabi et al. The Timing of Development and subsequent clinical course of heart failure after a myocardial infarction. *EHJ* 2008; 29: 859-870.
- ² National Heart Failure Audit April 2010 – March 2011 NICOR: National Institute for Cardiovascular Outcomes Research. www.ucl.ac.uk/nicor/audits/heartfailure/additionalfiles/pdfs/annualreports/11.pdf.
- ³ NICE (2010) Chronic heart failure: Management of chronic heart failure in adults in primary and secondary care. <http://publications.nice.org.uk/chronic-heart-failure-cg108>.
- ⁴ NICE (2011) Chronic heart failure quality standard www.nice.org.uk/guidance/qualitystandards/chronicheartfailure/home.jsp.
- ⁵ Stewart S, McAlister FA, McMurray JJ. Heart Failure management programmes reduce readmissions and prolong survival, *ARCH Intern Med* 2005 June 13;165(11):1311-12.
- ⁶ Holland R, Battersby J, Harvey I, Lenaghan E, Smith J, Hay L. Systematic review of multidisciplinary interventions in heart failure. *Heart* 2005 July; 91(7):899-906.
- ⁷ Pattenden J et al. The development and impact of the British Heart Foundation and Big Lottery Fund heart failure specialist nurse services in England. Final report 2008 British Heart Foundation.

Children's Heart Federation



Congenital heart disease (CoHD) affects one in every 133 children born each year. This equates to around 5000 children a year making it one of the most significant birth disorders. Due to improvements in treatment most now survive into adulthood and can lead long lives with their condition. This has created new challenges and an expanded population with CoHD.

CoHD is a cardiovascular condition and therefore The Children's Heart federation (CHF) feel that it should be considered as part of any Department for Health strategy which is to be produced. CHF cannot stress enough the strength of feeling amongst the congenital heart community about the necessity for equal recognition of congenital heart patients, their rights and needs.

This point was stated clearly in previous work from the Cardiovascular Coalition (CVC) in Destination 2020. In fact this document correctly stated that 'this group of patients was not included in the CHD NSF and needs to be included in future planning' (CVC, 2009, p.20). This point was correct and this necessity remains the case today.

To not include CoHD would weaken and undermine any strategy which is to be produced by the Department for Health. It is essential that the Joint APPG report stresses this point and by including CoHD, ensures the Government receives the message that without consideration for CoHD their Outcomes Strategy would be incomplete and lack the joined up approach which all patients want.

Prevention, awareness and early diagnosis

There have been major advances in the quality of treatment available to many CoHD patients over recent years and around 80-85% survive into adulthood. It remains however essential that conditions are detected early, as this offers many benefits both to parents, the children in question and the health service more widely. It enables parents to plan and make important decisions about the future. It ensures that adequate care is planned for both baby and mother during delivery and that babies are born in the right surroundings to meet their needs.

Before birth, it is important that parents and professionals understand the importance of the 20 week ultrasound scan. The reason for these checks should at all times be stressed as far to often mothers approach the scans not knowing the important role they have in detecting anomalies.

CHF supports using a 5 View protocol for screening across the NHS as the example of best practice. There should also be adequate resources for ongoing training and accreditation of health professionals who perform screening scans to maintain standards. CHF support the integration of Pulse Oximetry testing into the Newborn Physical Examination Programme (NIPE). The test has shown very positive results in trials in the West Midlands, concerns over time and resources are shown to be largely unfounded and the test should be one part of the various key elements in early detection of heart conditions. Midwives should also be fully trained to administer this test in hospitals and the community.

More widely we support the NIPE programme which is currently piloting the SMART computer system and new standards for both the 72 hour and 6-8 week tests on newborns. CHF believe that NIPE, as demonstrated in the current pilot, offers the potential to ensure higher quality newborn testing, reduce those who slip through the net and miss these vital checks. It also provides the ability to have fail safes, data sharing, audit and monitoring with comprehensive data available nationally for the first time.

Whilst relatively rare, CoHD still affects 1 in every 133 children, around 5000 a year. This makes it one of the most common birth defects. This is why it is essential that health professionals remain vigilant in detecting the condition. Far too often professionals fear unnecessarily worrying parents; however parents want and need honest advice. Parents benefit from the full discussion of the facts in a sensitive way.

Empowering parents and patients should be the mission of the NHS. They should not be seen as passive but instead active partners in diagnosis, treatment and prevention. CHF has recently launched a 'Think HEART' campaign which provides parents with the information to spot underlying heart conditions if their child is unwell. This is a key example of how parents with the right information can work with medical professionals to aid earlier diagnosis. Medical professionals should not be afraid to provide patients and parents with more information.

In terms of measuring and monitoring the quality of care, currently little information is on offer to patients. The Central Cardiac Audit Database (CCAD) is hard to navigate, unfriendly to patients and most find it almost impossible to use adequately. It takes a great deal of time for data to be made available for use online and is limited to simply mortality based measures. Parents and patients want and deserve and more rounded and adequate analysis of care quality on which to base their decision about treatment options. They particularly want to see measures of quality based on morbidity. In determining the quality of care, parents of children with CoHD also value other indicators such as the rate of cancellations of surgical procedures and the facilities on offer at units, such as accommodation.

Treatment

There have been great advancements in medical treatment for those with CoHD, with increase in life expectancy, new treatments available and examples of top quality treatment. However, whilst the quality of treatment whilst good in some places, it is patchy and in many others quality is variable. This is why CHF support the Safe and Sustainable process which aims to ensure that all patients have access to the highest quality specialist surgical units. This offers the chance for larger units, round the clock care and reduced cancellations due to emergencies. It is essential that once the decision is made about which units should provide cardiac surgery; the required investment is made to bring these units up to the necessary high quality level which has been promised.

Across all ages of treatment it is important to have clear care pathways; for antenatal care and scans, for children and adults with CoHD. Clear, easy to understand pathways, will ensure consistent care across the country as well as enabling patients to best understand their treatment, what to expect and how to hold to account their healthcare providers.

Patients and families also stress the importance of Cardiac Liaison Nurses in supporting the patient and family. Specialist nurses are a crucial resource and enable individuals to understand more about their treatment as well as often providing outreach and care back at local hospitals and clinics. It is key that the funding of these nurses by Trusts must be continued due to the major difference they make to the quality of care and all round support on offer. Whilst these specialist nurses are extremely important, it is worth noting the need for common standards or job descriptions across the country to ensure that best practice is shared and patients can expect the same quality of care and support wherever they might live.

Congenital heart patients whilst different in some regards do have many similar needs to other heart patients. Many tell us, that they would like access to the quality services available to other patients. Particularly this is the case with the cardiac rehabilitation services which are on offer. Whilst take up is low of existing services, and this must be addressed, CoHD patients want the option to access these services too and share in the benefits they offer. These services should be better highlighted, open to more patients and easily accessible. Congenital heart patients would stand equally to benefit from added information, exercise programmes and help improving their lifestyle and health.

Living with cardiovascular disease

80-85 per cent of those born with CoHD will now survive to adulthood and life expectancy as well as the number of adults with congenital heart conditions is increasing due to improvements in treatment options.

CHF support the ACHD review currently being undertaken. This is long overdue and adults with CoHD deserve to be seen by specialist expert surgeons and professional teams as well as well resourced local centres which meet their needs. There are still examples of occasional practice on those with CoHD of which CHF remains strongly critical.

Transition between child and adult services remains a problem. This process needs careful management and follow-up to ensure that patients continue to receive the support they need despite entering adulthood. This issue is even more important due to the correlation between certain congenital heart conditions and developmental issues/learning difficulties. There is an established relationship between Downs and CoHD as well as DiGeorge syndrome for example. There is growing evidence of this relationship due to factors like oxygen deprivation. In light of this relationship it is essential that in communication with patients, the planning and delivery of services, this factor is taken fully into account.

Patients must be involved in their care. Self-management of individuals' conditions must be a priority, allowing maximum independence. CoHD is a long-term condition and must be understood as such. Currently the NHS does not do all it can to ensure that patients are supported to live independent lives. Instead some practices can reinforce dependence. For example, patients on Warfarin who must carefully monitor their levels of the drug must be tested sometimes 3-4 times a week. This often takes place in hospital and a small device, an INR machine/CoaguChek is not provided on the NHS to allow home testing. Such a device, relatively inexpensive, would enable children and individuals on Warfarin to lead more normal lives not having to travel each time to the hospital. In some instances parents and children have to travel hundreds of miles to attend these appointments having major impacts on children and their families' lives. Focus on care close to home where possible and self-management of their condition must be a priority for all patients including those with cardiovascular conditions.

Voluntary sector organisations, such as CHF provide vital support and services to patients and their families. Such groups provide rounded, holistic support far beyond that on offer from the NHS. Children and their parents tell us that they need and value independent advice, however they are not always aware of valuable resources from support groups and the Third Sector. Far too often the NHS does not signpost or provide patients with information about such groups. The NHS should seek to improve the information it provides to patients and parents and wherever possible provide them with contacts to such support groups.

Concluding comments

As Destination 2020 (CVC, 2009) correctly stated, CoHD has not always been considered in previous guidance, policy documents and Government reviews and CoHD therefore requires attention in future planning. This point was correct and CHF believes strongly that CoHD must be part of this review and ultimately the Government's Cardiovascular Disease Outcomes Strategy. Not only is this important for patients and parents, but also for the strategy itself. If the aim of the strategy is truly to create a joined-up approach for cardiovascular diseases across the NHS, then ultimately this would be seriously undermined by the exclusion of CoHD.

With growing numbers of people living with CoHD mean the condition must be seen as a long-term one. Patients want access to specialist services providing top quality care, as well as the provision of routine services closer to home where possible.

Patient's experiences can be greatly improved by the provision of more information about how they will be treated, through clear standard care-pathways. They also want access to information about the quality of services in terms of mortality rate, morbidity measures and other more rounded indicators of quality.

Individuals with CoHD and their families can lead more independent lives though key support from the NHS, where possible self-management should be encouraged and information should be provided to patients about independent sources of advice and support.

About diabetes

Diabetes has become one of the biggest health challenges of our time, with 3.7 million people¹ living with diabetes in the UK and 7 million people at high risk of developing Type 2 diabetes. Numbers are rising rapidly with 140,000 new diagnoses each year and it is estimated that over 5 million people in the UK will have diabetes by 2025.² Around three people are diagnosed with diabetes every 10 minutes in the UK.³ The prevalence of diabetes is nearly 4 times higher than the prevalence of all cancers combined and is still rising.⁴

Diabetes is serious. If left untreated or poorly managed, it can lead to heart disease, stroke, amputation, blindness, and kidney failure.

The impact of diabetes

Cardiovascular disease is a major cause of death and disability in people with diabetes, accounting for 44 per cent of deaths in people with Type 1 diabetes and 52 per cent in people with Type 2.⁵ People with Type 2 diabetes have a two-fold increased risk of stroke within the first five years of diagnosis compared with the general population.⁶ Diabetes is now the biggest cause of stroke.

People with diabetes account for an estimated 15 to 16 per cent of deaths occurring in England.⁷ Life expectancy is reduced on average by more than 20 years in people with Type 1 diabetes and up to 10 years in people with Type 2 diabetes.⁸ Each year diabetes results in 24,000 excess deaths.^{9,10}

Last year over £10 billion (about 10%) of the NHS budget was spent on diabetes and 80% of this NHS spending is going into managing expensive, but potentially preventable complications.¹¹ Complications of diabetes make up around one in five of all coronary heart disease, foot and renal admissions.¹²

What should be addressed in the Cardiovascular Disease Outcomes Strategy?

- Prevention, risk assessment and early diagnosis which are key to:
 - Reducing the number of those at risk of Type 2 diabetes.
 - Ensuring that people at risk of Type 2 diabetes can receive timely advice and interventions to prevent onset.
 - Ensuring that people who have Type 2 diabetes can be diagnosed earlier and before they have developed serious complications, such as cardiovascular disease (CVD).
- The geographical variation in care and treatment for people with Type 1 and Type 2 diabetes and effective management of complications.
- Access to care planning, education and support, including psychological support, to ensure people with diabetes can effectively self manage their condition to prevent complications, including CVD.

Prevention of Type 2 diabetes and CVD

The key to prevention of Type 2 diabetes and CVD is to reduce obesity in the population, increase levels of physical activity and to raise awareness of the risk factors for Type 2 diabetes.

Obesity is the most potent risk factor for Type 2 diabetes and accounts for 80-85 per cent of the overall risk of developing Type 2 diabetes.¹³ The latest health survey for England shows that 62 per cent of adults are overweight or obese and 30 per cent of children are overweight or obese. 21 per cent of all adults and children are obese.¹⁴

If no action is taken it has been predicted that 60 per cent of men, 50 per cent of women and 25 per cent of children would be obese by 2030.¹⁵ The Department of Health's strategy on obesity¹⁶ sets out good practice in tackling obesity at a national and local level.

From April 2013 local authorities have the lead role in developing and implementing strategies to tackle obesity. They can do this through:

- Commissioning a range of interventions to promote weight management for individuals.
- Prevention strategies which involve local transport, catering providers in schools and other local authority premises, leisure and recreation providers.

At a national level the Government has a key role in:

- Helping people to make healthy food and drink choices.
- Helping people to be more active.
- Raising awareness of the risk factors of Type 2 diabetes (and other cardiovascular conditions).

NICE has produced public health guidance on the prevention of Type 2 diabetes¹⁷ which should be fully implemented through action at a national level to promote healthier diets and increase physical activity, and through NHS and local authority commissioning and delivery plans.

Early diagnosis and identification

Early diagnosis and identification of those at high risk of Type 2 diabetes

About 850,000 people with Type 2 diabetes remain undiagnosed.¹⁸ By the time they are diagnosed 50 per cent of people with Type 2 diabetes show signs of complications such as CVD, retinopathy or neuropathy.¹⁹ Complications may begin five to six years before diagnosis and the actual onset of diabetes may be ten years or more before diagnosis.²⁰

Evidence shows that 60 per cent of people at high risk will not go on to develop Type 2 diabetes if it is detected early and they are given lifestyle interventions.²¹ Up to seven million people are at high risk of developing Type 2 diabetes. Only 75 per cent of the expected cases of diabetes are detected in PCTs in England and the gap between actual and expected rates is closing at a very slow rate.²² Before people develop Type 2 diabetes they almost always have pre-diabetes.²³ Around 15 per cent of the population have pre-diabetes and so are at high risk of developing Type 2 diabetes.

NHS Health Checks

NICE draft guidance²⁴ sets out best practice relating to risk assessment and early diagnosis of Type 2 diabetes. This states that identification of people with Type 2 diabetes, and of people at risk of Type 2 diabetes, is most effectively done as part of other healthcare examinations such as screening for cardiovascular risk factors through NHS Health Checks.

It is estimated that up to 19,000 cases of diabetes could be detected early each year (127 cases per PCT) through NHS Health Checks, producing a gross saving of £1m a year over 4 years.²⁵ In addition, up to 9,700 cases of Type 2 diabetes could be prevented each year (64 per PCT) through non-diabetic hyperglycaemia detection (pre-diabetes²⁶) producing a gross saving of £40m a year over 4 years.²⁷ Overall NHS Health Checks could produce a gross saving of £132m a year over 10 years (averted strokes, averted MIs, Type 2 diabetes prevented and detected early, CHD detected early), equivalent to more than 40 per cent of the cost of the programme.²⁸

The NHS Health Checks programme was introduced in April 2009 for people aged 40–74 years. 15 million people are eligible to be offered a check every 5 years. The programme aims to reduce health inequalities (including socio-economic and ethnic inequalities) that result from Type 2 diabetes (and other conditions).²⁹

Concerns about poor and patchy implementation of the NHS Health Checks Programme

PCTs are expected to report the percentage of people eligible for the NHS Health Check programme who are offered an NHS Health Check and the numbers of people eligible for the programme who have received an NHS Health Check.³⁰ The same indicator is included in the public health outcomes framework³¹ which will be used to assess the performance of local authorities (after April 2013) in promoting public health. This data has been collected and published by the Department of Health in 2011/12 for the first time.

From April 2011 the Department of Health recommended that PCTs set themselves a target of offering a Health Check to 18% of the eligible population in one year. However, a survey last year³² found that a number of PCTs will fall short of the target of offering 18% of the eligible population with NHS Health Checks in the year and that only 36 PCTs had actually set a target of 18%. By December 2011 only half of the expected offers for the year 2011-12 had been made across England as a whole and there is wide variation in the numbers of checks offered.³³ Some PCTs had offered health checks to over 20% of the eligible population, but others had offered less than 3%. Five PCTs had failed to offer or do a single NHS Health Check in 2011–12 so far.³⁴

The number of checks delivered is also very low with only 50% of the offers being taken up and resulting in NHS Health Checks being done.³⁵

There is also a wide variation across England in the rate of implementation – a “postcode lottery effect” has been described due to the freedom that PCTs have in the funding and design of their local Health Checks Programme.³⁶

In April 2013 the responsibility for commissioning NHS Health Checks will be transferred to local authorities. This presents a risk of wider variation and fragmentation of the Programme.

Awareness of risk factors

There is a need to raise awareness nationally and locally of:

- the risk factors of Type 2 diabetes
- the importance of seeking a risk assessment
- the benefits of early diagnosis.

This can be done locally as part of the NHS Health Checks Programme.

Examples of how Diabetes UK is working to raise awareness

"The thought of developing diabetes never entered my mind until I went shopping one day and seen the pink van in the city centre. I decided to give it a go and I was shocked with my result and I knew that something had to be done and I needed to improve my lifestyle"

Diabetes UK runs healthy lifestyle roadshows providing information about the condition and how leading a healthier lifestyle can reduce the risk of developing Type 2 diabetes. The only UK validated risk assessment (Diabetes UK and Leicester University Trust Risk Score) is used at the roadshows. In 2011 there were:

- 52 road shows
- Over 10,000 risk assessments
- Over 5,000 (48%) people assessed at moderate to high risk and referred to their GP for further tests.

