

BETTER HEART DISEASE AND STROKE CARE ACTION PLAN

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FOREWORD BY THE CABINET SECRETARY FOR HEALTH AND WELLBEING

As the Government made clear in *Better Health, Better Care*, heart disease and stroke continue to be clinical priorities for NHSScotland.

I very much welcome the wide range of contributions received as a result of the consultation which I launched in July 2008. I'm sure that those who wrote in, and those who attended the consultation event in December last year, will see that we have paid great attention to the responses in developing the Action Plan. We have also worked closely with the three main voluntary sector organisations – the British Heart Foundation, Chest, Heart & Stroke Scotland and the Stroke Association in Scotland – in finalising the Action Plan's contents.



The Action Plan aims to offer comprehensive coverage of all the issues relating to heart disease and stroke. As it now includes inherited cardiac conditions, we've broadened the title beyond Coronary Heart Disease and are referring to it as our 'Heart Disease and Stroke Care Action Plan'. The stroke section has a much-overdue emphasis on the longer-term support people need to help them recover from the effects of the stroke in their own communities, the aspect of the consultation that generated more responses than any other.

As well as its many recommendations for improving the services needed by people with established heart disease, or who have had a stroke, the Action Plan emphasises the importance the Government attaches to preventing cardiovascular disease (the collective name for heart disease, stroke and diabetes). It also reflects our determination to tackle the unacceptable health inequalities associated with cardiovascular disease.

As a result of our policies, healthcare in Scotland is shifting from a reactive system that treats illnesses to one that anticipates and prevents health problems before they develop, as well as one that promotes a positive sense of wellbeing. The risk factors dealt with in this Action Plan are common to a wide range of diseases. Policy and services have too often been developed in separate silos, with activity fragmented according to disease, stage of disease, risk factors or the way in which services are delivered. In taking forward this Action Plan, the Government will therefore seek to make links to policy and delivery such as targeted primary prevention, the Long Term Conditions Action Plan, the revised Diabetes Action Plan and the work on mental health. All of this work is being brought together in the context of the Healthcare Quality Strategy which we announced at this year's NHS Conference. It is complemented by the CHD Improvement Management Programme which NHS Quality Improvement Scotland has just issued – the first ever nationally-coordinated quality improvement programme for heart disease in Scotland.

Most of the responsibility for actions falls on NHS Boards, but the cardiac and stroke Managed Clinical Networks in each Board are the main vehicles in enabling them to take these actions forward. Like all Networks, they allow managers, planners, clinicians, the voluntary sector, people with a personal interest in the services concerned and NHS Boards' local partners to work together on improving the care and support needed by people with heart disease or who have had a stroke.

Naturally, we will want to make sure that the actions in the Action Plan are being implemented. NHS Boards' performance will be monitored by the Scottish Government Health Directorates (SGHD) through scrutiny of NHS Boards' Local Delivery Plans, and through the HEAT target process. The National Advisory Committees on Heart Disease and Stroke will provide general oversight in monitoring progress and will be responsible for reporting to SGHD.

This Action Plan sets out a clear list of focussed pieces of work for taking forward the next phase of the work in tackling the burden of heart disease and stroke which has blighted our population for too long. We firmly believe that implementation of the Action Plan will allow Scotland to continue to reverse its current reputation and become a world leader in tackling cardiovascular disease.



Nicola Sturgeon, MSP
Deputy First Minister and Cabinet Secretary for Health and Wellbeing

ACTION PLAN

Heart Disease & Stroke Care Action Plan – Summary of Actions

Health Improvement

Paragraph	Issue	Action	Responsibility	Target date
3.7	Promoting Healthy Lifestyles	All GPs and practice nurses should undertake training in brief intervention/health behaviours and inequalities change, to help them support their patients to make positive lifestyle changes. Greater use could be made of community pharmacists, who should also be included in brief intervention training programmes, and trained in the use of CVD risk assessment tools. There is also a role for health coaches, as the Stroke Association work in England indicates.	NHS Boards	Ongoing
3.9	Promoting Healthy Lifestyles	NHS Boards, through their cardiac and stroke MCNs, should ensure appropriate referral to community advice and support on alcohol use.	NHS Boards	Ongoing
3.29	Promoting Healthy Lifestyles	ASSIGN should be promoted more actively within primary care, and integrated with current GP systems. ASSIGN must be available easily, in a variety of formats, to all clinicians dealing with CVD.	SGHD/ NHS Boards	Ongoing
3.32	Promoting Healthy Lifestyles	The Scottish Government Health Directorates (SGHD) should use the outputs from the 2009 national conference to further develop the Health Promoting Health Service concept, and issue a follow-up CEL.	SGHD	By spring 2010
3.35	Improving mental health	Once evaluated, the lessons from the 'Living Better' pilots should be rolled out by NHS Boards and their cardiac and stroke MCNs.	NHS Boards	

Health Improvement *(continued)*

Paragraph	Issue	Action	Responsibility	Target date
3.39	Reducing health inequalities	The Scottish Government should consider extending the community pharmacy contract to include blood pressure measurement, phlebotomy and ECGs where appropriate.	SGHD	
3.44		NHS Boards, through their cardiac and stroke MCNs, should develop plans for adopting the flexible and culturally-sensitive approach to services developed by the NHS Tayside 'Community Heart' project.	NHS Boards	March 2010

Heart Disease

Paragraph	Issue	Action	Responsibility	Target date
4.6	New definition of AMI/ACS	Patient groups and charities are informed of the national consensus on the new definition of Acute Myocardial Infarction/Acute Coronary Syndromes (AMI/ACS), particularly in areas where this represents a significant change in the diagnosis rates of AMI/ACS.	SGHD/ NHS Boards	
4.6	New definition of AMI/ACS	All clinical staff involved in caring for CHD patients must understand the rationale for the change in the definition of AMI/ACS and promote it within their own hospital, participating in the education of colleagues outwith the specialist cardiology environment.	NHS Boards	

Heart Disease (continued)

Paragraph	Issue	Action	Responsibility	Target date
4.6	New definition of AMI/ACS	Cardiac rehabilitation departments are aware of the change of AMI/ACS definition, and make sure service provision matches the likely increase in those diagnosed with non-ST elevation MI (NSTEMI).	NHS Boards	
4.6	New definition of AMI/ACS	Hospital coding departments are informed of the change of AMI/ACS definition.	NHS Boards	
4.6	New definition of AMI/ACS	GPs are made aware that the change in AMI/ACS definition may result in an apparent rise in the number of patients coded as having MI, and that this could have an impact on their CHD registers.	NHS Boards	
4.6	New definition of AMI/ACS	Hospital biochemistry departments should review their troponin assay in relation to the new AMI/ACS definition to ensure a standardised approach across Scotland.	NHS Boards	
4.6	New definition of AMI/ACS	The National Advisory Committee on Heart Disease should monitor progress of all actions relating to raising awareness of the new definition of AMI/ACS, to ensure consistency of approach to ACS diagnosis and treatment across Scotland.	National Advisory Committee on Heart Disease	
4.17	Improving delivery of pre-hospital thrombolysis	The Scottish Ambulance Service should review current arrangements for delivery of pre-hospital thrombolysis across Scotland, particularly in rural areas, including assessment of staff training needs, and submit a report to the National Advisory Committee on Heart Disease.	SAS	March 2010

Heart Disease (continued)

Paragraph	Issue	Action	Responsibility	Target date
4.19	Improving delivery of ORT	The inter-regional cardiac group will re-convene to ensure consistency of approach across Scotland, for example in relation to Optimal Reperfusion Therapy (ORT).	NHS Boards	
4.24	Developing approaches to public access defibrillation	NHS Boards should seek advice from their cardiac MCNs in considering the introduction of both static and non-static approaches to public access defibrillation (PAD) in particular whether there are suitable locations in their area in which the static approach might be beneficial. If recommended, NHS Boards should introduce these.	NHS Boards	March 2010
4.31	Improving access to cardiac rehabilitation	NHS Boards should, through their cardiac MCNs, undertake a needs assessment of their cardiac rehabilitation process for all eligible patients, identify priorities and allocate appropriate resources.	NHS Boards	end March 2010
4.33	Improving patient experience of cardiac rehabilitation	NHS Boards, through their cardiac MCNs, should implement the 'Heart Manual' or equivalent to ensure that people receive structured information, education and develop the skills needed to help them manage their own condition.	NHS Boards	
4.33	Improving patient experience of cardiac rehabilitation	NHS Boards, through their cardiac MCNs, drawing on the Network's patient representatives, should adopt the 'Braveheart' approach to cardiac rehabilitation.	NHS Boards	end December 2009

Heart Disease (continued)

Paragraph	Issue	Action	Responsibility	Target date
4.37	Improving Heart Failure Services	NHS Boards, through their cardiac MCNs and CHPs, should adopt the BHF Scotland Heart Failure Nurse Educator project.	NHS Boards	March 2011
4.40	Improving Heart Failure Services	NHS Boards, through their cardiac MCNs, should consider the recommendations of the short life working group involving NHS 24 and the chronic heart failure nurses as soon as they are available.	NHS Boards	
4.44	Improving Heart Failure Services	In preparation for the publication of the new CHD clinical standards, NHS Boards, through their cardiac MCNs, should undertake a needs assessment of cardiovascular nurse specialists delivering care to heart failure patients, including the potential for delivering out-of-hours cover through the education of primary care nurses.	NHS Boards	end December 2009
4.45	Improving Heart Failure Services	NHS Boards, through their cardiac MCNs, should work with Chest, Heart & Stroke Scotland to replicate its heart failure support service initiatives across Scotland.	NHS Boards	Ongoing