Evaluation shows high memory recall of risk factors, and of intention to take action to address them, one to two months after their visit.³⁷

Diabetes UK also trains "Community Champions" to undertake risk assessments engaging with BAME communities. For example, in NHS Haringey Community Champions ran six events in the borough and risk assessed 200 people from Black and Asian minority ethnic communities. Of these 28% were found to be at high risk and 35% at moderate risk of developing Type 2 diabetes.

Diabetes UK's Measure Up advertising and integrated awareness campaign, 2007, resulted in a 29% increase in awareness of the risks of diabetes amongst those at high risk of developing the condition.³⁸

Diabetes UK's online risk assessment tool <http://www.diabetes.org.uk/riskscore> raises awareness of the risk factors for Type 2 diabetes and encourage people to assess their own risk and take appropriate action.

What is needed:

- The CVD strategy should clearly set out why prevention of Type 2 diabetes and CVD should be a key part of the local JSNA, Health and Wellbeing strategy and the commissioning plans of CCGs and recommend that a range of effective interventions to promote weight management and increase physical activity are commissioned and delivered. Clear recommendations in this area are needed and will contribute to the diet and obesity indicators in the Public Health Outcomes Framework.
- The definition of the diet indicator in the public health outcomes framework should be fully developed and included in the strategy.
- The CVD strategy should ensure that local authorities comprehensively commission the NHS Health Check programme and that effective incentives are in place to promote commissioning and delivery of the NHS Health Checks. The Public Health Outcomes Framework should include reporting specifically on the percentage of eligible people receiving an NHS Health Check.
- The Public Health Outcomes Framework indicator should be developed to capture uptake of the NHS Health Check by Black, Asian and minority ethnic communities.
- NICE guidance (currently draft)³⁹ on the commissioning and provision of intensive life-style change programmes for people at high risk of developing Type 2 diabetes should be implemented.

- The QOF should include an additional indicator – "having a register of those at high risk of developing diabetes" in line with NICE draft guidance that recommends screening the practice list to identify those at high risk.⁴⁰
- The public health outcomes framework could include an indicator: "prevalence of impaired glucose regulation (IGR or pre-diabetes)".
- The public health outcomes framework could include an indicator: "percentage of people at high risk receiving lifestyle intervention support to reduce their risk of developing Type 2 diabetes".
- Public awareness of the risk factors and symptoms of Type 2 diabetes should be increased and measured.

Treatment of diabetes and CVD

People with Type 1 and Type 2 diabetes are at high risk of cardiovascular disease. These risks can be reduced by achieving tight blood glucose, blood pressure and blood fat control; together with weight management, taking prescribed medication appropriately, and making healthy lifestyle choices. If cardiovascular complications develop, their impact can be reduced through taking similar action. This involves following a strict regime of medical treatment, monitoring and self-care activities. It is critical for quality of life and increased life expectancy that people with diabetes receive essential healthcare checks and essential healthcare services.

Essential healthcare checks

Healthcare checks are the cornerstone to reducing CVD risk for people with diabetes. Every person with diabetes is supposed to receive a planned programme of nationally recommended checks each year.⁴¹ They assess significant CVD risk factors.

- Blood glucose levels should be measured at least once a year. The HbA1c test measures overall blood glucose control which directly relates to risk of CVD.
- Blood pressure should be measured and recorded at least once a year. High blood pressure puts people with diabetes at significantly higher risk of CVD, and particularly increases the risk of stroke.
- Blood fats (cholesterol) should be measured every year and targets set that are realistic and achievable. Poor cholesterol control raises the risk of developing CVD.

Despite over 90 per cent of people with diabetes having regular checks for blood glucose, blood pressure and blood fats; around only 60 per cent are achieving the recommended target range for their HbA1c, around 50 per cent targets for blood pressure, and around 40 per cent for cholesterol.⁴² These sub-optimal targets increase the risk of people with diabetes developing complications including CVD.

- Weight should be checked and a waist measurement recorded to assess risk of CVD and a need for weight loss. Weight reduction for the overweight or obese person with Type 2 diabetes is effective in improving blood glucose, blood pressure and blood fat control. The National Diabetes Audit Data for 2009/10 shows that around 89 per cent of people with diabetes had a weight check but many are not getting adequate support to take action on weight reduction.⁴³

Specialist healthcare professionals: Diabetes, with or without CVD, is a complex condition to manage. People with diabetes should see specialist diabetes healthcare professionals to help them manage their diabetes and any related CVD. Recent workforce audits of specialist nurses, consultant diabetologists and specialist dietitians show an overall downward trend and gaps in services.⁴⁴ The 15 Healthcare Essentials online survey showed that 40 per cent of people had not been referred to specialist care when needed.⁴⁵

Access to multi-disciplinary specialist health care is essential in the management of complications of diabetes including foot ulcers and neuropathy, diabetic retinopathy, kidney and cardio-vascular disease.

Care planning: People with diabetes should also receive care planning to meet their individual needs. Their yearly care plan should be agreed as a result of a discussion between the person with diabetes and their diabetes healthcare team outlining individual needs and setting targets. Successful care planning helps to achieve both good care processes and outcomes.

In the Year of Care Programme Evaluation people reported an improved experience of care and real changes in self-care behaviour; professionals reported improved knowledge and skills, and greater job satisfaction, and practices reported better organisation and team work.⁴⁶ The data from Diabetes E PCT survey in England shows that a high percentage of both PCTs and providers state that personal care plans are required for people with diabetes, or should be developed. However, only a third of people had an individual care plan to meet their needs.⁴⁷

Smoking cessation support: Having diabetes increases the risk of CVD and smoking further increases this risk. People with diabetes, who are also smokers, should receive advice and support on how to quit. Only 85 per cent of people with diabetes have their smoking status recorded.⁴⁸ Data is not available to show whether support is offered and whether there is a positive outcome.

What is needed:

- People with diabetes should experience a more integrated pathway between primary and secondary care and enabled to access the appropriate level of specialist services at the right time and in the right place.
- Support to self manage should include providing people with their HbA1c, blood pressure and cholesterol results prior to their annual review. The Commissioning Outcomes Framework must include targets to support this.
- Personalised care planning should become embedded in routine care with GP commissioning consortiums ensuring support for this new approach.
- People who require support or management to help them lose weight should be referred for specialist advice (e.g. from a dietitian, exercise specialist, smoking cessation service). A clear strategy for weight management and smoking cessation should be in place which is monitored and reported.

Living with diabetes

Structured Education: Day to day treatment of diabetes, the prevention of CVD and treatment of CVD relies on self-management. Adherence can be exceedingly demanding, often requiring fundamental life-style changes. These include behavioural change, diet, physical activity, daily medication and/or injections and glucose monitoring. It is imperative that people with diabetes possess the necessary information and skills to self-manage their condition. This may only be achieved through the provision of high quality structured education and support. NICE guidance was devised in order to standardise the way education courses are developed and run.⁴⁹

All people with diabetes, whether recently diagnosed or those with pre-existing diabetes, should receive access to structured education (that meets national standards) and support they need to enable them to manage their own diabetes. This should be available in their local area and be accessible and flexible to meet individual needs.

Access to psychological and emotional support: People living with diabetes experience twice the amount of depression of those who do not live with a long-term condition. 41 per cent of people with diabetes suffer with poor psychological well-being.⁵⁰ Poor mental health is associated with an increased risk of cardiovascular disease and also has a negative impact on diabetes self-care and medication adherence, leading to hyperglycaemia and increased risk of CVD complications and death. There is an established evidence base of psychological need in people with diabetes, and addressing psychological needs has been shown to improve HbA1C in people with Type 2 diabetes.⁵¹

A report by Diabetes UK found that 85 per cent of people with diabetes do not have access to specialist psychological services and there are long waiting times for services that exist.⁵² No national data is routinely collected in relation to the provision of emotional and psychological support for people with diabetes.

What is needed:

- Service developers must ensure that the provision of structured education is prioritised, planned as a long-term activity and that is sufficiently resourced to meet the needs of the population.
- Access to and the uptake of structured education for diabetes should be built into the Quality Outcomes Framework and the Commissioning Outcomes Framework.
- Emotional and psychological care needs to become a routine part of diabetes management.
- Expert psychological care for people with diabetes needs to be provided by professionals with specific knowledge and experience in the area of diabetes.
- Specialist psychological services should be able to provide education and training for members of the diabetes multi-disciplinary team.
- Access to psychological support for people with diabetes should be monitored and reported.

Notes

Diabetes mellitus is a condition in which the amount of glucose (sugar) in the blood is too high because the body cannot use it properly. There are two main types of diabetes.

Type 1 diabetes develops if the body cannot produce any insulin. Insulin is a hormone which helps the glucose to enter the cells where it is used as fuel by the body. Type 1 diabetes is the least common of the two main types and accounts for around 10 per cent of all people with diabetes.

Type 2 diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). In most cases this is linked with being overweight. This type of diabetes usually appears in people over the age of 40, though in South Asian people, it often appears after the age of 25. However, recently, more children are being diagnosed with the condition, some as young as seven. Type 2 diabetes is the more common of the two main types and accounts for around 90 per cent of people with diabetes.

References

- ¹ 2.9m are diagnosed and 850,000 estimated undiagnosed.
- ² Figures based on AHPO diabetes prevalence model <http://bit.ly/aphodiabetes>. The AHPO model estimates that by 2025 there will be 4,189,229 people with diabetes in England.
- ³ This figure was worked out using the diagnosed figure from the 2009 Quality and outcomes framework with figures from the 2010 Quality and outcomes framework.
- ⁴ QOF prevalence data 2006-2010 – derived from QOF diabetes prevalence (2010) and APHO Diabetes prevalence Model estimate for diagnosed and undiagnosed cases of diabetes in 2010 <http://www.yhpho.org.uk/default.aspx?RID=81090>.
- ⁵ Morrish NJ, Wang SL, Stevens LK et al (2001). Mortality and causes of death in the WHO multinational study of vascular disease in diabetes. *Diabetologia* 44 suppl 2; s14-s21.
- ⁶ Emerging Risk Factors Collaboration (2010). Diabetes mellitus, fasting blood glucose concentration, and risk of vascular disease: a collaborative meta-analysis of 102 prospective studies. *Lancet* 375 (9733); 2215-2222; Jeerakathil T, Johnson JA, Simpson SH et al (2007). Short-term risk for stroke is doubled in persons with newly treated Type 2 diabetes compared with persons without diabetes: a population based cohort study. *Stroke* 38 (6); 1739-1743.
- ⁷ Information Centre (2011) National diabetes Audit (NDA) Mortality Analysis 2007-2008.
- ⁸ Department of Health (2001). National service framework for diabetes: standards.
- ⁹ Excess death – a premature death, or one that occurs before the average life expectancy for a person of a particular demographic category.
- ¹⁰ National Diabetes Audit Mortality Analysis 2007-8, (2011), NHS Information Centre.
- ¹¹ Hex, N., Bartlett, C., Wright, D., Taylor, M., Varley, D. Estimating the current and future costs of Type 1 and Type 2 diabetes in the United Kingdom, including direct health costs and indirect societal and productivity costs. *Diabetic Medicine*. In press.
- ¹² NDST (2005). National Diabetes Support Team fact sheet: no 10: Working together to reduce length of stay for people with diabetes.
- ¹³ Hauner H (2010). Obesity and diabetes, in Holt RIG, Cockram CS, Flyvbjerg A et al (ed.) *Textbook of diabetes*, 4th edition. Oxford: Wiley-Blackwell.
- ¹⁴ <http://www.ic.nhs.uk/statistics-and-data-collections/health-and-lifestyles-related-surveys/health-survey-for-england>.
- ¹⁵ <http://www.bis.gov.uk/foresight/our-work/projects/published-projects/tackling-obesities>.
- ¹⁶ Healthy Lives, Healthy People: A call to action on obesity in England, DH October 2011.
- ¹⁷ Preventing type 2 diabetes: population and community-level interventions in high risk groups and the general population.
- ¹⁸ Figure based on data from AHPO diabetes prevalence model figures <http://bit.ly/aphodiabetes> and the QOF 2010 figures <http://bit.ly/prevalence2010>.
- ¹⁹ UKPDS Group: UK Prospective Diabetes Study VIII: study design, progress and performance. *Diabetologia* (1991) 34; 877-90.
- ²⁰ Harris MI, Klein R, Welborn TA et al (1992). Onset of NIDDM occurs at least 4-7 years before clinical diagnosis. *Diabetes Care* 15 (7); 815-819.
- ²¹ State of Diabetes Care report, Diabetes UK 2009.
- ²² APHO and QOF data, 2011.
- ²³ Pre-diabetes refers to Impaired Glucose Tolerance (IGT), Impaired Fasting Glycaemia (IFG) or Impaired Glucose Regulation (IGR).
- ²⁴ Preventing Type 2 diabetes: risk identification and interventions for high-risk for individuals, NICE Public Health Draft Guidance, Nov 2011.
- ²⁵ NHS Diabetes and Kidney Care, The NHS Health Check Programme Evidence base http://www.healthcheck.nhs.uk/_PresentationsandFeedback.aspx 16th November 2011.
- ²⁶ Pre-diabetes refers to Impaired Glucose Tolerance (IGT), Impaired Fasting Glycaemia (IFG) or Impaired Glucose Regulation (IGR).

- 27 NHS Diabetes and Kidney Care, The NHS Health Check Programme Evidence base <http://www.healthcheck.nhs.uk/PresentationsandFeedback.aspx> 16th November 2011.
- 28 NHS Diabetes and Kidney Care The NHS Health Check Programme Evidence base <http://www.healthcheck.nhs.uk/PresentationsandFeedback.aspx> 16th November 2011.
- 29 <http://www.healthcheck.nhs.uk/Default.aspx>.
- 30 Technical Guidance for the 2012/13 Operating Framework, Department of Health, 22nd Dec 2011.
- 31 Improving outcomes and supporting transparency. A public health outcomes framework for England 2013-2016 Department of Health Jan 2012 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132358.
- 32 Cholesterol and a healthier nation: Shared responsibility for better public health, Heart UK, December 2011 www.heartuk.org.uk.
- 33 Department of Health NHS Health Checks, 15th February 2012, Number of eligible people that have been offered and received NHS Health Checks http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Perfomancedataandstatistics/Integratedperfomancemeasuresmonitoring/DH_129481.
- 34 Department of Health NHS Health Checks, 15th February 2012, Number of eligible people that have been offered and received NHS Health Checks http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Perfomancedataandstatistics/Integratedperfomancemeasuresmonitoring/DH_129481.
- 35 Department of Health NHS Health Checks, 15th February 2012, Number of eligible people that have been offered and received NHS Health Checks http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/Perfomancedataandstatistics/Integratedperfomancemeasuresmonitoring/DH_129481.
- 36 Graley et al; Postcode lotteries in public health – The NHS Health Checks Programme in North West London. BMC Public Health 2011 11:738.
- 37 Roadshows 2011: Key statistics, Diabetes UK.
- 38 Diabetes UK, Measure Up campaign evaluation, 2007.
- 39 Preventing Type 2 diabetes: risk identification and interventions for high-risk for individuals, NICE Public Health Draft Guidance, Nov 2011.
- 40 Preventing Type 2 diabetes: risk identification and interventions for high-risk for individuals, NICE Public Health Draft Guidance, Nov 2011.
- 41 National service framework for diabetes: standards http://www.dh.gov.uk/en/publicationsandstatistics/publications/PublicationsPolicyAndGuidance/DH_4002951; National Institute for Health and Clinical Excellence Clinical Guidance on Diabetes CG15: Type 1 diabetes: Diagnosis and management of type 1 diabetes in children, young people and adults and CG66: Type 2 diabetes: the management of type 2 diabetes (update) National Diabetes Audit 2009-10.
- 42 National Diabetes Audit 2009-10 http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/National_Diabetes_Audit_Executive_Summary_2009_2010.pdf.
- 43 National Diabetes Audit 2009-10 http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/National_Diabetes_Audit_Executive_Summary_2009_2010.pdf.
- 44 Diabetes UK and NHS Diabetes. (2011). 2010 Diabetes Specialist Nursing Work Force Survey Report. Available: http://www.diabetes.org.uk/Documents/Reports/2010_DSN_survey_report.16-05-11.pdf. Last accessed 25th April 2012; NHS Diabetes, Diabetes UK, Diabetes Management and Education Group (DMEG). (2012). 2010 Dietitian Workforce Survey Report. Available: http://www.diabetes.nhs.uk/our_publications/. Last accessed 25th April; Diabetes UK and Royal College of Physicians. (2012). Diabetes UK / RCP Diabetes and Endocrinology National Manpower Report 2011(interim). Available: <http://www.diabetes.org.uk/upload/Professionals/Reports/Manpower%20interim%20report%202012.pdf>. Last accessed 25th April 2012.
- 45 Diabetes UK. (2011).15 Healthcare Essentials online survey. Available: http://www.diabetes.org.uk/About_us/Our_VIEWS/15-healthcare-essentials/ Last accessed 24th April 2012.
- 46 Year of Care Partnership*. (2011). Report of findings from the pilot programme *NHS Diabetes, Diabetes UK, Department of Health, The Health Foundation.
- 47 Analysis of DiabetesE Primary Care Trust Questionnaire Data 2011 (courtesy of Innove).
- 48 National Diabetes Audit 2009-10 http://www.ic.nhs.uk/webfiles/Services/NCASP/Diabetes/200910%20annual%20report%20documents/National_Diabetes_Audit_Executive_Summary_2009_2010.pdf.
- 49 National Institute for Health and Clinical Excellence. (2003). TA60 – Guidance on the use of patient-education models for diabetes. Available: <http://publications.nice.org.uk/guidance-on-the-use-of-patient-educationmodels-for-diabetes-ta60>. Last accessed 24th April. HbA1c targets also set by QOF.
- 50 Minding the Gap, 2008, Diabetes UK.
- 51 Mental Health Network NHS Confederation, 2012, Investing in emotional and psychological wellbeing for patients with long-term conditions: A guide to service design and productivity improvement for commissioners, clinicians and managers primary care ,secondary care and mental health.
- 52 Minding the Gap, 2008, Diabetes UK.