Heart Disease (continued)

Paragraph	Issue	Action	Responsibility	Target date
4.52	Improving Palliative Care	NHS Boards' cardiac and palliative care MCNs should jointly undertake an audit of practices' implementation of the palliative care Directed Enhanced Service, and collaborate to ensure implementation of Boards' <i>Living and Dying Well</i> Delivery Plans.	NHS Boards	end December 2009
4.63	Coordinating the introduction of new technologies for heart disease	When considering the introduction of highly specialised new technologies, NHS Boards should continue to ensure that their MCNs are fully integrated with local and regional planning and prioritisation processes.	NHS Boards	
4.69	Improving psychological support for Advanced Heart Failure	National Services Division of NHS National Services Scotland, as commissioners of the National Centre for the Treatment of Advanced Heart Failure, should as a matter of urgency address the issue of provision of psychological support at the Centre.	NSD	
4.78	Improving Adult Congenital Cardiac Services	NSD and the Golden Jubilee National Hospital should work towards achievement of the Department of Health in London's commissioning standards for adult congenital heart disease and address issues of awareness raising, development of referral pathways and data collection.	NSD, GJNH	

Heart Disease (continued)

Paragraph	Issue	Action	Responsibility	Target date
4.82	Supporting people with inherited cardiac conditions	ISD should work with the Familial Arrhythmia Network Scotland (FANS) towards developing a national register of familial arrhythmias.	ISD, NSD	
4.94	Supporting people with inherited cardiac conditions	Over time, there should be a single national Managed Clinical Network covering all forms of inherited cardiac disorders covering arrhythmias, cardiomyopathies and multi-system genetic diseases with a substantial cardiac involvement.	NSD	
4.97	Supporting people with Familial Hypercholesterolaemia (FH)	A national forum for Familial Hypercholesterolaemia (FH) should be established by SGHD to raise awareness of FH among primary care professionals, to prioritise the need for diagnosis, to define and agree referral protocols, and to develop good practice for clinical investigations, genetic testing and cascade screening within families.	SGHD	end December 2009
4.100	Supporting people with Familial Hypercholesterolaemia (FH)	The Aberdeen molecular genetics laboratory should develop a funding proposal for a pilot project of cascade testing for FH, for submission to CSO.	Aberdeen molecular genetics laboratory	

Stroke

Paragraph	Issue	Action	Responsibility	Target date
5.1	Improving stroke services	NHS Boards, through their stroke MCNs, should ensure their stroke services are comprehensive and include each of the essential elements identified in Chapter 5.	NHS Boards	Ongoing
5.4	Raise public awareness of stroke	The Scottish Government Health Directorates and NHS Boards, through their stroke Managed Clinical Networks, should continue to support the ongoing (FAST) public awareness campaigns run by Chest, Heart & Stroke Scotland, taking account of the evaluation of the Stroke Association campaign in England.	SGHD/ NHS Boards	Ongoing
5.4	Raise public awareness of stroke	The National Advisory Committee on Stroke should consider how best to develop a national strategy for the evaluation and delivery of FAST.	SGHD	end March 2010
5.4	Raise public awareness of stroke	NHS Boards, through their stroke MCNs, in conjunction with CHPs and the voluntary sector, should develop a local communications strategy to raise public awareness of stroke.	NHS Boards	end March 2010
5.5	Raising awareness of stroke	NHS 24 staff, primary care staff, ambulance crews and A&E department staff should all receive appropriate stroke awareness training, including FAST.	NHS Boards, NHS24, SAS	

Stroke (continued)

Paragraph	Issue	Action	Responsibility	Target date
5.8	Supporting stroke services	ISD will integrate audits of pre-hospital and hospital-based stroke care, building on the Scottish Stroke Care Audit work, and provide a minimum dataset to reflect performance against NHS QIS stroke standards.	ISD	end December 2009
5.12	Improving TIA services	NHS Boards, through their stroke MCNs, should engage with the Scottish Centre for Telehealth, to ascertain whether the Unscheduled Care TIA & Stroke Telemedicine Service to Orkney model is a viable option for TIA outpatient redesign in their area.	NHS Boards	
5.17	Improving thrombolysis services	NHS Boards, with advice from their stroke MCNs, should consider appropriate models to facilitate access to thrombolysis for stroke patients, particularly in areas with limited medical cover.	NHS Boards	
5.20	Improving stroke care	The Regional Planning Groups, in conjunction with the local stroke MCNs, the Scottish Ambulance Service and the Scottish Centre for Telehealth, should consider how to deliver optimal hyper-acute stroke care, including thrombolysis.	NHS Boards, SAS, SCT	end December 2010