Education For Health



Overall vision for the outcomes strategy?

To continue to build on the valuable and effective CVD work undertaken so far and explore new ways of working which will enable and benefit prevention and awareness, risk assessment and early diagnosis, treatment and long term care.

To facilitate the integration of CVD throughout mainstream healthcare i.e. primary prevention, early diagnosis, management in primary care, emergency care, management in hospital, post hospital management, rehabilitation, end of life care.

Key priorities

Education and training

A crucial element in improving the outcomes for people living with or at risk of CVD is better education of both patients and the public, but more significantly of health and social care professionals. Research has shown that, in tackling long term cardiovascular conditions, a focus on education at primary care level has a huge impact. As we move to a new NHS arena with a shift in emphasis towards clinical commissioning groups it is essential, especially in these financially difficult times, that the Cardiovascular Outcomes Strategy articulates and facilitates the imperative for education and training that is validated and of high standard.

<http://www.educationforhealth.org/news.php/113/education-must-be-key-facet-in-cardiovascular-disease-cvd-strategy>

Access to information

Build and improve on access to reliable sources of information for patients, the public and health care professionals looking in particular at methods with a good return on minimal investment, such as social media applications (eg Webapps etc).

Monitoring

Appropriate monitoring to facilitate timely interventions, including looking at new ways of enabling independence through self-monitoring and self-management.

Environmental adaptations

Multidisciplinary working, including the voluntary sector, to identify areas / tools / aids which will support those living with cardiovascular disease enabling them to live as full a life and remain as healthy as possible.

Care planning

Care planning which will incorporate the wishes and goals of patients and which will be shared with health and social care professionals right across the pathway in order to ensure best outcomes for the CVD patient journey. The importance of holistic care which takes into consideration co-morbidities.

Access to specialist teams

The right service available in the right place at the right time, right across the board.

Emotional / social / psychological support

For example, improved staff, patient and public awareness for recognition of depression and appropriate processes in place for signposting and follow up.

Users having financial control

Consider looking at how personal health budgets might be appropriated to CVD.

'Large scale' public health initiatives

The escalation of risk factors such as smoking and, in particular, obesity are worrying. Initiatives that can have a wide and far-reaching impact (large scale) need investment and new ideas.

How to measure progress on ambitions

What to measure

Patient centredness

Whether services are focused around the patient and provide a sustainable model for engendering shared decision making and confident self management.

<http://www.bmj.com/content/341/bmj.c5146>

Complexity

Complex disease requires complex care models. With a widening focus that will include liver and kidney disease it is important to consider different healthcare delivery models.

<http://www.ncbi.nlm.nih.gov/pubmed/16340668>

Multidisciplinarity

Services and care which span the pathway creating a joined up approach across the NHS, public health and social care, minimizing disruption to the individual, involving carers and families, addressing inequalities and exploring new ways of working.

<http://ndt.oxfordjournals.org/content/20/1/10.full>

Accessibility

New modes of working, with full consideration of the scope for technology and CVD management / self management.

<http://cpr.sagepub.com/content/16/3/281.abstract>

How to measure

Quality, Innovation, Productivity and Prevention (QIPP)

The QIPP challenge aims to ensure that the NHS progresses from good to great, introducing a new drive towards a more preventative and people-centred service that is better for patients and also more productive, acquiring more for the public from a much-expanded and more capable and resilient system.

<http://www.networks.nhs.uk/nhs-networks/qipp-network/news>



Familial hypercholesterolaemia screening

Familial hypercholesterolaemia (FH) is a dominantly inherited condition which causes an elevated level LDL cholesterol in the blood. The high level of cholesterol accelerates the thickening of arterial walls (atherosclerosis), significantly raising the risk of coronary heart disease (CHD), which may have an age of onset as early as 30 years. FH is a treatable cause of CHD, as the high level of cholesterol can be effectively be reduced to normal levels with the use of medicines and adjustments to lifestyle.

FH is estimated to occur in 1 in 500 people, roughly 120,000 people in the UK, but only 18,000 of these are diagnosed and receiving the management that can prevent FH from causing CHD.¹ For individuals with untreated FH, there is approximately a 50% risk of CHD in men by the age of 50 years and at least 30% in women by the age of 60 years. Due to the poor rate of diagnosis, there is a large population of people in the UK at high risk of early onset CHD who are not accessing effective treatment and management.

Cascade screening for FH is a screening programme to identify people at risk of FH by testing the relatives of patients who have been diagnosed with FH. Screening individuals who are at high risk can give a clear diagnosis, allowing for effective management with lifestyle modification and cholesterol-lowering medication. It is an approach to identifying patients with FH that has been piloted, examined, and implemented extensively across the globe.

In December 2010, the Welsh Assembly Government announced it was funding (in association with the British Heart Foundation) a cascade screening service for FH in Wales. This flagship NHS service is now in place. Index patients are being identified and their at-risk relatives are being screened using family pedigree assessment, blood cholesterol levels and genotyping. The Welsh service is currently the only cascade screening initiative in the UK, despite a large body of evidence in favour of implementation.

Previous to the full commissioning of the all Wales service, a smaller-scale pilot had been underway in south east Wales. Both this earlier implementation and the present service should be seen as pilots of a scheme for the United Kingdom, informing health service commissioners and providers of an effective way of delivering this service for primary prevention of coronary heart disease. The success of the programme in Wales should be built on and its developmental issues learnt from. Programmes have also been running in other European countries for a number of years. Each programme takes a differing approach, and can be examined for evidence and indication of the best strategy for UK health services.

The NICE CG71 guideline on FH, published in 2008 recommended cascade screening. This document has now been cited across the world as evidence that a cascade screening programme is the best practice strategy for identifying FH patients.

The strongest case for a UK FH screening programme is given by the simple facts: that FH is a common condition; that untreated affected FH patients develop coronary heart disease and are at significant risk of premature death; and that the condition can be effectively diagnosed, managed and treated through a screening programme.

References

- ¹ Heart to Heart, Inherited Cardiovascular Conditions Services, A Needs Assessment and Service Review; June 2009; Hilary Burton, Corinna Alberg, Alison Stewart; PHG Foundation

Grown Up Congenital Heart Disease



It is important for congenital heart disease to be included in the outcomes strategy. It is still the case that adult congenital heart disease is the worst catered for of cardiovascular diseases and recently the number of adults with congenital heart disease overtook the number of children and the number is rising rapidly. There is currently a review of children's cardiac surgical centres (Safe & Sustainable) to reduce the number of centres and a review of the standards for adult congenital heart disease services.

Early identification

Early identification of congenital heart disease is important to reduce its effect in both mortality and morbidity and the proper screening processes need to be in place.

Prevention

There is little hope for prevention of congenital heart disease as there is a lack of understanding as to why the condition exists. There is on-going work on this matter but it is years away from any hypothesis let alone consideration of prevention.

Treatment

To treat adult congenital heart disease properly there needs to be both designated services and a route to those services both from transition from paediatric services as well as from other medical professionals (GPs, DGH etc).

There are two very important issues which need to move forward and be carried out correctly.

Safe & Sustainable

The review of children's cardiac centres is likely to recommend a reduction in the number of units. Whilst this review has only taken into account paediatric surgery, the decision will significantly affect adult surgical services as well as the surgeons are congenital surgeons operating on both children and adults. The reduction in the number of units is sensible but the determination of which needs to work for both children and adult even though the decision is only being made taking into account the requirement for paediatric services.

Grown Up Congenital Heart Disease Review

The services for adults are not currently designated and therefore there is occasional practice taking place. It is also very difficult for patients to know where to go for expert services. The review is to set standards and then designate the service. It is important that this happens and that the services are designation as Specialist services through Specialist Commissioners.

Progress

Currently without designated services, the specialist care which is needed is sourced and provided based on opinion rather than any measure of expertise. The reduction in congenital, and not just based on paediatric requirements, surgical centres and the designation of adult congenital services will make significant progress if done right. It is very important that this occurs and is done recognising the needs of the whole congenital heart population.

Voluntary organisations

The Grown UP Congenital Heart Patient Association is the only national body purely representing adults with congenital heart disease and has been involved in the work done by the DoH and NHS both in the publication of the GUCH Guide in May 2006 as well as the designation standards now going out to engagement. It fully supports the standards and will be pushing for them to be acted upon taking a positive role in this wherever it can.

This is the first time that adults with congenital heart disease will have an opportunity to be recognised as deserving the specialist treatment which they need, it being properly designated and easier to access. They deserve every support in this being achieved.

Heart of Mersey



About Heart of Mersey

Heart of Mersey (HoM) is a heart health charity based in Liverpool. HoM aims to co-ordinate a strategic approach to preventing the high rates of cardiovascular disease (CVD) and associated inequalities in our region. We advocate a population-based approach to heart disease and stroke prevention. NW England has long suffered disproportionately from CVD which is the biggest contributor to health inequalities in our region.

Although our principal activity is to work with local organisations to achieve improved access to healthy food and a reduction in exposure to smoking, we believe that local action alone is not enough to improve the health of our population. We therefore work in partnership with national and international organisations where appropriate to advocate for healthier policy in tobacco control (such as standardised tobacco packaging) and food and agricultural production (including advocating for a European Common Agricultural Policy which supports healthier nutrition).

HoM welcomes the opportunity to respond to The All-Party Parliamentary Groups on Heart Disease, Stroke, Kidney and Diabetes who are holding meetings to examine the key priorities for the forthcoming Cardiovascular Disease Outcomes Strategy.

1. What is your vision for the outcomes strategy? What conditions should be covered by the outcomes strategy? Where do we need to focus efforts in the coming decade and what is the balance between prevention and treatment? What needs to be sustained and what has been overlooked?

Our responses are from the perspective of a heart health charity and focus on the prevention of cardiovascular disease. However the key risk factors for the prevention of cardiovascular disease – smoking and a poor diet – are also applicable to other noncommunicable diseases such as type 2 diabetes and obesity.

Government spend on prevention is tiny as compared to that on treatment.¹ A small readjustment and an increased focus on prevention would have a major impact on cardiovascular morbidity and mortality.

HoM believes that ‘giving every child the best start in life’ is crucial in promoting long term health benefits throughout the lifecourse. In order to provide families and communities with the opportunity to make changes in their lifestyle to reduce risk factors, it is necessary to have a supportive environment and public policies (both directly related to health affecting the wider determinants) to enable the “healthy choice to become the easy choice”.²

Creating supportive environments through legislation, regulatory and voluntary approaches to public health policy would help to reduce inequalities and minimise the socio-economic disadvantage of children.

HoM acknowledges the attempts made by the government to change individual behaviours by developing the Change4Life Campaign for example. However sustaining behaviour change long term can be challenging, however by protecting children from the marketing of unhealthy food and drink products and supported by environments that promote healthy food practices would help to sustain healthy behaviours. Providing environments supportive of improving children’s diets will not only tackle high levels of cardiovascular disease but also the many risk factors associated such as type 2 diabetes and obesity. Stronger regulation to limit the advertisement and marketing of unhealthy foods (those high in fat, sugar and salt) is required.

2. Who needs to do what to achieve the ambitions for reducing cardiovascular diseases and improving treatment for people with inherited heart disease? What is the role of national government, the NHS Commissioning Board, Public Health England, local directors of public health and clinical commissioning groups?

Whilst HoM believes in empowering local communities to help address CVD prevention issues, we believe that national oversight and monitoring by Public Health England will be vital to maximise public health improvements.

We also believe that although local leadership is critical, there is still an important role for supra-local commissioning or shared services to address important prevention issues such as illicit tobacco and that there remains a need for national regulation around for example food labelling, reduction in dietary salt, saturated fats and sugars, and the elimination of industrial trans fats.

We strongly support the concept of the Nuffield ladder of intervention.³ We further believe that interventions are necessary at all levels as appropriate. In other words, you should not always start at the foot of the ladder. We thus strongly support effective smokefree legislation including the standardised packaging of tobacco products. Likewise a ban on the advertising of foods and drinks that are high in fat, salt and sugar before 9 p.m. in order to better protect children and young people. We strongly welcomed the government's ban on retail tobacco Points of Sale displays as announced in the Tobacco Control Plan for England. This is already helping to protect children from a serious health hazard.

HoM welcomes the recognition of the important role of Directors of Public Health as strategic leaders in local public health, health inequalities and health partnerships. We recommend that Directors of Public Health must have the authority and independence to advise on policy areas which impact on CVD prevention such as smoking cessation, physical activity, healthy eating and all aspects of population health and health inequalities. In addition, we note the work of Dr Laurence Gruer, which finds that half the difference in life expectancy between richest and poorest is attributable to smoking and that the poorest non smokers have better survival rates than the richest smokers.⁴ Directors of Public Health should ensure that NICE public health guidance is implemented including guidance on the prevention of cardiovascular disease,⁵ overweight and obesity,^{6,7,8} physical activity and the environment,⁹ and on reduction in smoking.^{10,11} They must also have their independence to comment on any problems and deficiencies and to know that when in the right, they will have the backing of Public Health England.

3. How will we know whether progress is being made on these ambitions? What should be measured and how?

HoM supports the Public Health Outcomes Framework (PHOF)¹² and believes that open access to data and shared priorities will enable a common focus on health and wellbeing priorities. We need to ensure data is available at various levels (national, supra-local, local) to inform practice and to be aware that some data (around CVD mortality for example) will necessarily involve a time lag in reporting.

Effective tobacco control and improving diets are essential to reducing health inequalities and reducing CVD and should be pivotal in data availability and focus.

Public health practice should always be underpinned by evidence. It is important that the various contributions by the academic sector, by the charitable and voluntary sectors and national organisations such as NICE are recognised. Key national surveys such as the Health Survey for England provide essential information on lifestyles including biomedical measures such as blood cholesterol levels (important in assessing risk for heart disease). At the same time it is critical that quantitative and qualitative data is maintained on tobacco usage and food and nutrition intake.

It is of concern that the PHOF lists diet as an indicator for the Health Improvement objective – People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities – but gives no detail of how this will be measured. It is noted that 'major development work' is required to set out the rationale and technical information to support the diet indicator.

Local organisations (working both within specified communities and at supra-local level) are well placed to provide appropriate data to inform local programmes. Examples of effective practice should be shared wherever possible. Joint strategic health assessments and health and wellbeing boards will be key mechanisms for ensuring that there is effective collaboration between public health, health and social care. HoM strongly advise that there must be genuine engagement with patients, the public, the voluntary sector, and multi-disciplinary and multi-agency professionals in order to improve the use of evidence in public health effectively.

Public Health England and Local Authorities should assess all public policy and programmes for the potential impact on CVD and other related chronic diseases and to monitor the outcomes of policy and programmes after the assessment. Data on CVD prevention should also be available for scrutiny by the public health community.

4. A key challenge is the need to properly re-frame cardiovascular diseases as long term conditions, how can we ensure that people get the support that they need to live well and manage their health?

We have no comment on this question.

5. How will voluntary organisations be contributing to meeting these ambitions?

We believe that third sector organisations make an important commitment to public health¹³ and CVD prevention in demonstrating and sharing good public health practice, in providing independent scrutiny, in a key advocacy role, in engaging local communities and helping to provide an evidence basis to support public health policy. The role of the third sector should be explicitly laid out wherever possible in the new CVD Outcomes Strategy and be seen as key and active partners in CVD prevention given the sector's expertise.

Contact name: Robin Ireland, Chief Executive
Address: Burlington House, Crosby Road North, Liverpool, L22 0QB
Tel: 0151 928 7820
E-mail: robin.ireland@heartofmersey.org.uk

References

- ¹ Health England (2009). Public Health and Prevention Expenditure in England, London: Health England.
- ² Lewis B and Rose G. Prevention of coronary heart disease: putting theory into practice. J R Coll Physicians London. 1991. Jan;25(1):21-6.
- ³ Nuffield Council on Bioethics (2007). Public health:ethical issues, London: Nuffield Council on Bioethics.
- ⁴ Gruer L, Hart CL, David S Gordon DS, Watt GCM. Effect of tobacco smoking on survival of men and women by social position: a 28 year cohort study. BMJ 2009;338:b480.
- ⁵ NICE (2010). Prevention of cardiovascular disease at population level, London: NICE.
- ⁶ NICE (2006). Obesity. Guidance on the prevention, identification, assessment and management of overweight and obesity in adults and children, London: NICE.
- ⁷ NICE (March 2008) Maternal and Child Nutrition. NICE.
- ⁸ NICE (July 2010) Dietary interventions and physical activity interventions for weight management before, during and after pregnancy. NICE.
- ⁹ NICE (2008). Promoting and creating built or natural environments that encourage and support physical activity, London: NICE.
- ¹⁰ NICE (2002). Smoking cessation – bupropion and nicotine replacement therapy (replaced by PP10). London:NICE.
- ¹¹ NICE (In progress – expected date of issue to be confirmed). Smoking cessation in Secondary Care. London:NICE.
- ¹² Department of Health (2012). Improving outcomes and supporting transparency. Part 1: A public health outcomes framework for England, 2013-2016, London: Department of Health.
- ¹³ ACEVO (2010). The Organised Efforts of Society/the role of the voluntary sector in improving the health of the population, London. ACEVO.



1. What is your vision for the outcomes strategy? What conditions should be covered by the outcomes strategy? Where do we need to focus efforts in the coming decade and what is the balance between prevention and treatment? What needs to be sustained and what has been overlooked?

HEART UK – The Cholesterol Charity – notes that, despite real progress in the management and treatment of cardiovascular disease (CVD), it remains the UK's number one killer. As such, CVD should be at the top of the health agenda, and this should be reflected in the deliverables included in the Outcomes Strategy.

HEART UK's vision for the Outcomes Strategy is reflected in these key recommendations:

- **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.
- **National Oversight of Health Checks** – The NHS Commissioning Board should oversee the continued delivery of the Health Checks programme.
- **Review QOF Indicators on CHD** – NICE should review QOF indicators for secondary prevention of coronary heart disease (CHD) to incorporate uptake and quality of cardiac rehabilitation and ensure that all existing targets reflect best practice guidelines and are sufficiently ambitious to help individuals achieve the best possible outcomes.
- **National Programme for Familial Hypercholesterolaemia (FH)** – A national programme for FH under the NHS Commissioning Board should be established and funded centrally. NICE guidelines on FH should be fully implemented.
- **Strengthen Local Authority Capability on Public Health** – Ensure that local authorities have the resources, skills and capability to undertake its new public health responsibilities.
- **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.
- **Health literacy and prevention** – Advice to patients should improve understanding of CVD risk factors, where possible incorporating the latest patient tools published in Joint British Societies guidelines.

Further work is needed to improve primary prevention of CVD. Of particular concern to HEART UK is the very low level of diagnosis and treatment of Familial Hypercholesterolaemia (FH), a relatively common genetic disorder, affecting 1 in 500 people. If the condition remains untreated, people with FH suffer a much higher premature death rate from CVD than the general population. Yet it can be easily diagnosed and treated affordably. The condition has been poorly overlooked, as the NICE guideline on FH (2008) has not been well implemented, and only some 15-20% of the FH population has been diagnosed.

The Outcomes Strategy should adopt the principles of innovation for health, as expressed in the Nicholson Innovation Review. HEART UK recently commissioned new health economic research into FH, which revealed that diagnosing and treating people with FH not only saves lives, it is also more cost effective than not treating them. Yet HEART UK's calls for a national programme for FH continue to go unheeded. (Download the report at: http://www.heartuk.org.uk/pressroom/images/uploads/SavingLivesSavingFamilies_FHreport_Feb2012.pdf)

The Outcomes Strategy must ensure that the NHS Health Checks programme, which has proven a cost-effective way of tackling CVD, reaches as many people as it can to both raise awareness of CVD risk factors and help prevent heart attacks and strokes.

2. Who needs to do what to achieve the ambitions for reducing cardiovascular diseases and improving treatment for people with inherited heart disease? What is the role of national government, the NHS Commissioning Board, Public Health England, local directors of public health and clinical commissioning groups?

This is a joint endeavour between primary, secondary and tertiary care, commissioners and the voluntary sector. In many cases, services will be commissioned locally. However, in some cases, it is apparent that localised commissioning has not been effective, often because the condition is too rare to warrant focus. In the case of Familial Hypercholesterolaemia (FH), HEART UK recommends that the NHS Commissioning Board (NHS CB) creates a national programme for FH in England. Given that FH is a genetic condition affecting family members scattered around the country, a national programme is the best means of ensuring that FH services are available beyond the limited boundaries of a PCT or CCG. Other parts of the UK are achieving a great deal more on FH, precisely because they have national programmes or clinical standards designed to improve diagnosis and treatment of the condition. With no national FH programme in England, health inequalities will soon emerge for those with the condition living in different countries of the UK.

Considering the better position of other countries in the UK, this national programme should include the following key elements:

- A new national register of FH patients. The register should serve as patient database and accommodate cascade screening and clinical management tools and ideally should be able to link to similar systems in Wales, Scotland and Northern Ireland.
- A dedicated network of involved professionals, including lipid clinics, primary care and genetic services. This is critical in the multidisciplinary management of FH patients.
- Clear referral pathways at the local level.
- The employment of FH nurses to rollout the cascade screening process.

Such a programme could commence as a pilot in an area equivalent to an SHA and involve Cardiac and Stroke Networks to help deliver the programme locally. Given the importance of genetic services and the role of CCGs/PCTs in local delivery, these organisations should also be involved.

The NHS CB or similar national body could have direct oversight of an FH programme, with ringfenced money dedicated to rolling out the recommendations of the NICE Guideline.

3. How will we know whether progress is being made on these ambitions? What should be measured and how?

The Outcomes Strategy should include means to measure delivery, in the same manner as the NHS Operating Framework. The Cancer Outcomes Framework states that,

"It is envisaged that the Commissioning Outcomes Framework, which will be used to incentivise high quality commissioning, will be closely aligned with the NICE Quality Standards. And for commissioners, the Commissioning for Quality and Innovation (CQUIN) payment framework will be important for ensuring the implementation of NICE Quality Standards by providers."

(see http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_123394.pdf).

HEART UK welcomes this development, as a means of ensuring that the highest standards can be achieved through links to NICE Quality Standards.

However, HEART UK feels that, for some conditions, it will be difficult to manage the rollout of improvements without national leadership. For conditions like Familial Hypercholesterolaemia (FH), which represent a smaller (though still significant) population, the NHS Commissioning Board should make these a priority for itself to manage, with their own performance being scored according to a set of goals and outcomes. This would be in line with the NHS CB's remit to directly commission services and help reduce health inequalities.

4. A key challenge is the need to properly re-frame cardiovascular diseases as long term conditions, how can we ensure that people get the support that they need to live well and manage their health?

One means of doing this is to ensure that cardiac rehabilitation is not just measured according to whether it is being offered, but that uptake and quality are also measured. This could include altering the Quality and Outcomes Framework indicator on cardiac rehabilitation to include the uptake as well as the offer of rehabilitation. This will help increase the uptake for cardiac rehabilitation, and with it the long term health of those living with CVD.

Greater resources need to be spent on primary prevention, including initiatives to improve health literacy. If people better understand the risk factors for CVD, it will help prevent CVD from occurring in the first place.

5. How will voluntary organisations be contributing to meeting these ambitions?

Voluntary organisations will be contributing as providers of services, as voices for patients, and as sources of expertise and knowledge.

Kidney Alliance



Vision for the outcomes strategy

Vision

The ambition to build a strategy across the vascular pathway of heart disease, stroke, kidney disease and diabetes is both challenging and productive. From a patient perspective such a strategy has many potential benefits by integrating several major medical specialities to improve partnership working. It also offers the opportunity for a patient to be treated as a whole person rather than in silos related to the various conditions they may have, and to offer a way for them to make an informed decision about how they wish to be cared for and how they wish to care for themselves.

The vascular pathway encompasses several specific medical specialities. By careful integration patient outcomes should be improved, be that in prevention or reduction of complications, whilst potentially reducing resource requirements in health care. The strategy needs to be balanced across the pathway specialities so that it encourages the best overall treatment outcomes and choices for patients and prevention outcomes for people at risk of one or more of these disease processes.

The strategy must encourage the use of the most effective public health or health interventions across a wide range of options, taking into consideration potential interactions between what might previously have been considered separate care pathways. It is essential that expectations on outcome in the respective medical specialities are sufficiently flexible to permit this.

This strategy should:

- Be patient centred, providing a holistic approach to vascular disease management.
- Result in better prevention, diagnosis and treatment outcomes in a balanced way across heart disease, stroke, kidney disease and diabetes.
- Highlight potential areas of synergy in terms of prevention, diagnosis or treatment and encourage greater focus on them.
- Identify points at which there may be tension between different medical specialities and devise a patient centred approach to prioritisation of care.
- Influence the development of outcome measures in each related medical speciality in such a way as to accommodate patient centred prioritisation between specialities.
- Foster research that has an outlook across broader outcomes.
- Optimise the potential quality gains and cost savings of better outcomes across these areas as a result of more integrated care.

Conditions covered

Early Kidney Disease

Kidney disease is common, harmful and can be treatable. Up to 10% of the general population have significant kidney impairment, and treatment of end stage kidney disease costs over £2 billion. Many die prematurely of heart attacks and strokes linked to kidney disease.

Common causes of kidney disease include diabetes and vascular disease, whilst hypertension and vascular complications are increased in both severity and prevalence in individuals with chronic kidney disease (CKD). The early detection and management of Chronic Kidney Disease in primary care and associated conditions directly relates to prevention of premature death. Kidney disease often shows no symptoms, only being detected if an abnormal blood test is noted or if the urine is tested and elevated levels of protein detected. However, there are increased risks with even mild CKD so it is important to detect the condition in a timely and effective way.

Even early stages of CKD are an independent risk factor for CVD, and in common with these other long-term conditions, can disproportionately affect some black and minority ethnic groups. The risk increases as kidney disease worsens and this risk applies to both the general population and to high risk groups. It is not confined to the elderly – for example, in a study of volunteers aged on average 45,¹ the risk of stroke and heart attack was doubled in the presence of CKD. High blood pressure can lead to kidney damage or, in some cases, be a sign of kidney disease.

People with diabetes are at high risk of kidney disease, and approx 15% of those whose kidneys fail have diabetes.

Therefore, evaluating a high-risk individual for CVD (e.g. those people who are diabetic, have high blood pressure, or who are already known to have CVD) should include screening for kidney disease.

Dialysis and Transplantation

Over 2% of the total NHS budget is spent on renal replacement therapy (dialysis and transplantation) for those with established renal failure. There are approximately 50,000 people with end stage kidney disease in the UK.² About 26,000 of these are on dialysis, at a disproportionate cost to the NHS, and an enormous personal burden. It costs around £30,000 pa to support someone on dialysis and while transplantation is a good option for those who are fit enough to be join the 6,500 on the transplant waiting list, and continue to remain fit enough to receive a transplanted kidney, this is not a viable option for many.

The numbers reaching end stage kidney failure increase every year; 20% of these people present when their kidneys have already failed. Whilst this is an improvement from previous years, strategies aimed at earlier identification and (where possible) prevention of progression to established renal failure are therefore clearly required.

Acute Kidney Injury

Acute kidney injury (AKI) is another important burden to all patients and to the health care system, leading to worse outcomes and longer lengths of stay. Up to 5% of hospital admissions are complicated by AKI, resulting in poorer outcomes for people and higher cost to the NHS. If 30% of AKI was prevented in hospital, the NHS would save £150 million on excess bed days. Studies indicate that between 5-20% of people with any acute illness develop AKI. It is both harmful and preventable. AKI is potentially fatal but in many cases reversible. The recent NCEPOD reports ('Adding Insult to Injury' and 'An age old problem') have highlighted a number of deficiencies including failure to identify people at risk, delays in recognition and insufficient recognition and treatment.³

This is an issue for all acutely ill patients in hospital, and any overarching strategy should take this into account. Treating AKI more effectively will result in better outcomes for all.

Areas for focus

Despite the high cost of renal replacement therapies (dialysis and transplantation), the earlier stages of kidney disease share the principal management strategies utilised in other vascular preventative and treatment programmes:

This covers:

- Lifestyle management – following a healthy diet, keeping active and the need for smoking cessation are shared with all vascular disease groups.
- Blood pressure control – the control of blood pressure is vital to slowing the progression of kidney disease.
- Management of specific issues, such as diabetic control and appropriate medication.

By careful management at the early stages of CKD, progression to and risk of end stage renal failure may be substantially reduced. Other related vascular complications may also be mitigated.

However, the traditional approach to educating people on disease prevention has been to issue a separate set of recommendations for each therapy area. This needs to change substantially.

The impact is likely to be greater if information focuses on single but broad measures, pointing out all of the potential benefits from making that one individual change to life style. For example, eating a healthy diet protects your kidneys and can reduce your chances of contracting diabetes and can help keep your blood pressure down etc.

These preventative strategies require a holistic approach to patient led management. The renal community provides an excellent example in the web based information system 'Renal Patient View'⁴ that allows patients and carers to view their own information and results, with supporting guidance.

The challenge is to simplify the overall approach for patients by providing them with a Vascular Care plan that:

- Empowers them to understand their condition.
- Unifies preventative and basic treatment strategies across all vascular groups.
- Simplifies self management models, such self directed blood pressure monitoring.
- Provides relevant information that enables an individual to take part in managing their overall condition

For clinicians in both primary and secondary care, there needs to be uniformity of guidelines. A crucial example would be the variety of blood pressure targets operating within individual disease silos that are confusing for both clinicians and patients. This also applies to clinical pathways, where local commissioners vary in the way they work in different parts of the country.

We believe that, when considered across all of the therapy areas, such investment becomes more viable. However, this is an area in which low-level investment can easily become wasteful and duplicative. In the present economic environment, we believe that it may be best to concentrate on effective diagnosis and treatment.

The commissioning structures that underpin service planning and delivery

It is essential to position cardiovascular diseases within a long-term conditions framework. This is key to the adequate provision of diagnosis and treatment. Only by adopting the view that these are long-term conditions will policy and strategy lead to the allocation of resources for diagnosis and treatment that will optimise outcomes.

It is also clear that the commissioning of pathways that cross from primary to secondary care, and from CCG to SCG responsibilities must be coherent from the perspective of commissioners, clinicians and most importantly, patients. Potential barriers here are lack of knowledge of specialist renal care amongst GPs and commissioners, and service fragmentation during the transition to the NHS and Social care reforms, which would detrimentally affect efficiency and cost effectiveness.

For example, for patients who may progress towards end stage renal failure, adequate care and support to allow informed decision making and choice are essential. Linking CCG (with a pathway for CKD) to SCG (dialysis and transplantation) commissioning must ensure first class therapy and seamless integration for the patient to maximise benefit. This must be the case regardless of the part of the country in which care is being delivered.

The NHS Commissioning Board has a clear role to play in addressing this, supported by clinical networks. Clinical networks which provide a unified structure and approach to addressing identification and management of linked vascular conditions will be key to achieving consistency of best practice.

The strategy must encourage integration not only between therapy areas but also across Clinical Commissioning and Specialist Commissioning Groups, and the NHSCB must be accountable for and measure the quality of care.

Quality should be measured in terms not just of patient outcomes, but of patient reported outcomes. Quality measures should be reported transparently and regularly.

Implementing the Strategy

Government

Whilst remaining committed to its goals to place greater control and decision-making powers at local level, the government will need to provide the leadership and accountability for the implementation of this strategy. It will need to reinforce the reasons for producing the strategy and the benefits it sees in having it. In addition, it will need to actively endorse the mechanisms that will support and provide the incentives for the strategy's implementation.

NHS Commissioning Board

In April 2013, the NHS Commissioning Board will take full responsibility for commissioning. It will need to carry out a re-evaluation of the commissioning of services in line with the strategy to ensure that commissioning allows sufficient cross over. The Kidney Alliance firmly believes that specialist kidney services, including dialysis and transplantation, must remain as specialised services, commissioned nationally by the NHSCB. There are services in other parts of cardiovascular diseases that should be similarly commissioned. One challenge for the NHSCB will be to make sure that CCG commissioning reflects the strategy and results in integrated services throughout the country.

Public Health England

Public Health England will have the difficult challenge of addressing prevention and encouraging early diagnosis. As we have already stated, we believe that, unless significant additional funding can be made available, the effectiveness of health education programmes etc. will be very limited. However, the obesity agenda fits closely with this strategy and may present an opportunity.

Nevertheless, we believe that Public Health England is likely to have greatest impact by targeting and concentrating on certain groups. Segmentation could be carried out on several bases from geographical area to age group. One other important priority for PHE will be to ensure that patients receiving a diagnosis for one of the diseases covered in this strategy is monitored for others.

Achieving the Strategic Goals

The strategy should have some clear goals and these will be measurable. In many respects these goals will not be substantially different in their nature from those that already exist within individual therapy areas. The strategy will be aimed at achieving existing goals more effectively.

The Commissioning Outcomes Framework (COF) has proposed a number of indicators in all of these areas, on which there has been a consultation. This provides a suitable starting point for the measures that will be needed. However, the COF is really aimed at CCGs, so there will need to be additional measures added from the specialised services.

One area where additional measures do need to be considered is in measuring the impact of the integrated strategy. It will be important to know whether the envisaged benefits are occurring in the intended areas and to the extent that was planned.

QIPP may have a significant role to play here. However, delivering QIPP across boundaries and care pathways is complex. Links between primary and secondary care (GPs, Diabetes, Vascular, Renal) in a multidisciplinary framework are essential

To develop and deliver on the QIPP agenda requires strategic planning on a national and regional basis. This needs agreement on priorities and a clear quality improvement programme with support to patients, providers and commissioners.

Excellent examples of delivering QIPP by engagement of providers, commissioners and patients have been shown within renal networks in England. For example, in the East Midlands, infection rates have been reduced as vascular access provision for haemodialysis patients has improved across the region. This reduces harm to patients and yet reduces health costs related to dialysis associated complications.

A further important opportunity is the improvement of the Quality Outcomes Framework (QoF), so that instead of driving towards single targets it rewards the achievement of several goals related to cardiovascular outcomes. QoF could also be extended to reward practices for encouraging self-management for their patients.

Supporting people to manage their health

The needs of patients will change with time. It is important that this strategy takes this into consideration and recommends routine reviews across all of the potential disease areas. If an individual has been initially diagnosed with diabetes, it is important that routine reviews are not solely confined to diabetes, but check for other risk factors.

Patients will need to be supported in self-managing across all of the cardiovascular diseases they have, or are at risk of having. This also needs to be built into the strategy.

Quality of life, including the ability to continue to work, is already an important factor in all of the individual therapy areas. The integrated strategy is an opportunity to encourage broader approaches to treatment that may help provide greater protection against related risk factors. By taking a more proactive approach such as this, it may be possible to reduce the incidence of complications and in addition, patients would have more opportunity to accommodate treatment into their lifestyle.