Stroke (continued)

Paragraph	Issue	Action	Responsibility	Target date
5.23	Improving stroke services	A short life working group of the National Advisory Committee on Stroke should be established, to include representation from the Directors of Planning Group, to draw on NHS Boards' existing experience to explore the service and other implications of developing a HEAT target relating to stroke unit admissions.	SGHD	
5.25	Improving stroke services	SGHD should continue to highlight NHS Boards' performance in the SSCA on an annual basis and NHS Boards should provide action plans that will address any shortcomings.	NHS Boards	
5.27	Improving stroke services	NHS Education for Scotland should establish a method for nurses working in a stroke unit to demonstrate that they have achieved the defined level of specialist knowledge and skills.	NES	end December 2011
5.29	Improving access to imaging	The newly-established Scottish Imaging Managed Diagnostic Network, in conjunction with the SAS and NHS 24, should as a matter of urgency be asked to address whether duplex ultrasound, CT and MRI services can be delivered on a 24-hour basis in all hospitals admitting those who have had a stroke, and the additional neuroradiology capacity required.	Scottish Imaging Managed Diagnostic Network, SAS, NHS24	

Stroke (continued)

Paragraph	Issue	Action	Responsibility	Target date
5.31	Supporting younger people who have had a stroke	NHS Boards should adopt the model developed by Chest, Heart & Stroke Scotland and NHS Lanarkshire which helps younger people deal with the wider social consequences of stroke such as access to education and training, employment, family relationships and the economic impact of stroke. Access to vocational rehabilitation support should also be provided.	NHS Boards	
5.34	Improving early supported discharge	NHS Boards with their local planning partners must ensure that early supported discharge and community rehabilitation teams are integrated and easily accessible to assist people who have had a stroke to become as fully independent as possible.	NHS Boards	
5.37	Improving early supported discharge and long term support	NHS Quality Improvement Scotland should consider the wider standards that could be developed to reflect the most up to date evidence once the revised SIGN guideline 64 on Stroke Rehabilitation is published and discuss options for taking forward this work with the National Advisory Committee and stroke MCNs.	NHS QIS	
5.39	Improving rehabilitation and recovery	NHS Boards, through their stroke MCNs, should investigate the implications of allowing self referral to AHP services by those recovering from a stroke.	NHS Boards	

Stroke (continued)

Paragraph	Issue	Action	Responsibility	Target date
5.40	Improving rehabilitation and recovery	NHS Boards, through their stroke MCNs, should continue to work with leisure industry representatives to make best use of the new training course 'Exercise After Stroke: Physical Activity and Health' to improve access to exercise and fitness training for people with stroke in their area.	NHS Boards	
5.41	Improving rehabilitation and recovery	NHS Boards, through their stroke MCNs, should prioritise the provision of Occupational Therapy services for stroke rehabilitation, given the strong evidence base in this area.	NHS Boards	
5.42	Improving rehabilitation and recovery	NHS Boards, through their stroke MCNs, should ensure implementation of the Best Practice Statement on Ankle-Foot Orthoses, once available.	NHS Boards	
5.45	Improving rehabilitation and recovery	NHS Boards, through their stroke MCNs, should ensure that provision of speech and language therapy services is included in the mapping exercise being undertaken by the Rehabilitation Co-ordinator in each NHS Board, and supported appropriately, including voluntary sector communication support services.	NHS Boards	

Stroke (continued)

Paragraph	Issue	Action	Responsibility	Target date
5.46	Improving rehabilitation and recovery	NHS Boards, through their stroke MCNs, should encourage the use of the Stroke Workbook which provides information and support to patients who have had a stroke and their carers.	NHS Boards	
5.52	Improving palliative care	NHS Boards' stroke and palliative care MCNs should collaborate to implement the objectives in NHS Boards' Living and Dying Well Delivery Plans, and ensure that the best practice statement on palliative care is implemented once it is available.	NHS Boards	
5.54	Reducing delays to carotid surgery	NHS Boards and Regional Planning Groups should urgently implement the kind of service re-design undertaken in NHS Lothian and elsewhere to reduce the current unacceptable delays in time to carotid endarterectomy for eligible patients.	NHS Boards	
5.61	Improving stroke services	NHS Boards should ensure that their stroke MCN is providing in-service training opportunities such as STARS (Stroke Training and Awareness Resources) to staff involved in stroke care. Boards should also ensure that staff have access to on-line training through their hospital IT systems.	NHS Boards	March 2010
5.62	Improving stroke research	The Chief Scientist Office should be able to demonstrate increasing year-on-year recruitment to clinical stroke studies through the Scottish Stroke Research Network.	Scottish Stroke Research Network	

Patient Information

Paragraph	Issue	Action	Responsibility	Target date
6.5	Improving patient information	NHS Boards, through their cardiac and stroke MCNs, need to make concerns about communication issues for heart disease and stroke patients one of their priorities, and develop plans to tackle these concerns locally.	NHS Boards	

Data to Support Patient Care

Paragraph	Issue	Action	Responsibility	Target date
7.7	Improving HD data collection	NHS Boards, through their cardiac MCNs, should ensure that information systems are in place to meet the requirements of NHS QIS and ISD for the reporting of information relevant to cardiac care from a range of core indicators.	NHS Boards	May 2010
7.7	Improving HD data collection	NHS QIS, ISD and other relevant bodies, including the SAS, are required to establish mechanisms for reporting and publishing data relating to patient care for cardiac conditions.	NHS Boards, ISD, SAS	
7.8	Improving HD data collection	The cardiac MCNs, and staff collecting information, should ensure that data definitions meet NCDDP criteria.	ISD, NHS Boards	
7.8	Improving HD data collection	The NCDDP should be extended to include familial hypercholesterolaemia.	ISD	

Data to Support Patient Care *(continued)*

Paragraph	Issue	Action	Responsibility	Target date
7.10	Improving HD data collection	The Scottish Government will establish an eCardiology Strategic Group to develop an action plan for consideration by the eHealth Programme Board.	eCardiology Strategic Group	end 2009
7.13	Improving HD data collection	The eCardiology Strategic Group should look at extending information gathering on cardiology patients to primary care.	SAS	
7.14	Improving HD data collection	NHS Boards, in conjunction with their cardiac MCNs, need to establish mechanisms to collect the NCDDP ACS data set through SCI-CHD ACS (or a compliant alternative system).	SGHD	by March 2010
7.14	Improving HD data collection	The eCardiology Strategic Group, working closely with representatives from the Scottish Government, will ensure development priorities for cardiac data are delivered within the agreed funding arrangements and timetable.	eCardiology Strategic Group	
7.16	Improving HD data collection	The Scottish Ambulance Service, working with other national bodies, should continue to explore mechanisms to link their databases with SCI-CHD, to improve national data collection on the delivery of optimal reperfusion services.	SAS	

1: INTRODUCTION

1.1 *Better Health, Better Care*, the Scottish Government's action plan for health and wellbeing, confirmed that Coronary Heart Disease (CHD) and stroke together remain national clinical priorities in Scotland and contained a commitment to refreshing the version of the national clinical strategy published in 2004. This Action Plan reflects the direction set out in *Better Health, Better Care* in the way in which it seeks to respond to a series of challenges:

- listening to what people with, or at risk of, heart disease or who have had a stroke tell us about the kind of services they want;
- responding to developments in the evidence base, as reflected in the suite of SIGN Guidelines on CHD and cardiovascular disease (CVD) published in February 2007, and the revised stroke Guideline published in December 2008;
- introducing a new focus on prevention of ill health through anticipatory care approaches;
- reducing health inequalities across Scotland;
- meeting the needs of increasing numbers of older people; and
- responding to changes in our workforce.

1.2 This Action Plan responds to these challenges by setting out the ways in which we can prevent CVD, improve people's experience of services, embed services to a greater extent in local communities and ensure that high quality services are planned and delivered efficiently. It responds to the clear evidence of health inequalities in heart disease and stroke in terms of both deprivation and ethnicity and sets out actions to ensure that we better engage with those groups that have often proved to be most challenging to reach, and provide targeted interventions to address preventable heart disease and stroke.

1.3 In producing this Action Plan, we have worked closely with key voluntary sector organisations such as the British Heart Foundation, Chest, Heart & Stroke Scotland and the Stroke Association's Scottish branch, in keeping with the commitment given by the Scottish Government to strengthening its ties with the voluntary sector because of its key role in providing support and services. In line with the principle set out by the Chief Medical Officer in his work on long term conditions, we must learn from the experiences of those who are living with heart disease, or have had a stroke, and their families and unpaid carers. We will work with the voluntary sector to help implement the actions in this Action Plan.

1.4 The Action Plan also takes account of the responses to the consultation document *Better Coronary Heart Disease and Stroke Care* launched in July 2008, and the outputs from the consultative event held in Glasgow in December 2008, which was attended by 150 people with a personal or a professional interest in these conditions.

1.5 As a result of the consultative process, the Action Plan has been extended beyond the traditional view of CHD, by including heart failure and inherited cardiac conditions. In order to reflect that wider perspective, the Action Plan refers where appropriate to 'heart disease' rather than 'CHD'.