Information for patients is essential. There is already a great deal of information available within each of the therapy areas. However, this will need to be more integrated to cover across cardiovascular diseases and reduce confusion. It will also need to cover advice for patients at different stages in their life.

The contribution of voluntary organisations

All the comments in this document are predicated on the necessary involvement, advice from and direction given by people who have experience in vascular conditions, and their voluntary organisations.

Networks and strategies can only work if they are understood and owned by service users, so the contribution by and support of voluntary organisations is vital to the success of a cardio and vascular strategy.

The Kidney Alliance is a national group representing the main patient and professional charities in the kidney community. Its goal is to promote prevention and early identification of kidney disease and high quality treatment for all patients at risk from or identified with kidney failure on an equal and uniform basis throughout the UK. Our membership organisations support those affected by kidney disease in a range of ways – from giving grant aid, to dedicating themselves to research to improve outcomes for those with kidney disease, to promoting both the best renal medical practice and treatment, and the health of people with CKD or renal failure and their families, to driving for effective patient-centred multi professional care to improve quality of life for people with kidney failure, their families and carers.

The support of and promotion by such groups must be built into an outcomes strategy.

Kidney Alliance members: British Kidney Patient Association, British Renal Society, Kidney Research UK, National Kidney Federation, Renal Association, Renal Nutrition Group, Association of Renal Managers, Royal College of Nursing (Renal Forum), British Association of Paediatric Nephrologists

Secretariat Kidney Alliance 37 Rosemary Drive St Albans Herts AL2 1UD www.kidneyalliance.org Tel: 01727 826241 Email: info@kidneyalliance.org

References

- ¹ McCullough PA, Li S, Jurkovitz CT, Stevens L, Collins AJ, Chen SC, Norris KC, McFarlane S, Johnson B, Shlipak MG, Obialo CI, Brown WW, Vassalotti J, Whaley-Connell AT, Brenner RM, Bakris GL; KEEP Investigators. Chronic kidney disease: prevalence of premature cardiovascular disease and relationship to short-term mortality. *Am Heart J.* 156:277-83, 2008.
- ² 12th Annual UK Renal Registry Report, 2010, UK Renal Registry, Southmead Hospital, Bristol.
- ³ <http://www.ncepod.org.uk/reports.htm>.
- ⁴ <https://www.renalpatientview.org/>.

Kidney Research UK



Kidney Research UK presents its submission, following consultation with its research, clinical, primary care and patient stakeholders.

Principal disease stages (kidney specifically) covered:

- Education and the Identification of Chronic Kidney Disease at an early enough stage.
- Effective management at Primary Care and preparation for Renal Replacement Therapy.
- Ongoing Support (End of Life Care).
- Renal Replacement Therapy (Dialysis and Transplantation), is outside the planned remit of this submission.

Section One:

What is our Vision for the Outcomes Strategy?

To reduce amenable morbidity and mortality due to cardiovascular disease, through a focus on preventative strategies, early detection, improved treatment and ongoing quality of care.

Issue: New initiatives are required that build on the success of the respective NSFs which are recognised as best practice worldwide. However, more focus is required on tackling variation in the quality of care in the UK.

What conditions should be covered?

- HT (Hypertension), CVA (Cerebrovascular Accident), IHD (Ischaemic Heart Disease), PVD (Peripheral Vascular Disease), Heart Failure, DM (Diabetes Mellitus), CKD (Chronic Kidney Disease). Plus, AKI (Acute Kidney Injury).

Where do we need to focus efforts in the coming decade and what is the balance between Prevention and Treatment?

Overall: balance should be weighted towards prevention, focusing on public awareness; lifestyle modification, risk factors and the promotion of patient-led self-management activities.

There is a key requirement to standardise approaches within capacity and developing expertise in order to integrate and share best practice along the CVD pathway.

Key Areas:

- Improving Primary Prevention – Risk assessment Management; lifestyle factors and behaviours etc.
- The integration of care across the vascular disease spectrum with improved interface between primary care – secondary care – tertiary and Social Care.
- Enhanced integration and utilisation of IT resources across the treatment pathway and spanning all agencies.
- Review and re shaping of financial incentives; QOF, Tariffs and reward on a graded achievement against targets/standards.
- Ensuring access to specialist care.
- Developing and the successful implementation of Self-management – enable and empower.
- The effective utilisation of data and audit to drive quality.
- Enhanced, early, quality based and tailored patient education and shared decision making support to promote prevention and maximise treatment.

- Prevention:
 - Auditing the achievements of targets as there is evidence of the values of numerous outcome measures and surrogates that will inform future policy and practice.
 - There is a requirement to cover CKD detection with the use of nurses for screening programmes and their role in education for lifestyle change and the importance of medication regimes.
 - The early markers of kidney disease requires more emphasis as patients with cardiac/vascular disease should have eGFR and proteinuria measured with this detail recorded such as: when, how often and by whom.
 - Requirement to cover CKD detection with the use of nurses for screening programmes and their role in education for lifestyle change and the importance of medication regimes.
 - Accurate risk stratification tools for CKD and CVD: Around 50 per cent of the increased risk of CVD in people with CKD is with non-traditional risk factors. As more than 20 per cent of people with CVD may have CKD, better identification of these risk factors may better stratify people with CKD and identify new targets for treatment.
 - To focus on ensuring that patients with CKD have enhanced management of CVD risk and risk factors.
 - A focus on albuminuria as a screening tool for risk. Despite QOF the evidence is that the majority of people with CKD and/or with risk factors for CKD are not being screened for albuminuria. A focus on Primary Care education and thresholds for referral in this area would provide a solution.
 - Informatic based clinical infrastructure – advice and guidance that produces service specifications that link primary and secondary care.
 - Simplified pathways, perhaps through a map of medicine.
 - A focus on paradoxical causality in CVD and CKD; as people progress through stages of CKD traditional risk factors become less relevant and non-traditional risk becomes dominant.
- Treatment:
 - There needs to be consideration of who should manage the patient. There is a danger that with multi-disciplinary teams there are a number of people contributing to care but no person co-ordinating the therapeutic strategy; there needs to be careful consideration of potential interactions and that this is really the remit of primary care.
 - Whilst the practicality of 'joint clinics' of care, placing greater emphasis on specialisms coming together to deliver care at the point of delivery may be a challenge, perhaps focusing on specific aspects such as genetic and transition could overcome the complexity of addressing so many related conditions. Improving clinical effectiveness through diagnostics and therapeutics in a joint clinic approach with co-existent diseases would still be a sensible way forward.
- Combined clinics, whether in hospital or the community, would be a potential solution but this would require a significant investment in manpower and training.
- Focus on the optimal management of those patients who have been identified with accurate follow-up etc as, for example. Primary Care CKD registers are inaccurate and if people are on registers they are better managed.
- Research – suggested CVD study areas include:
 - Any large randomised controlled trials of intervention in cardiovascular disease to focus recruitment on including people with CKD; these patients have historically been excluded from large RCTs. Consequently, there is a major shortfall in the evidence base for patients with CKD around CVD risk management.
 - Requirement for the further evaluation of current and new methods for assessing risk of cardiovascular disease in people with CKD.
 - Studies focusing on the early markers of disease are required.
- It is recommended that best use of high quality clinical registry data (The Renal Registry Data) is used as an epidemiology research tool.
- Often in the past, CVD and renal disease have been studied separately on the basis that a more homogenous patient group is more valuable to study. However, as renal patients have the highest risk of dying from CVD and there is an acceleration of the CVD pathophysiology in uraemia, it is recommended that the focus is now to look for the factors that synergize to make the CVD risk so high in this group. This means studying prospective cohorts from CKD3 in general practice through to progression in joint cardiovascular/renal clinics. There are implications here for investment in biomarker screens, (proteomics/metabolomics) to detect the early signs of CVD and identify those that will progress to CKD5.

What needs to be sustained and how do we address gaps; what has been overlooked?

- There has been great progress in the last 10 years in the management of CKD in primary care that needs to be sustained. Variation remains a big issue across the vascular disease spectrum (illustrated by QOF, and the Renal Registry data). This may be brought into sharper focus by the CKD National Audit, which will also examine important dimensions of ethnicity, socio-economic status and geography. Acute Kidney Injury (AKI) is a new priority for Primary Care and Secondary Care.
- An important issue is how to keep the focus on CKD in primary care when there are so many competing interests. We know that there are still issues with prevalence recording of CKD, but not much practical support available to help Practices work at that.
- Incentivising primary care to sustain CV interventions appears to work and this may need to be looked at in more detail especially with development of CCGs.
- The QOF drove eGFR reporting and improved identification of CKD3+ patients at a pace; NSF and many guidelines and other documents since have highlighted and educated on cardiovascular risk. Proteinuria testing is increasing but it has further to go as the value in terms of improved outcomes is still to be proven and there is a clear requirement to do this, so that it will be impossible to deny the value in future different political or economic climates.

- Requirement to consider vascular imaging as new techniques are available that will be important over the timescale covered. The most important one is Positron Emission Tomography (PET); the study of inflammatory vascular conditions (including vasculitides as well as plaque formation) is important. New techniques such as PET and a variety of tracers will offer an important contribution to this end. There may well be a role for these techniques in brain ischaemia (stroke).
- There is a complete dearth of research studies on carers of patients on conservative care; support for carers is essential if we are going to increase home-based therapies.
- Inequalities: geographical and socio-economic groups remain an issue for inequality of care. Kidney Research UK is widely recognized for its work involving patient education and self management in Primary Care and the community. This needs to be further developed and sustained; more work with BME groups in primary care could be done through the use of Kidney Research UK's Peer Educators facilitating information and shared decision making.
- There is an increasing problem where a new laboratory investigation has been shown to have for example, improved sensitivity and specificity for a given diagnosis. However, that is a demonstration of clinical validity; it is not a demonstration of clinical utility. Clinical utility additionally demands proof that implementing the new test in the NHS actually generates patient benefit. It's not until you have a demonstration of patient benefit that a 'NICE-style' cost benefit analyses can be carried out. This is sometimes referred to as the 'second translational research gap' and it's a major concern for the whole of diagnostics. The interminable arguments about the use of BNP assays to evaluate heart failure are one example of this, but molecular genetics is rapidly developing many more examples.

Section 2

Who needs to do what to achieve the ambitions for reducing cardiovascular diseases and improving the treatment for people overall responsibilities for reducing cardiovascular disease and improving treatment for people with inherited heart disease?

- This is a multi agency responsibility concerning Primary Care, Secondary Care, Tertiary Care, Public Health/Social Care and the Voluntary Sector.
- There is a requirement for a nationally defined minimum service specification for CVD and CKD at the primary and secondary care interface – this will keep the CCGs and nephrology secondary care focused.
- Key issue concerning the training of primary care practitioners in CVD; how will this be managed by CCGs as it is clearly a priority if quality CVD management is to be delivered and sustained.

What are the roles of National Government, the NHS Commissioning Board, Public Health England, Local Directors of Public Health and Clinical Commissioning Groups?

There needs to be greater focus on health promotion and importance of empowerment/self-management at a national level, and consideration given to how this might be incentivised locally.

Commissioning guidance and tools framed by NHS CB must recognise commonalities between vascular diseases. The activities of all these bodies needs to be supported by high quality comparative data, e.g.: national data used by DH and public health to understand and tackle variation; CCGs should have information necessary to highlight disease burden (and latent disease burden) in their catchments. CCG's being used as a case study e.g. Kidney Research UK have been invited by the MD of the Leicester CCG to put together a proposal on reducing CKD in patients with diabetes through a Carer/Peer Educator focus. This collaborative model could be replicated in other locations in the future.

Section 3

How will we know whether progress is being made on these ambitions? 'What' should be measured and 'How'?

The development of integrated models of care may be hindered by pay for performance indicators that are disease-specific. Consideration should be given to outcome measures that are relevant across the vascular disease spectrum and measures that promote maintenance of health. Development of joined-up quality indicators may facilitate integrated management of multi-morbidity.

Section 4

A key challenge will be re-framing cardiovascular diseases as long term conditions; how can we ensure that people get the support that they need to live well and manage their health?

Through a multi-faceted approach involving:

- Health promotion.
- Education.
- Information Technology – more development work required in Telehealth and Telecare.
- Scope for improving nurse-led interventions in the home; reframing the role of district nurses/community matrons. might be useful.
- Greater integration across the pathway between health (PC and SC), public health and social care.
- Providing self management skills training to GP Practice teams with patients involved in all aspects; development of resources/ tools to assist with shared decision making; Peer Educators to support this work in primary care, especially for non-English speaking BME patients.

Section 5

How will the voluntary organisations be contributing to meeting these ambitions?

The voluntary sector is a vital element in the development and successful implementation of the CVD Outcomes Strategy.

Charities will be able to assist in:

- Sharing best practice across the co-existing co-morbidities.
- Contributing to the delivering of standardized and consistent practice.
- Contributing to the achievement of sustaining new approaches.

Through targeted research charities will be able to provide the evidence required to inform and influence future policy development and practice; encouraging the best use of high quality clinical registry data (The Renal Registry Data) as an epidemiology research tool.

Voluntary organisations will also be best placed to develop and deliver:

- Improved social marketing techniques and screening approaches to assist in raising the levels of awareness and understanding; risk factors of CVD.
- Better approaches to the successful identification and treatment of the early stages of CVD.
- Better approaches to ongoing care of people with CVD.

Charities can also play a key role in developing best practice in Patient and Public Involvement in all aspects of the Cardio Disease Outcomes Strategy – (PPI).

Voluntary organisations can play a major role in recruiting, training and supporting volunteers, especially if volunteers are to become peer educators, self-care facilitators etc; evidence suggests that people who have long-term conditions themselves are best-placed to change and sustain behaviour in others.

The voluntary research charities can continue to work collectively on recommendations that will remove obstacles to important research work in CVD; the Human Tissue Act and getting ethical approval with concerns about use of anonymised data, and clinical trial issues and evidence from post-mortem investigations.

A unanimous viewpoint is that the UK is slow to translate advances and implement new approaches in the NHS, as the regulatory environment for research in the UK has become a significant inhibitory factor to progress. The Research and Development and Ethical approval systems plus the inflated costs as perceived by industry and other funders act as major disincentives to pursuing this area of work.

Kidney Research UK has a recognised track record in working to raise awareness of and reduce variation in CKD; the development of patient self-management resources, tools and training; and the development and effective implementation of a Kidney Research UK Peer Educator based approach which working with other stakeholder charities, can be used on CVD social marketing campaigns with tailored messages to the “at risk” BME and other “hard to reach” communities.

Little Hearts Matter



The following comments are a submission from Little Hearts Matter, a national charity representing the needs of service users and carers affected by single ventricle congenital heart disease.

The world of congenital heart disease has been expanding exponentially every year. Advances in the medical support and surgical treatment of complex congenital heart disease means that children who would have died in infancy are surviving into adulthood.

Their treatment is palliative and their cardiac disabilities affect every day of their life. As they move into adulthood their hearts will fail and their need for ongoing medical services will increase. Adult congenital cardiologists calculate that these complex patients form 10% of their patient number but 50% of their workload.

The newly agreed Standards of Care for Children with Congenital Heart Disease will offer children throughout England, and ultimately we hope throughout the United Kingdom, the chance of a gold standard medical service. To date many children with complex surgical needs have to travel for treatment or are offered substandard care within their local unit.

The promise of new foetal diagnostic standards and ongoing linked standards for adult congenital care are the beginnings of a pathway of diagnosis, treatment and life time care that will follow a child with complex congenital heart disease from foetal life into adulthood. Networks of congenital cardiac medical care are needed to emulate the network services successfully set up for adult acquired heart disease.

Care needs to be seamless, service provision and funding should be secured for a patient from diagnosis throughout their life. Many of these patients will also need ongoing treatment and care from their community medical teams who need to be supported in gaining a greater understanding of congenital heart disease.

The service provision, medical expertise and funding streams for congenital services need to stand alone from adult acquired disease. The needs of the patient, although no more important than any patient with a heart condition, are distinctly different and are often more complex especially in adulthood.

It is important that there is a growing understanding within the medical profession, department of health and ultimately government of the needs of this growing and aging group of patients. Their treatment and care pathway need to be joined and the expertise of specialist medical teams must be available to all.

It is essential that this area of care forms an important, but distinctly different, part of the national strategy for cardiac services. Congenital Heart Disease needs the power of the national voice, a greater understanding of specialist care and the support of relevant funding that will only come if the congenital lobby can sit next to the needs of adults with acquired heart conditions.

As the country undergoes massive change in the provision and funding of all areas of medical care it is essential that children and adults born with heart conditions, conditions that they have not brought upon themselves, remain high on the cardiac agenda. They are not the poor relation to acquired heart disease but deserve equal recognition, support and funding.

11 Greenfield Crescent, Edgbaston
Birmingham, B15 3AU, United Kingdom
Telephone: 0121 455 8982
Facsimile: 0121 455 8983
info@lhm.org.uk
www.lhm.org.uk

Mental Health Foundation



The Mental Health Foundation is the UK's leading mental health research, policy and service improvement charity. We are committed to reducing the suffering caused by mental ill health and to help everyone lead mentally healthier lives.

We do this by carrying out research; developing practical solutions for better mental health services; campaigning to reduce stigma and discrimination; promoting better mental health for us all.

This response focuses on the importance of building mental health into the CVD Outcomes Strategy, for the reasons we set out below.

1. What is your vision for the outcomes strategy?

Poor mental health is associated with an increased risk of diseases such as cardiovascular disease and diabetes. Good mental health is a known protective factor against these and other long term conditions. Poor physical health also increases the risk of people developing mental health problems.

The Foundation would therefore like to see a CVD Outcomes Strategy that (among other things) makes clear the link between CVD and mental health, and contains specific outcomes around:

- Improving the mental health of people with CVD, and reducing the risk of comorbid mental health problems.
- Reducing the risk of CVD among people with mental health problems.

We would also want a link to, or overlap with, the Public Health Outcomes Framework that suggests an indicator on 'mortality rates from CVD and chronic respiratory diseases, which will be influenced by improvements in the mental health of people with these conditions'; and the NHS Outcomes Framework indicator of 'reducing premature death in people with serious mental illness'.

To achieve these outcomes, the CVD Outcomes Strategy should include as indicators:

- Regular physical health checks and accessible physical health care for people with severe mental illness.
- Routine assessment of the psychological needs of patients suffering from chronic heart disease and other serious physical conditions.

This is an area that has traditionally been overlooked, with either a mental illness diagnosis 'overshadowing' potential CVD issues, or a CVD diagnosis 'overshadowing' mental health issues. This fails to take into account the strong evidence of the inter-relationship and connectivity between CVD and mental health, and increases the risk of both CVD and mental health problems.

It is not good enough that many people with mental health problems are likely to have their physical health needs unrecognised or poorly managed: those who use mental health services are less likely than the general population to be offered blood pressure, cholesterol, urine or weight checks, or to receive opportunistic advice on smoking cessation, alcohol, exercise or diet.

A brief overview of the evidence includes:

Royal College of Psychiatrists (2010) No Health Without Public Mental Health

Depression is associated with 67% increased mortality from cardiovascular disease, 50% increased mortality from cancer, two-fold increased mortality from respiratory disease and three-fold increased mortality from metabolic disease.

Rates of depression are double in those with diabetes, hypertension, coronary artery disease and heart failure, and triple in end-stage renal failure, chronic obstructive pulmonary disease and cerebrovascular disease.

Depression almost doubles the risk of later development of coronary heart disease. Increased psychological distress is associated with 11%-increased risk of stroke. Depression predicts colorectal cancer, back pain and irritable bowel syndrome later in life.

People with schizophrenia and bipolar disorder die an average 25 years earlier than the general population, largely because of physical health problems. Schizophrenia is associated increased death rates from cardiovascular disease (two-fold), respiratory disease (three-fold) and infectious disease (four-fold).

Keyes, Corey L. M. (2004) The Nexus of Cardiovascular Disease and Depression Revisited: The Complete Mental Health Perspective and the Moderating Role of Age and Gender. Aging and Mental Health. 8:267-275.

Keyes' study examined the prevalence of mental health issues among people with cardiovascular disease, the leading cause of death in the United States. It found that attaining and sustaining good mental health is just as vital as other factors, such as exercise and diet, in the prevention of cardiovascular disease, especially for women over the age of 45. Cardiovascular disease was lowest in adults who were the most mentally healthy, and higher among adults with major depressive episodes, minor depression and moderate mental health. The relationship between cardiovascular disease and mental health was the same for age and sex, except for females between the ages of 45 and 74, where mental health issues under his "complete state" measure were much more prevalent.

Previous research has found major depression and stress to be contributing factors for, and a consequence of, cardiovascular disease. "We seriously underestimate the connection between mental health and cardiovascular disease, especially for post-menopausal women. We are not doing as well in treating mental health on par with other risk factors," says Keyes.

Goodwin et al (2009) Mental disorders and cardiovascular disease among adults in the United States. J Psychiatr Res. 2009 Jan;43(3):239-46. Epub 2008 Jul 9.

The research findings suggest that anxiety disorders, mood disorders, and CVD are highly comorbid among adults in the United States, and demonstrate the importance of including anxiety disorder assessment in studies of mental and physical comorbidity. These results reveal how the lack of investigation into specific relationships between CVD and the range of mental disorders in population-based studies of risk factors for CVD may obscure important relationships.

Osborn DPJ, Levy G, Nazareth I, et al. (2007) Relative risk of cardiovascular and cancer mortality in people with severe mental illness from the United Kingdom's General Practice Research Database. Arch Gen Psychiatry 2007; 64:242-9.

Severe mental illness increases the risk of death from coronary heart disease or stroke. The risk of mortality from coronary heart disease is increased in people with severe mental illness in the 18–75 years age group. Mortality from stroke is increased in people with severe mental illness aged 50 years and above.

British Heart Foundation (2010) Mental Health and Heart Disease: A Complex Connection

Studies show that if people have both heart disease and anxiety, they're at a greater risk to experience heart failure, heart attack, and stroke. Thus far, it's unknown exactly the connection between the two. Anxiety in general could lead to more stress, which could manifest physically as heart disease. But heart disease may also cause anxiety if the patient worries what will happen to them and their families because of the disease. Either way, dealing with anxiety (and with depression; the two often coexist) can be preventive for both mental health and physical health complications down the line.

2. Who needs to do what to reduce cardiovascular diseases and improve treatment for people with heart disease?

All professionals involved in providing services to people with CVD and people with mental illness need to be aware of the connectivity between the two.

This means that the issue is covered at an early stage of medical training; that it is acknowledged and publicised by the relevant professional bodies; that there are local protocols in place to ensure that CVD patients have a psychological assessment and that people with a mental illness have regular physical health checks; and that commissioners of services understand the value of commissioning these services and both the health and financial benefits.

We know that there are extremely high rates of smoking among people with a mental illness, and that many within this group also have a very poor diet. Given the impact of smoking and poor diet in terms of risk of developing CVD, the CVD Outcomes Strategy should cite people with a mental illness as a high-risk group that needs to be offered smoking cessation support and dietary advice routinely. The provision of such advice and levels of take-up could be indicators within the strategy.

See the King's Fund (2012) Long-term conditions and mental health: The cost of comorbidities for an analysis of the financial costs of comorbidity and the potential savings. This report calls for Clinical Commissioning Groups to prioritise integrating mental health and physical health care more closely as a key part of their strategies to improve quality and productivity in health care.

3. Measuring progress

We will know the CVD Outcomes strategy is working when there is a reduction in the prevalence of co-morbid mental health problems; and a reduction in the number of people with mental illness dying prematurely as a result of CVD. Of course this means improving the assessment and identification of mental health problems among people with CVD in the first place, as the evidence suggests there are currently high levels of unmet need within the NHS.

4. Support for people to live well and manage their health

Here we are talking about mental health support for people with CVD, and advice and support on physical health for people with a mental illness.

There are four key elements that might be built into the CVD Outcomes Strategy.

First, the checks and assessments we have mentioned already:

- regular physical health checks and accessible physical health care for people with severe mental illness
- routine assessment of the psychological needs of patients suffering from chronic heart disease and other serious physical conditions.

Second, accurate and accessible information available to patients about the connectivity between CVD and mental health problems, and between physical and mental health, with signposting to where people can seek advice and support.

Third, the understanding among health professionals of the connectivity between CVD and mental health problems, and the ability to establish interdisciplinary teams of support for individual patients. This would include early access to liaison psychiatry services for CVD patients in hospital, and support for assessed mental health needs on discharge from hospital as required.

Fourth, local systems for ensuring that people with CVD or mental health problems are involved in drawing up their own care plans, including taking into account the impact of the disease and/or illness on carers and family members.

5. How will voluntary organisations contribute to meeting the ambitions of the CVD Outcomes Strategy?

Relevant national and local voluntary organisations have a great deal of expertise in both CVD and mental health issues. They can legitimately put pressure on local planners, commissioners and providers of services to take on board the issues raised in this submission; provide information to patients; give advice on models of good service; undertake and publish surveys and research studies; act as local advocates for good quality care; facilitate access to patient views; and hold to account local services against the wider outcomes and specific indicators of the Outcomes Strategy.

At the same time, many voluntary organisations are also service providers, supporting both patients and carers and families. In this role they can themselves ensure that good practice is followed in the services they offer, both separately and as part of wider interdisciplinary and cross-organisational support teams.

Further information

The Living Better Project: Addressing Mental Health and Well-being in People Living with Long-term Conditions, Final Report 2011

The Living Better project, in Scotland, was a partnership between ourselves, the Royal College of GPs and University of Glasgow. The principle aim of the project was to work with primary care health services to improve the way they address mental health and well-being – and in particular the detection and management of depression and anxiety – among people living with long-term conditions across Scotland. It focused primarily on CHD, diabetes and COPD. Our research confirms findings of other research which indicates that about 30% of people with heart disease will have depression or anxiety.

We think the APPG inquiry will be interested in the findings. I can only highlight some here but they include the messages (which complement our earlier submission) that:

- Co-morbidity and multiple morbidity rates are higher in areas of high deprivation.
- Early identification and diagnosis of mental health problems in patients with long term conditions is essential to help people recover from physical and mental health problems alike.
- We need to offer mental health awareness training for people with heart disease and the clinical professionals who support them.
- Patients need to be able to access local mental health support, peer support and self management information.

- Changing assessment processes within primary and secondary care settings requires strategic buy-in and ongoing support from GPs and other line managers.
- Promoting local sources of emotional support continues to be an important function for health professionals to perform.
- Comorbidity or multiple morbidity can be addressed by better joint working between primary and secondary care (mental health and long term condition services) and voluntary and community groups. But joint provision of training between different agencies, while facilitating communication and learning between the professionals and other providers involved, demands greater administration and management input.

In particular, the work with the South East Asian community in Glasgow led to some key messages, including

- South Asian women wanted access to culturally sensitive support that was locally accessible. South Asian men preferred to access broad social support services (exercise classes, etc.) rather than those which explicitly addressed emotional wellbeing.
- health professionals felt there was more that could be done to raise awareness of mental health issues in the South Asian community. But not all primary care staff are aware of local services and available resources.
- GPs, practice nurses and specialist nurses lack the time to tease out emotional issues with South Asian patients.
- The stigma of mental illness can make it difficult for many South Asian people to verbally express their emotional feelings regarding the stresses of living with diabetes and/or CHD. Many health professionals believed that addressing mental health and well-being in South Asians living with diabetes and/or CHD requires a wider strategic campaign linking with key South Asian community agencies to address the stigma of mental illness.

Of course the stigma that unfortunately surrounds mental illness is a challenge for everyone, patient and staff alike, in terms of identifying a problem and intervening quickly and effectively.

I also attach for information a recent article by Barnett et al (published earlier this month) that examines the distribution of multimorbidity, and of comorbidity of physical and mental health disorders, in relation to age and socioeconomic deprivation (based on a study of 314 GP practices). The findings “challenge the single-disease framework by which most health care, medical research, and medical education is configured. A complementary strategy is needed, supporting generalist clinicians to provide personalised, comprehensive continuity of care, especially in socioeconomically deprived areas”.

Contact:

Simon Lawton-Smith
Head of Policy
Mental Health Foundation
1st Floor
Colechurch House
1 London Bridge Walk
London SE1 2SX
Tel: 020 7803 1106

National Council for Palliative Care

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

Our key recommendation

We urge the APPGs to recommend in its report that palliative and end of life care be included as one of the key priorities for the Cardiovascular Disease Outcomes Strategy (CVDOS). This area of care and support is essential to people with cardiovascular disease and their carers, but too often overlooked. The significant amount of work that has already been undertaken in this area, including the national End of Life Care strategy (2008), End of Life Care in Heart Failure – a framework for implementation (2010) and NICE End of life care Quality Standard (2011) must be reflected and taken forward in the CVDOS and implementation plans.

This message will be reflected in our oral evidence on 12 June 2012, when we also hope to be able to develop some of the themes set out below.

Our full response

We welcome the opportunity to comment on the All-Party Parliamentary Groups on Heart Disease, Stroke, Kidney and Diabetes' joint report outlining key priorities for the Cardiovascular Disease Outcomes Strategy (CVDOS). NCPC is the umbrella charity for all those involved in commissioning, providing and using palliative, end of life and hospice care in England, Wales and Northern Ireland.

We hope you find our response useful and adopt our key recommendation that ensuring people with cardiovascular disease can access palliative and end of life care when necessary is included as one of the key priorities for the Cardiovascular Disease Outcomes Strategy (CVDOS).

Key facts

- More people die with cardiovascular disease than any other set of conditions: it is an 'underlying' or 'mentioned' cause in 45% of all deaths in England.¹
- Heart failure affects at least 1% of people in the UK, increasing steeply with age, and is projected to rise with improved survival rates and an ageing population.²
- Most people would prefer not to die in hospital, but at home or in their care home. In reality, 57% of people with cardiovascular disease die in hospital.³
- Conversations focus largely on disease management, end of life care is rarely discussed with people with heart failure and clinicians are often unconfident in discussing this.⁴
- Of people accessing specialist palliative care services 18.3% have a primary diagnosis of heart failure or other heart or circulatory condition (including stroke) and 4.5% have chronic renal failure.⁵
- The latest National Heart Failure Audit reported that referral to palliative care upon discharge from hospital was "very low" with less than 4% recorded as being referred to these services.⁶
- People who die from cardiovascular disease are less likely to report that community services worked well together than those dying from other conditions.⁷
- Cardiovascular disease accounts for around 17%, and stroke 12%, of emergency admissions lasting 8 or more days and ending in death. Reducing the number of unnecessary hospital admissions at the end of life is a QIPP (Quality Innovation Productivity Prevention) priority.⁸

Why is palliative and end of life care so important?

The fact that the end-stage of a cardiovascular condition can be hard to determine should not be used as a reason to avoid talking about and planning for the future including end of life care. People with cardiovascular disease will die, and many of them will wish to discuss and think about this stage of their lives. Services and professionals have a responsibility to support them in this.

The unpredictability of the disease trajectory can often restrict choice of where a person is cared for and dies⁹ but this can be changed through early planning. Advance care planning can help ensure that people with cardiovascular conditions get the care they need, in a setting which they chose, and, ultimately, experience a good death. Indeed one of the key recommendations for commissioners in the End of life care in heart failure – a framework for implementation (2010) was that ‘advance care planning should be endorsed’.¹⁰ This needs to be in conjunction with good service planning, so that palliative and end of life care services are available locally to meet this need.

Advance care planning is not only vital to ensuring that people are cared for and die in the setting which they chose, but also to ensure that devices, such as implantable cardioverter defibrillators (ICDs), are discussed and deactivated before death.¹¹ Active ICDs can cause shocks at the end of life which can be very painful for the person and upsetting for those around them. Careful planning can ensure that deactivation of devices is handled correctly and sensitively, and can make the end stages of life much more manageable for people with heart conditions and their families. NCP’s Heart Failure Group has found that specialist palliative care services are not uniformly equipped to deactivate devices, and want help in this area. Previous work of the group has found that good practice usually comes about through partnership working between heart failure nurses and specialist palliative care, links which are slowly strengthening.¹²

People with cardiovascular disease often have multiple conditions that require a range of services, which should be coordinated around the person’s needs and wishes. However, with only 6% of people with heart failure discharged from hospital being referred for palliative care, many people are experiencing poor symptom control, lack of psychological support and a lack of open and honest communication with professionals.¹³ Early, honest discussions and access to high-quality symptom control can ensure that the final stages of life for someone with cardiovascular disease are made as manageable and comfortable as possible.

Finally, it is important to remember that palliative care is of benefit from diagnosis through to the end of life. This must be reflected in the CVDOS, as it would be a mistake (often made) to think of palliative and end of life care as an ‘add on’ or something that comes at the end of a person’s journey only. For people who experience a stroke or those who develop dementia in addition to a cardiovascular condition, early planning before capacity or the ability to communicate ones wishes is lost, is absolutely essential.

Building on what has already been done

The Terms of Reference state that the CVDOS will be written with reference to published frameworks and guidance. The following documents should be referenced in relation to palliative and end of life care:

- Department of Health, End of Life Care Strategy (2008) www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277.
- National End of Life Care Programme, End of life care in heart failure – a framework for implementation (2010) www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework.
- NICE, End of life care Quality Standard (2011) www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp.
- The NHS Outcomes Framework contains the outcome ‘improving the experience of care for people at the end of their lives’ with an indicator being derived from a national survey of bereaved carers. This survey will be able to track the experiences of end of life care in cardiovascular disease, amongst other conditions. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700.
- National Council for Palliative Care, Focus on Heart Failure: A national survey of heart failure nurses and their involvement with palliative care services (2006) and Strengthening the relationship between heart failure nurses & specialist palliative care: Results from two national surveys – 2005/2010 (2011). A number of locally developed referral guidelines are also available at www.ncpc.org.uk/page/HFNS-Survey.
- British Heart Foundation, An everyday guide to living with heart failure (updated in January 2012 to include revised pages on palliative and end of life care which NCP helped to write) www.bhf.org.uk/publications/view-publication.aspx?ps=1001793.
- British Heart Foundation, Implantable cardioverter defibrillators in patients who are reaching the end of life: A discussion document for health professionals (2007) www.bhf.org.uk/publications/view-publication.aspx?ps=1000155.
- University College London, National Heart Failure Report April 2010-March 2011 (2012) www.ucl.ac.uk/nicor/audits/heartfailure/additionalfiles/pdfs/annualreports/annual11.pdf.
- A wealth of data and profiles can be found on the National End of Life Care Intelligence Network website www.endoflifecare-intelligence.org.uk.
- The inquiry has expressed interest in ways of measuring CVDOS outcomes, for end of life care measurement see www.nice.org.uk/guidance/qualitystandards/endoflifecare/MeasuringTheQualityStatements.jsp.
- The Key Performance Indicator for the QIPP end of life workstream is the proportion of deaths in usual place of residence.