1.6 The Action Plan needs to be set in the context of a range of other policies and strategies, such as:

- the generic work on the management of long term conditions, including *Gaun Yersell*, the national strategy for self management of long term conditions produced by the Long Term Conditions Alliance Scotland;
- the Long Term Conditions Action Plan;
- *Equally Well*;
- inequalities-targeted high-risk primary prevention, 'Keep Well';
- 'Life Begins ...' checks;
- Early Lives;
- *Better Together*;
- Partnership Improvement and Outcomes;
- Healthy Working Lives;
- the Delivery Framework for Adult Rehabilitation;
- the disability strategy and the Scottish Vision Strategy;
- *Towards a Mentally Flourishing Scotland*;
- the community empowerment plan;
- *Living and Dying Well, a National Action Plan for Palliative and End of Life Care in Scotland*;
- the National Performance Framework.

1.7 The Scottish Government has set out an ultimate 'Purpose' which unites public services across Scotland and requires them to work in partnership to deliver sustainable economic growth and opportunity for everyone in Scotland to flourish. NHSScotland has a key role in supporting this, particularly through the underpinning requirement to provide services which will enable people in Scotland to live healthier, longer lives. *Better Health, Better Care* (Scottish Government, 2007) set out the action plan for NHSScotland which is intended to deliver this outcome. Increasingly, this will be focussed on the priority of raising the quality of NHSScotland healthcare services to world-leading levels.

1.8 A new Healthcare Quality Improvement Strategy is being developed to create a clear vision and focus for the range of improvement work already being driven forward across NHSScotland. The proposed approach will support the six dimensions of quality:

Patient centred	providing care that is responsive to individual patient preferences, needs and values and assuring that patient values guide all clinical decisions
Safe	avoiding injuries to patients from care that is intended to help them
Effective	providing services based on scientific knowledge
Efficient	avoiding waste, including waste of equipment, supplies, ideas, and energy
Equitable	providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status
Timely	reducing waits and sometimes harmful delays for both those who receive care and those who give care

Source: Institute of Medicine

1.9 One of the key drivers of healthcare quality is patient-centred services. The Scottish Government is currently pursuing a range of approaches across NHSScotland which will increasingly focus the development and delivery of healthcare services around each individual's preferences and requirements. These approaches include the work in train to develop a 'mutual' NHS. Establishing and communicating patients' rights, expectations and responsibilities is a major strand of this approach. Another strand is the *Better Together* programme which is gathering evidence on what people in Scotland expect of their NHS. It will then measure people's actual experience of healthcare services, producing information which will in turn inform action to improve services. We will ensure that that work aligns with the actions set out in this Action Plan.

2: PROGRESS SINCE 2004

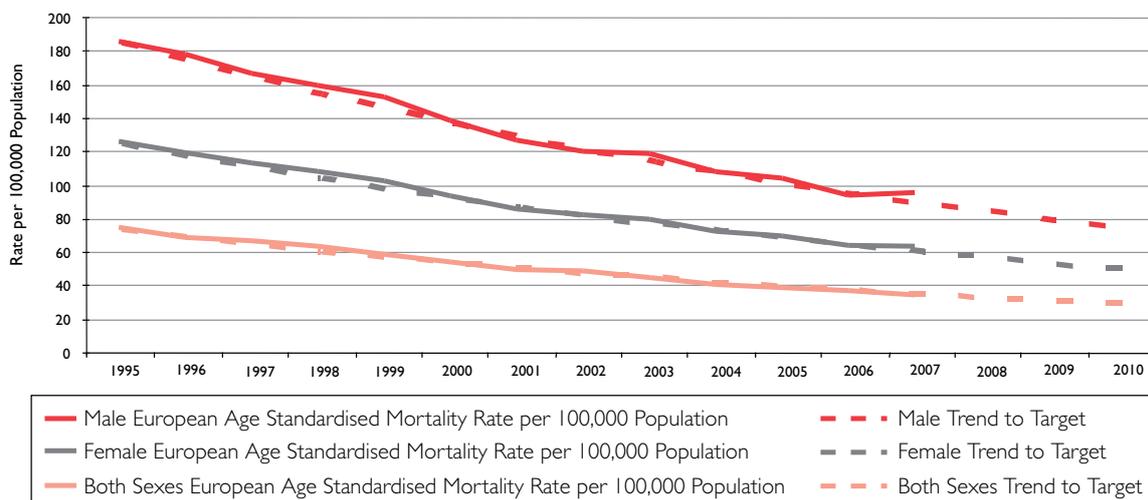
Cardiovascular Disease Mortality

2.1 Across Scotland, all sectors of society have seen over the past decade a continuing and welcome downward trend in cardiovascular mortality, and the gap in mortality between the least and most deprived has narrowed. Graphs 1 and 2 illustrate progress towards the targets of a 60% reduction in premature (<75) CHD mortality and 50% reduction in premature mortality from Stroke between 1995 and 2010 (see graphs below). A further target was set in 2004, aimed at achieving an additional 27% reduction in premature mortality from CHD by 2008 for the most disadvantaged communities. The <75 CHD mortality rate in these communities has decreased by 17% from 135 per 100,000 population in 2003 to 112 in 2007. If this trend continues, the 2008 target should be met. In 2007 this target was superseded by one aiming to reduce CHD mortality among the <75s in the most deprived 15% of areas in Scotland, using 2006 data as the baseline.