The NCPC has eight groups of professionals and people with personal experience which drive and inform our policy and campaigning work, publications and activities. One of these groups specifically focuses on improving palliative and end of life care for people with heart failure. Its membership is:

- Dr James Beattie, Consultant Cardiologist, Birmingham Heartlands Hospital (Chair).
- Dr John Baxter, Consultant Geriatrician, Department of Care of the Elderly, Sunderland Royal Hospital.
- Mubeen Bhutta, Policy Manager, British Heart Foundation.
- Jane Butler, Consultant Nurse – Heart Failure, Barts & The London NHS Trust.
- Simon Chapman, Director of Policy & Parliamentary Affairs, NCPC.
- Alice Fuller, Policy & Parliamentary Affairs Lead, NCPC.
- Dr Miriam Johnson, Reader in Palliative Medicine, Hull York Medical School & Honorary Consultant, St Catherine's Hospice, Scarborough.
- Dr Mike Knapp, Associate Medical Director, Prevention & Care, British Heart Foundation.
- Annie MacCallum, Professional Lead for Specialist Services, NHS Gloucestershire.
- Alice Rigby, Policy & Events Officer, NCPC.
- Karen Sweeney, Programme Lead for the Healthcare Professionals Programme, British Heart Foundation.

The Heart Failure Group has produced and contributed to many policy documents, conferences and surveys since its formation in 2005, as outlined in the Appendix below.

Other cardiovascular diseases

Our response has primarily focussed on heart failure, as this is the expertise of our group. However NCPC promotes palliative and end of life care for people with all conditions. Publications related to other cardiovascular diseases will need to be referenced by the CVDOS, such as:

- End of Life Care in Advanced Kidney Disease: A Framework for Implementation (2012).
- NHS Diabetes, Commissioning for Diabetes End of Life Care Services (2009).

See also:

- NCPC, Multiple Conditions: Multiple Challenges – Exploring Palliative and End of Life Care for Older People with Multiple Conditions (2008).

Appendix

NCPC's Heart Failure Group timeline:

Feb 2005

Circulatory & Respiratory Conditions Policy Group is set up by NCPC, chaired by John Mount, then NCPC trustee and CEO at St Catherine's Hospice. Group includes the needs of people with heart failure at the end of life within its remit.

Dec 2005

Palliative Care in Heart Failure: Moving Forward Together event takes place in Birmingham.

Jan 2006

Group publish Focus On Heart Failure – A National Survey of Heart Failure Nurses & Their Involvement with Palliative Care Services.

Jan 2006

NCPC host Palliative Care and Heart Failure: Moving Forward Together event in London. Speakers included NHS Heart Improvement Programme's Mike Connolly, BHF's Steve Shaffellburg and Dr Miriam Johnson.

June 2007

The Circulatory and Respiratory Conditions Policy Group splits into two groups – Chronic Respiratory Disease (CRD) Group and the Heart Failure & Renal Group. The CRD group continues under John Mount (see separate timeline). The HF Group is chaired by Dr. James Beattie NCPC Trustee and Consultant Cardiologist; NHS Improvement (Heart Failure) Clinical Lead.

July 2007

Discussion document is produced by Jim Beattie for BHF with NCPC input Implantable cardioverter defibrillators (ICDs) in patients who are reaching the end of life.

May 2008

Group joins the Cardio and Vascular Coalition.

June 2008

Group run workshop at British Cardiovascular Society annual conference entitled Advanced heart failure: optimum clinical care includes embedded supportive strategies.

March 2009

Cardio and Vascular Coalition's Destination 2020: a plan for cardio and vascular health published including a section on end of life care.

June 2009

Publication of End of Life Care in Advanced Kidney Disease by the National End of Life Care Programme, to which the group had contributed.

July 2009

Jim Beattie and Emily Sam present on palliative care for heart failure and the group's work to the Dept of Health Heart Disease Programme Board chaired by Roger Boyle.

October 2010

Poster of NCPC's HFNS survey published at the International Congress on Palliative Care in Montreal.

March 2011

The survey is published in full in the European Journal of Cardiovascular Nursing – more information.

September 2011

Group publishes the results from two national surveys of heart failure nurses carried out in 2005 and 2010 in a NCPC briefing, Strengthening the relationship between heart failure nurses & specialist palliative care: Results from two national surveys – 2005/2010 – more information.

March 2012

On 22nd March 2012 the group, with funding from the British Heart Foundation and Marie Curie Cancer Care, hosted our second national heart failure conference which focused on breaking down the barriers to end of life care in heart failure – more information.

Present

The group are currently exploring the ICD deactivation policies in hospices and other specialist palliative care units, and preparing a Difficult Conversations for heart failure booklet.

Contact

Alice Rigby, Policy & Events Officer
The National Council for Palliative Care (NCPC)
The Fitzpatrick Building, 188-194 York Way, London, N7 9AS
T: 020 7697 1520/ F: 020 7697 1530/
E: a.rigby@ncpc.org.uk

About NCPC

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all. Visit www.ncpc.org.uk for more information.

We lead the national Dying Matters coalition, which currently has over 15,000 members, to change knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make 'living and dying well' the norm. Visit www.dyingmatters.org for more information.

References

- ¹ National End of Life Care Intelligence Network, Variations in Place of Death in England: Inequalities or appropriate consequences of age, gender and cause of death? (2010) [www.endoflifecare-intelligence.org.uk/resources/publications/variations_in_place_of_death.aspx].
- ² University College London, National Heart Failure Report April 2010-March 2011 [www.ucl.ac.uk/nicor/audits/heartfailure/additionalfiles/pdfs/annualreports/annual11.pdf] (2012).
- ³ National End of Life Care Intelligence Network & National End of Life Care Programme What do we know now that we didn't know a year ago? New intelligence on end of life care in England [www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx].
- ⁴ S Barclay et al End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis British Journal of General Practice, January 2011 www.ncbi.nlm.nih.gov/pmc/articles/PMC3020072.
- ⁵ Minimum Data Set (MDS) for Specialist Palliative Care Service 2010/11 NCPC (Due to be published shortly) www.ncpc.org.uk/page/MDS.
- ⁶ University College London, National Heart Failure Report April 2010-March 2011 [www.ucl.ac.uk/nicor/audits/heartfailure/additionalfiles/pdfs/annualreports/annual11.pdf] (2012) p.15.
- ⁷ National End of Life Care Intelligence Network & National End of Life Care Programme What do we know now that we didn't know a year ago? New intelligence on end of life care in England [www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx].
- ⁸ National End of Life Care Intelligence Network & National End of Life Care Programme What do we know now that we didn't know a year ago? New intelligence on end of life care in England [www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx].
- ⁹ National End of Life Care Programme, End of life care in heart failure – a framework for implementation [www.improvement.nhs.uk/LinkClick.aspx?fileticket=KBUEsR0mms%3D&tabid=57] (2010) p.19.
- ¹⁰ National End of Life Care Programme, End of life care in heart failure – a framework for implementation p.15 (2010).
- ¹¹ National End of Life Care Programme, End of life care in heart failure – a framework for implementation p.19 (2010).
- ¹² Focus on Heart Failure: A national survey of heart failure nurses and their involvement with palliative care services (NCPC 2006) and Strengthening the relationship between heart failure nurses & specialist palliative care: Results from two national surveys – 2005/2010 (NCPC 2011) www.ncpc.org.uk/page/HFNS-Survey.
- ¹³ Kendall, M. 'Palliative Care for patients with heart failure', Nursing in Practice, vol. 53 (March/April 2010).

National Heart Forum



The National Heart Forum welcomes the opportunity to submit evidence and comments to the All Party Parliamentary Groups to support the joint drafting of their report examining key priorities for the CVD Outcomes Strategy. We focus our comments on the issue of primary prevention of CVD.

What is your vision for the Outcomes Strategy?

Our vision for the Outcomes Strategy is one in which due emphasis is placed on effective and cost-effective prevention services to reduce ill-health and prevent premature deaths. It should seek to deliver equitable services which will tackle inequalities in health. It should reflect the origins of CVD in early life and aim to prevent disease across the life course. It should be framed around the major modifiable risk factors and their wider, social determinants and require multisectoral actions.

What conditions should be covered by the Outcomes Strategy (OS)?

In view of the common risk factors and determinants shared by many diseases of the cardiac and vascular system, the OS should cover coronary heart disease, stroke, kidney disease, diabetes, peripheral arterial disease and dementia.

Where do we need to focus efforts in the coming decade and what is the balance between prevention and treatment?

Prevention measures are the most effective way to reduce illness and prevent premature deaths, and should be at the centre of future planning for cardiac and vascular conditions.

Specific focus should be placed on:

- **Reducing smoking rates by helping smokers to quit, reducing exposure to second hand smoke and preventing young people starting to smoke.** Around 22% of the UK population still smoke and the current cost to the NHS from smoking-related ill-health is estimated at £2.7billion per annum.¹ Around one in five deaths from heart and circulatory disease are due to smoking.²
- **Reducing rates of overweight and obesity.** Excess body weight is a major risk factor for Type 2 diabetes, hypertension, stroke and kidney disease. We are observing an apparent flattening in the rising trend towards overweight and obesity among children, but adult rates continue to climb unabated.³ The drivers of the obesity epidemic are complex but it is clear that policy responses must focus on the extraordinary changes in the nutritional quality and the quantity of food consumed over recent decades.
- **Improving access to affordable, healthy foods and controlling the promotion of foods high in fat, sugars and salt.** Dietary risk factors including high salt levels in foods (leading to hypertension), high saturated fat intake (contributing to raised serum cholesterol levels) and low intakes of fruit and vegetables must be addressed as well as excess calorie intake.
- **Removing the barriers to active lifestyles.** Sedentary behaviour and low levels of daily physical activity contribute to overweight and obesity as well as being an independent risk factor for CVD. Policy responses must include legislative and regulatory measures to maintain green spaces for active play, create active environments and promote active means of travel such as walking and cycling.

What is the role of national Government, the NHS Commissioning Board, Public Health England, local directors of public health and clinical commissioning groups?

Central Government has a key role to play in providing leadership and delivering coordination of prevention strategies across Government departments (Health, Transport, Education etc.).

There is a clear role for central Government in setting minimum national standards (for school food and public procurement policies, for example). Evidence shows that the major population-wide public health gains are delivered by upstream policy actions (legislation for smoke-free public places, energy-efficient homes and a ban on tobacco advertising, for example). Upstream measures need public acceptance and this should be an important aspect of social marketing initiatives. Upstream measures also efficiently and proportionately reduce health inequalities.

NHS Commissioning Board will have responsibility for commissioning for some services such as national screening services and will be responsible for authorising and monitoring commissioning by Clinical Commissioning Groups (CCGs). One of the recommendations of the NHS Futures Forum⁴ is that the NHS Commissioning Board should ensure early intervention and prevention in a health service where 'every contact counts'.

The requirements on the health services include the delivery of the Marmot Review⁵ recommendations (all but one) for tackling inequalities as well as a general duty under the Health and Social Care Act (2012). The Equality Act (2011) requires equity in the provision of all publicly funded services (including the health services). The Long Term Conditions Agenda (currently out for consultation) is likely to have a focus on early intervention and both primary and secondary prevention of chronic diseases including CVD.

The NHS Commissioning Board will have responsibility for workforce roles in both health and social care.

Public Health England (due to be operational from April 2013) will play an important role in delivering services to national and local government, the NHS and the public (including the delivery of an information and intelligence service, disseminating evidence and best practice and promoting the use of social marketing and behavioural insight techniques). It will be key to developing the evidence base for national and local action and providing support to the specialist and wider public health force which will be responsible for disease prevention and health improvement strategies.

Local directors of public health (DsPH) will play a critical role in the development, delivery and reporting of local health plans and commissioning of local services. DsPH will provide public health expertise, advice and analysis to Clinical Commissioning Groups, Health and Wellbeing Boards and the NHS Commissioning Board. As statutory members of the NHS Commissioning Board they will be key to ensuring that local Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs) are reflected in NHS and local services. They will be required to produce independent reports on the health of their local area, annually. The autonomy they will have over these reports places them in a key position to identify and highlight both progress and deficits, and to report on addressing local health inequalities.

Under the reforms to the health service set out in the Health and Social Care Act (2012), local government take on a substantial share of the responsibility for public health, with particular responsibility for health improvement, which they inherit from primary care trusts (PCTs). Under the Act 'each local authority must take such steps as it considers appropriate for improving the health of the people in its area'.

Clinical Commissioning Groups (CCGs) will commission most healthcare services. Although they are not funded to carry out public health functions but will be involved in commissioning services for people with established disease or long term conditions. CCGs are expected to 'have regard' to JSNAs and JHWSs when preparing or revising commissioning plans. They, like the NHS Commissioning Board, will also be expected to ensure early intervention and prevention in local health services and to deliver the recommendations of the Marmot Review and the provisions of the Equality Act in order to tackle inequalities.

Health Education England (HEE) should be added to the list of bodies under the new health and social care arrangements which will potentially contribute to delivery of the CV Strategy. HEE will oversee 5% of the NHS budget for basic and continuing training in the publicly funded health services. Training will be delivered by Local Education Training Boards (LETBs) which will be authorised by the HEE to set standards.

Working with professional representative bodies and with the Centre for Workforce Intelligence, HEE will have a key role to play in workforce planning, training and education for all health and social care workers. The NHS Educational Outcomes Framework places early intervention and prevention in the training of all workers and it is expected that commissioning against this OF will support an inter-disciplinary approach to education and training.

How will we know whether progress is being made on these ambitions? What should be measured and how?

The CV Outcomes Strategy should reflect and reinforce monitoring against indicators already agreed in the Public Health Outcomes Framework (on child and adult obesity, smoking prevalence, breastfeeding and low birth weight for example). These indicators (for health improvement and prevention of premature mortality) include mortality from the major chronic diseases including CVD. In addition to those in the Public Health Outcomes Framework there should be indicators to measure morbidity caused by these conditions.

Progress will also be monitored through the other outcomes frameworks, including the Social Care Outcomes Framework and the NHS Educational Outcomes Framework. It will be important to align the different Frameworks as far as possible to support effective monitoring.

How will voluntary organisations be contributing to meeting these ambitions?

Voluntary organisations have an important role to play in supporting the delivery of primary prevention of chronic diseases, depending on their expertise, knowledge and experience. We identify the following contributions:

A role as provider of public health services:

One of the main advantages of third sector organisations compared to private sector providers is their focus on the needs of the whole person (a holistic approach). In addition, third sector organisations possess a wealth of knowledge and expertise about how to deliver services which reach all different population groups, including older people, marginalised groups and those which statutory agencies often find hard to reach.

A commissioning support role:

The third sector is well placed to provide information and guidance to the various commissioning bodies, raising local awareness of what kinds of services are already provided by third sector organisations and offering independent scrutiny of commissioning intentions to ensure that plans are equitable and optimal for the local population and are effective in tackling health inequalities.

This commissioning support role should include tools and expertise in chronic disease modelling to inform commissioning plans and to evaluate the effectiveness and cost effectiveness of prevention interventions.

A source of advocacy and scrutiny:

Third sector organisations can play a vital role in helping ensure that JSNAs maintain a coherent approach to reducing health inequalities. They will also be key members of Health and Wellbeing Boards. At the national level, some voluntary organisations play an important role in advocating for and providing scrutiny of national policies which will reduce the risk of chronic diseases and promote public health.

A source of information and support:

Third sector organisations play a very significant role in providing information and support to the public – both directly and via the health services. Through their knowledge and understanding of patients and their families, these same voluntary organisations are a vital resource to the health services – highlighting key issues, ideas, data and proposals on prevention as well as diagnosis, treatment and care.

Contact

Jane Landon
Director of Policy and DCEO
jane.landon@heartforum.org.uk

References

- ¹ ASH fact sheet July 2011.
- ² BHF Statistics 2008.
- ³ The Health and Social Care Information Centre, 2012. Statistics on obesity, physical activity and diet: England, 2012. [Online] Available at: <http://www.ic.nhs.uk/webfiles/publications/003_Health_Lifestyles/OPAD12/Statistics_on_Obesity_Physical_Activity_and_Diet_England_2012.pdf> [Accessed 9 May 2012].
- ⁴ NHS Futures Forum recommendations to Government. 2011.
- ⁵ Fair Society, Healthy Lives. The Marmot Review. 2010.

National Rheumatoid Arthritis Society



The National Rheumatoid Arthritis Society welcomes the Joint APPG Report examining the key priorities for the Cardiovascular Disease Outcomes Strategy. Our central concern with the new outcomes strategy is that it pays sufficient attention to the role of comorbidities in diseases such as Rheumatoid Arthritis (RA), which have historically been poorly understood and poorly treated.

Although not well known, the risk of cardiovascular disease for patients with RA is similar to patients with type-2 diabetes (Luqmani, R et al. *Rheumatology* 2006 (45):1167-9). It is thought this is due at least in part to the impact of inflammation on the body (Kelt, I & Uren, N. *British Journal of Cardiology* 2009 (16):113-15). The links between RA and cardiovascular disease are of sufficient concern that the NICE Clinical Guideline recommends in section 1.5.1.4 that RA patients are checked for comorbidities, including hypertension and ischaemic heart disease (NICE Clinical Guideline 79 – Rheumatoid Arthritis, 2009:16). The British Society for Rheumatology (BSR) also conducted a Quality Standards exercise on RA with the stakeholders, which identified the need to monitor cardiovascular disease (Top Ten Quality Standards for RA, BSR, 2012:2). There is also tacit acknowledgement of this risk factor in the recent proposed changes to QOF for 2013-14 (draft indicator 14).

In too many cases diseases are treated in isolation. With the desire to focus more on producing enhanced clinical outcomes for patients, it is very important that new outcomes strategy dovetails with the emerging quality agenda and promotes a holistic approach to treating patients. This needs to be done through cross-referencing to the NHS Outcomes Framework, the Commissioning Outcomes Framework, Best Practice Tariffs, CQUINs and the Quality Outcomes Framework for GPs.