2.2 Although excellent progress continues to be made in terms of overall mortality reductions, it is a matter of concern that rates of decline in CHD mortality for men and women aged 35-54 years show recent, significant flattening. Specifically, the annual percentage change in men was -6.28% between 1986 and 2003, but only -0.55% between 2003 and 2006. Furthermore, a small increase in mortality rates occurred in young men in 2005-06. Between 2003 and 2006 the two most deprived quintiles showed an increase of 16.8% and 10% respectively. This will clearly make the additional 15% mortality reduction target for the most disadvantaged groups more difficult to achieve. These adverse trends mirror what is happening in other parts of the world, including the US and England and Wales. It is clear that unfavourable trends in cardiovascular risk factors (for example, obesity and diabetes) are affecting CHD mortality trends in younger age groups. CHD prevention in younger people needs to be prioritised if the favourable reduction in mortality seen over so many decades in Scotland is to be maintained. This issue is explored in detail in the next chapter.

Graph 1

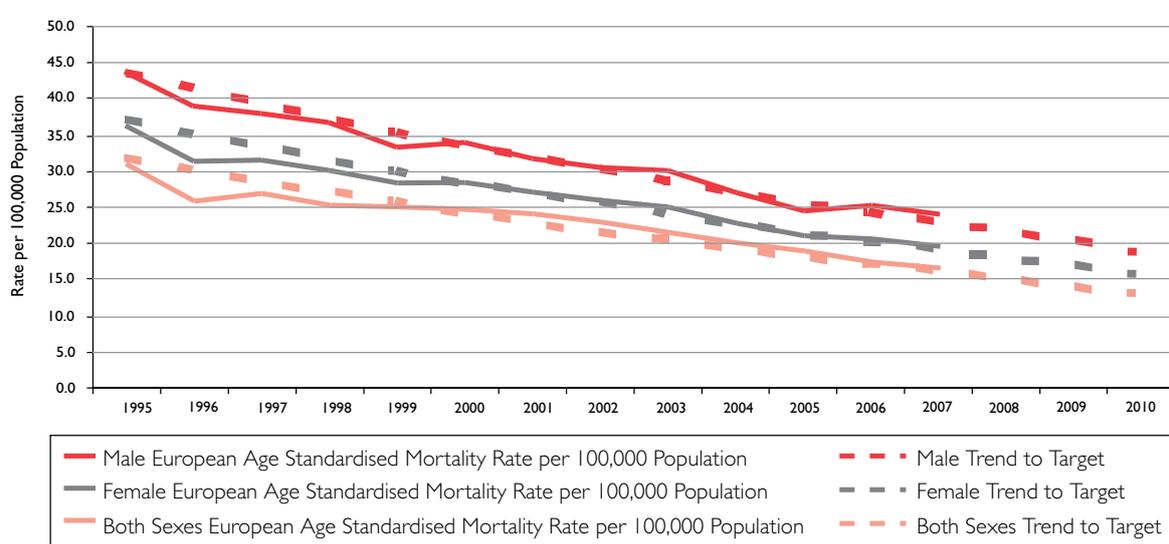
Coronary Heart Disease; Ages Under 75; European Standardised Mortality Rates per 100,000 Population



2.3 The trend in terms of stroke deaths is more consistent. The latest figures show a reduction in mortality from stroke in the <75s from 37.5 deaths per 100,000 in 1995 to 18.8 deaths per 100,000 in 2007. If this trend continues, the 50% target reduction in mortality from cerebrovascular disease in this age group should be met. However, it needs to be borne in mind that current demographic trends will result in an increase in the number of patients suffering a stroke, if the age specific incidence is not reduced by primary prevention. Future increases in stroke incidence may also be related to obesity, diabetes and alcohol misuse.

Graph 2

Cerebrovascular Disease; Ages Under 75; European Age Standardised Mortality Rates per 100,000 Population



Service Developments

2.4 The five years since the last Strategy update have seen significant service improvements for both heart disease and stroke. For example, Managed Clinical Networks are now well established in all NHS Board areas, and are being used increasingly as a source of expert advice in terms of service planning.