One mechanism that we believe will be particularly important across all these contexts is the implementation and monitoring of holistic annual reviews for patients, which should include assessments of cardiovascular risk. Holistic annual reviews can help to address the complex impacts of the disease on the physical health of patients with RA. However, there is poor implementation of care planning and annual reviews for patients with RA, with the National Audit Office finding that only half of the 147 acute trusts it surveyed provided care plans for all patients with RA and 30% not providing a care plan for any at all and it has been recommended that holistic annual assessments be offered to all RA patients (Services for People with Rheumatoid Arthritis, National Audit Office, 2009:10). NICE also recommends that an annual review is conducted to measure the impact of comorbidities, including cardiovascular risk (NICE Clinical Guideline 79 – Rheumatoid Arthritis, 2009:16). However, a year after the NICE made its recommendations NRAS research found that 57% of consultant rheumatologists claimed to have seen no change in accessing a holistic annual review (One Year On Report, NRAS, 2010:8). The continuing importance of offering a holistic annual review is reinforced by BSR's latest recommendations, which contains a statement that says people with RA are offered an annual holistic review to assess and record the effect the disease is having on the person's quality of life (Top Ten Quality Standards for RA, BSR, 2012:1).

Stroke Association



What is your vision for the outcomes strategy? Where do we need to focus efforts in the coming decade? What needs to be sustained and what has been overlooked?

Stroke is the third biggest killer and the largest single cause of severe adult disability in the UK. There are around 110,000 strokes and 20,000 Transient Ischaemic Attacks (TIA or “mini strokes”) in England a year and over 300,000 people are living with moderate to severe disability as a result of stroke.

Stroke is also one of the most expensive conditions, with direct care costs to the NHS of £3 billion every single year, within a wider economic cost of £8 billion.

The ten year National Stroke Strategy for England launched in December 2007 and the accelerated work conducted since 2011 through the NHS Stroke Improvement Programme (SIP) and the Stroke Care Networks has resulted in better outcomes for stroke including an increase in patient survival rates and improved value for money in stroke care.

However, areas of serious concern remain. In particular:

- More work needs to be done on stroke prevention.
- Improvements in acute care while impressive are not universal.
- Improvements in acute care are yet to be matched in post-hospital and longer term support.

The Stroke Association welcomes the renewed emphasis on tackling cardiovascular disease that the Cardiovascular Disease Outcomes Strategy (CVDOS) could bring. We hope that it will build on and complement the significant progress made in improving stroke care through the National Stroke Strategy and address areas of remaining concern in stroke care, many of which are common across a range of cardiovascular conditions.

Prevention, risk assessment and early diagnosis

Reducing stroke incidence requires managing the risk factors common to all cardiovascular disease including high blood pressure and cholesterol, smoking, unhealthy diet and lack of exercise.

There has been a unified approach to the prevention of cardiovascular disease since 2009 through NHS Health Checks. However, concerns remain about poor and patchy implementation of the Health Checks programme. There are also concerns about the potential for wider variation and fragmentation of the programme when the responsibility for commissioning Health Checks is transferred to local authorities. The CVDOS must emphasise the importance of prevention and help to ensure that local authorities comprehensively commission the Health Checks programme.

The CVDOS should also look to further progress on effectively treating stroke risk factors such as TIA and Atrial Fibrillation (AF) and to build on the current work in these areas being coordinated by SIP.

The early initiation of treatment following a TIA reduces the risk of stroke by 80 per cent. This could mean that almost 10,000 strokes could be prevented each year in the UK. However, the Third Report of the Royal College of Physicians (RCP) Carotid Endarterectomy Audit (2011) found that more than half of NHS patients with symptoms of stroke or transient ischemic attack are still failing to get fast access to life-saving, stroke prevention surgery. A lack of public and professional awareness about the need for quick treatment, combined with badly designed hospital services, is resulting in hundreds of preventable strokes.

About 750,000 people in the UK are living with AF. About 12,500 strokes a year are thought to be directly attributable to AF but with appropriate treatment approximately 4,500 strokes per year and 3000 deaths would be prevented. Despite this AF is currently under diagnosed and under treated.

The CVDOS must also look in particular to improve the prevention and early diagnosis of Type 2 Diabetes. People with diabetes are two to three times more likely to have a stroke and the rising numbers of people newly diagnosed with diabetes is a threat to the progress already been made in combating stroke in recent years. Tackling the rising tide of obesity will be the key factor in reducing the risk of diabetes.

Emergency and acute care for stroke

As a result of actions taken to implement the National Stroke Strategy we have seen vast improvements in public and professional awareness of the need to treat stroke as a medical emergency.

The Department of Health's "Act FAST" campaign launched in 2009 and subsequent phases of additional activity has successfully achieved a rapid change in behaviour ensuring more people reached hospital faster and received appropriate treatment. In 2010 the Department of Health estimated that the campaign achieved a payback of £3.16 for every £1 spent. The CVDOS should consider the importance and impact of public awareness campaigns such as "Act FAST" and how they can be regularly maintained in the future.

In many parts of the country (most notably the North West and London) acute stroke care has been reorganised to deliver the key elements of care known to improve outcomes. The result has been a large reduction in mortality, length of stay in hospital and new institutionalisation rates for stroke in England.

However, successive audits by the RCP have helped identify areas where improvement is still needed. They have also illustrated significant variations in the standards of care provided at hospitals around the country.

The CVDOS should support work to remove variations and improve hospital stroke care across the country in the following areas:

- Patients on stroke units have better outcomes than those admitted to and treated on general wards. Excellent progress has been made in increasing the number of patients who spend some time on a stroke unit. However, too many patients are still spending the majority of their time on a general assessment unit where stroke specialist care is not carried out quickly enough. There also needs to be improvements in the number of people who are admitted directly to a stroke unit or at least within a few hours.
- Despite a major increase in the number of people receiving thrombolysis (clot busting drugs) a large number of patients who could benefit from it still do not receive it. All stroke patients should have access to a stroke service that can deliver thrombolysis safely and effectively and patients who are eligible should receive it.
- Co-ordination of care in hospital must be improved to reduce delays within hospital control. Patients should also receive the same standards of care whether they arrive at hospital in hours or out of hours. Differences in the availability of specialist staff and interventions such as imaging out of hours need to be addressed.
- Care for patients who suffer a stroke while already in hospital also needs improvement. The RCP say that improving education about stroke symptoms throughout hospital sites and how to contact the stroke team will reduce current delays.
- Patients are not receiving enough face to face therapy in hospital. The RCP say that a review of therapy working practices and staffing levels is needed.

Post hospital stroke care and support

Progress reports on stroke care from the National Audit Office (NAO) in 2010 and the Care Quality Commission (CQC) 2011 review of life after stroke support conclude that the improvements in acute care for stroke are not yet being matched in post-hospital and longer term support. The CQC also found wide levels of variation both between and within different areas in the accessibility and quality of care and support provided to people following transfer home. Progress in this area must be the most important stroke related priority for the new CVDOS.

There must be a renewed focus through the CVDOS on increasing access to Early Supported Discharge (ESD) for stroke, which provides more rehabilitation at home rather than in hospital and is known to achieve better results and reduce pressure on hospital beds. According to the CQC this was available in only 37% of areas.

In May the Stroke Association published the results of one of the largest ever surveys of stroke survivors and carers in the UK based on responses from over 2,200 people (<http://www.stroke.org.uk/sites/default/files/files/StrugglingRptFIN%20lowres.pdf>). The Daily Life Survey provides an insight into the most pressing issues in post hospital stroke care and support which the CVDOS should aim to address. The survey found that in England:

- 39% of respondents had not been offered an assessment for their health and social care needs beyond hospital and so are missing out on services that could help them recover.
- Of those who had received an assessment of their needs, 60% of people who had received an assessment had not received a care plan – setting out how their health needs would be met beyond hospital.
- Best practice states that stroke survivors should have their health and social care needs regularly reviewed at six weeks after leaving hospital, six months and then annually. This allows them to access the right support. 47% of respondents who had received a review had only ever had one review.
- Survivors report access to therapies as too brief to enable best possible recoveries. Of those who answered a question about support from the NHS, 43% wanted more support, with physiotherapy (29%) cited as the biggest priority. The 2011 CQC review of life after stroke services also found particular problems with availability of stroke specialist physiotherapy and significant delays in accessing speech and language therapy.
- Survivors and carers are not always being made aware of free sources of information and help such as those provided by the voluntary sector. In England, nearly 30% of respondents were not aware of such help.
- Stroke has a huge impact on people's wellbeing, leaving many feeling lonely and isolated, with 74% reporting they have not been able to get out as much as before. The CQC review also found that less than 40% of PCT areas provided good access to psychological therapy or support from stroke councillors.
- 40% of carers said they had not had an assessment of their needs, because they were unaware they had a right to one.
- Health and social care often fail to join up for the benefit of stroke survivors, causing problems. 48% of people living in England reported problems due to poor/non-existent joint working.
- The barriers faced by stroke survivors and their families are compounded by limited understanding of stroke. Across the UK, 85% of survey respondents said that people they came into contact with did not understand the impact of stroke.

The CVDOS also needs to create a renewed emphasis on the scope of self-management activities and self-help groups for people after stroke offered by appropriately trained and supported statutory and voluntary agencies. In this context, support provided by the stroke specialist voluntary sector becomes increasingly important. Services provided by voluntary organisations such as stroke clubs and communication support groups enable individuals who have had a stroke to engage with lay stroke specialists and others who have experienced a stroke.

Stroke and care homes

The recent NAO and CQC reports have estimated anything from 25-50% of people in a care home have had a stroke. However, the CQC found that only 24% of local stroke pathways specifically mention care homes and only 10% of areas had reviewed the quality of care for stroke survivors in care homes. The CQC also found problems with access to certain support services for stroke survivors in care homes, low levels of involvement of care home based stroke survivors in the design and delivery of local services and low levels of stroke specific training for staff in care homes.

The CVDOS must build on the current work of SIP in this area and ensure that local health and social care providers better understand and respond to the needs of stroke survivors in care homes.

End of life care

Around 30% of people with stroke die in the first 28 days.

The National Clinical Guidelines for Stroke and the National Stroke Strategy recommend that all stroke patients should have access to specialist palliative care expertise, and that staff providing this care receive appropriate training.

However, stroke patients receive fewer specialist palliative and supportive end of life care services compared with other conditions, most notably cancer and responsibility for their care rests predominantly with stroke and rehabilitation specialists, general medicine and primary care.

95% of hospice and palliative care cater for cancer, but the skills and good practice in pain management and preparation for death which many cancer patients benefit from would be relevant and helpful to people who have had strokes.

The CVDOS must look to ensure that a greater emphasis is put on developing new models of best practice for palliative care for people with cardiovascular disease.

Who needs to do what to achieve the ambitions for reducing cardiovascular disease?

In 2010 the NAO identified a number of key factors that had helped accelerate improvements in stroke care in recent years. These included the clear guidance provided by the National Stroke Strategy, strong clinical leadership provided at the national level and the support provided by the Stroke Care Networks and SIP.

It is still unclear how the structure and responsibilities of the new NHS architecture will play out. However, we feel that at the national level the NHS Commissioning Board should have an important role in setting direction for stroke services and ensuring effective implementation of the National Stroke Strategy and the CVDOS. We would support the idea of the Board producing an annual report on implementation of CVDOS.

We also hope that the importance of strong clinical leadership such as that provided through the role of the National Clinical Director for Stroke and SIP will be recognised in implementation plans for the CVDOS.

On prevention it will be important that the Department of Health works across Government to ensure other departmental policies support the CVDOS prevention agenda. Public Health England will also have an important role through spreading best practice in prevention of cardiovascular disease and leading on public information and awareness.

At a regional level, it will be vital to continue the good work of the Stroke Networks and ensure they are adequately funded. They will have an important role in supporting emerging Clinical Commissioning Groups (CCGs) to make the best decisions about stroke care. Stroke Networks must also find better ways to more actively engage adult social services departments in their work.

One of the key debates at present is around how to ensure better integration between health and social care. From the stroke perspective, achieving integration around CVDOS will mean building productive, working relationships with those working in acute stroke units in hospital (professionals, AHPs, charities), stroke survivors themselves (and their support networks), local authorities and support groups to whom survivors can be referred.

At the local level Health and Wellbeing Boards could provide a forum for more effective integration between health and social care. They should ensure that joint strategic needs assessments take into account local prevalence of cardiovascular disease and that the resulting joint strategies utilise the CVDOS to drive local change.

How will we know we are making progress on these ambitions? What should we measure and how?

The CVDOS should ensure ongoing investment in established clinical audits for stroke and related conditions while also addressing issues around participation in such audits.

The RCP Stroke Audit has been an important driver for improvement in acute stroke care for the past 12 years. We welcome the development of the Sentinel Stroke National Audit Programme and its extension to cover longer term aspects of stroke care.

A number of the domains within the interlocking Outcomes Frameworks already cover cardiovascular disease in general and stroke in particular and these will also be extremely helpful in establishing a baseline and measuring ongoing progress. It is important that alongside the measurement of physical improvements made by stroke survivors that the experiences of care for stroke survivors are also measured.

The 2011 CQC stroke review and the Stroke Association Daily Life Survey have provided insights into how stroke survivors and carers can report their own experiences of life after stroke. The CVDOS should learn from these attempts to measure non clinical aspects of experience and consider the establishment of a regular cardiovascular disease patient experience survey.

It is vitally important that whatever measurements of progress are made, patients and the public are given access to this information in a clear and accessible form (especially for people left with cognitive and communication issues following stroke). The Stroke Association would be willing to work with the Department of Health and other bodies to ensure that the stroke community has the local information needed to help drive improvements.

How will voluntary sector organisations be contributing to meeting these ambitions?

As a major charity focused exclusively on stroke, we are keen to contribute to the development and rollout of the CVDOS (as we have with the National Stroke Strategy.)

Everything we do is focused on the needs of stroke survivors. With our extensive networks, we can help by bringing them in to the process of developing the CVDOS. By survivors sharing their stories, they can set out what works and what doesn't.

Through our commissioned services, we see 35,000 stroke survivors each year across the UK. Our work is needs led and supports the individual to return to their best possible quality of life after a stroke. Our work includes housing and benefits advice, stroke prevention, communication support and emotional support. As the CVDOS rolls out, we can continue to play a key role with local planners and providers of health and social care, ensuring that services are coordinated around the needs of the individual.

Integration of health and social care services for the benefit of stroke survivors must be a key priority for the CVDOS. Through our Information, Advice and Support Service we help to co-ordinate the health and social care needs of stroke survivors so that they are met. We have also begun work to offer a robustly-evaluated six-month and/or annual post-stroke review using our unique position between health and social care.

In our relationship with commissioners, particularly in local authorities, we are keen to help link up health and social care for the benefits of stroke survivors. It will be vital to look at how charities and the Department of Health can work together to promote CVDOS, particularly with social care colleagues.

We supplement this service delivery with information provision. We have a large range of advice leaflets (meeting the Information Standard), a website and a national helpline as well as expert staff and volunteers around the country. Local authorities and CCGs can consider these free and paid for resources as "at their disposal".

Survivors are also critical in promoting public health messages. Whether this is smoking cessation, healthy eating messages, knowing your blood pressure or the FAST campaign, those who have survived stroke are often the best advocates for helping others avoid it.

We are also encouraging survivors to read and share the Stroke Survivors' Declaration (http://www.stroke.org.uk/sites/default/files/files/SSD_Eng_Scot_version_ltr.pdf). This was written by 120 stroke survivors, and sets out the help those affected by stroke expect to be able to access across health and social care. We believe a key way of driving up outcomes will be a more assertive, dynamic and visible group of survivors demanding that local health and social care planners and providers do better.

Finally, we are the largest charity funder dedicated only to funding stroke research in the UK. We work in close collaboration with the Stroke Research Network to identify how the funds we raise can best lead to improved outcomes. We are keen to look at how CVDOS can bring together diverse research funders for better outcomes.

For more information please contact:
Chris Randell – Parliamentary and Policy Officer
Tel: 0207 566 0326 E-mail: chris.randell@stroke.org.uk



1. What is your vision for the outcomes strategy? What conditions should be covered by the outcomes strategy? Where do we need to focus efforts in the coming decade and what is the balance between prevention and treatment? What needs to be sustained and what has been overlooked?

Tiny Tickers focuses on early detection and diagnosis of serious congenital heart disease, which affects 2,500 children every year in the UK alone. Our vision is on 80% detection by screening around 20 weeks gestation. This will improve the outcomes for these "heart babies" year on year.

2. Who needs to do what to achieve the ambitions for reducing cardiovascular diseases and improving treatment for people with inherited heart disease? What is the role of national government, the NHS Commissioning Board, Public Health England, local directors of public health and clinical commissioning groups?

The NHS needs to work with us to achieve this – but they generally just ignore us; we don't get contacted by Commissioners etc.

3. How will we know whether progress is being made on these ambitions? What should be measured and how?

CCAD audit is a help, but the NHS needs to have simple & effective audit at hospital level; ask the NHS to ask us as we have a few simple suggestions

4. A key challenge is the need to properly re-frame cardiovascular diseases as long term conditions, how can we ensure that people get the support that they need to live well and manage their health?

Have a joined up approach to congenital heart disease through all of life, not the current piece-meal approach where children grow up and are lost.

5. How will voluntary organisations be contributing to meeting these ambitions?

Tiny Tickers is working with other congenital heart charities, but we need NHS involvement, funding & support.

© British Heart Foundation, July 2012

Published by
British Heart Foundation
Greater London House
180 Hampstead Road
London NW1 7AW

Registered Charity Number 225971

This publication can be downloaded at:
bhf.org.uk

Acknowledgements

Many individuals representing the voice of people living with cardiovascular conditions and healthcare professionals contributed to this publication. Particular thanks are due to the author, Melanie Sturtevant.