2.5 In 2007, comprehensive new SIGN Guidelines for CHD and Cardiovascular Disease were published, which include the development of the risk calculator, ASSIGN. The corresponding stroke Guideline was also revised in December 2008.

2.6 'Keep Well' services delivering inequalities-targeted health checks for those most at risk of preventable CVD are well established in primary care across Scotland, and continue to be refined to new 'at risk' populations. This is reflected in targets in the National Performance Framework and HEAT.

2.7 Waiting times for investigation and treatment of heart disease continue to fall, with cardiology blazing a trail in terms of progress towards achieving the 2011 target of a maximum waiting time of 18 weeks from referral to treatment for all conditions.

2.8 The Quality and Outcomes Framework (QOF) of the new General Medical Services (GMS) contract for primary care from April 2009 includes 134 indicators, covering 20 clinical areas, of which 10 relate to cardiovascular disease: Coronary Heart Disease; primary prevention of CVD; heart failure; stroke/TIA; hypertension; diabetes; Chronic kidney disease; atrial fibrillation; obesity; and smoking.

2.9 Scottish practice achievement against these indicators in 2007-08 was in the main above 99%, more than the average overall achievement of 98.21% for all indicators. The QOF data demonstrate consistently high achievements in the clinical domains of secondary prevention in CHD and stroke and transient ischaemic attacks, showing that general practice is delivering high quality care for people with these conditions.

2.10 In relation to CHD, technical advances such as drug eluting stents and cardiac resynchronisation therapy have been rolled out across the country by the Regional Planning Groups (RPGs). The Lothian pilot of primary PCI (percutaneous coronary intervention) has been completed successfully, and RPGs in conjunction with the Scottish Ambulance Service are considering how to implement its findings in other parts of the country. The National Centre for Treatment of Advanced Heart Failure is now well established at the Golden Jubilee National Hospital, and there has been significant progress towards the development of an electronic patient record for cardiology.

2.11 In relation to stroke, access to all-important stroke unit care has improved, with a significant rise in the number of units and designated stroke beds. The Scottish Stroke Care Audit (SSCA) (www.strokeaudit.scot.nhs.uk) demonstrates year on year improvements in the elements of stroke care, as measured against NHS QIS standards. As in the case of heart disease, good progress is being made in moving towards an electronic patient record for stroke (see paragraph 7.22 et seq.).

2.12 A number of important educational initiatives led by NHS Education for Scotland (NES) are also contributing to improved stroke care. The Stroke Core Competencies for staff working with people affected by stroke were launched in 2005, and in 2007 the Scottish Government funded a NES/Chest, Heart & Stroke Scotland project to develop an e-learning resource for health and social care staff based on the competencies. The STARs (Stroke Training and Awareness Resources) website was launched in May 2008 and provides an interactive way of learning the stroke competencies. Specialty registrar training in stroke medicine has also been established. Chest, Heart & Stroke Scotland provides stroke training programmes, with funding from NHS Greater Glasgow & Clyde, Lothian, Grampian, Lanarkshire, Fife, Dumfries & Galloway and Borders. These offer in-service training to acute and primary care staff and relevant local authority and other home-care services. The Stroke Research Network funded through the Chief Scientist Office is now very well established, and contributing to national and international trials which will ultimately benefit all those in Scotland who have had a stroke.

2.13 The Chief Medical Officer's annual report *Health in Scotland 2007* in its chapter on 'Coronary heart disease and stroke: Reducing amendable mortality', provides a useful summary of recent progress in reductions in the mortality rates of the cardiovascular diseases (CVD) of Coronary Heart Disease (CHD) and stroke. It also describes a range of health improvement measures and interventions that have the potential to save up to 10,000 lives from CVD each year in Scotland, if optimally applied.

2.14 This chapter has highlighted key achievements across Scotland since the Strategy was last updated. Chapters 3 and 4 focus on specific areas of heart disease and stroke service delivery which will need particular attention over the next period of the Action Plan, in order to sustain already significant improvements and address areas of relative neglect such as long term care for those who have had a stroke.

3: PREVENTION – HEALTHY LIFESTYLES AND HEALTH INEQUALITIES

3.1 Scotland's health is improving rapidly but it is not improving fast enough for the poorest sections of our society. Health inequalities remain our major challenge.

3.2 Healthcare in Scotland is shifting from a reactive system of healthcare to one which seeks to anticipate and prevent health problems before they develop. Public health measures relating to tobacco, alcohol and food have a central role in this work.

3.3 A useful survey of the international evidence for the prevention of cardiovascular disease is contained in *Healthcare Models for the Prevention of Cardiovascular Disease* published by the Health Foundation in April 2009.

Healthy Lifestyles

3.4 Cardiovascular disease (CVD) covers a spectrum of disorders which includes CHD, cerebrovascular disease, diabetes and peripheral vascular disease. All CVD is associated with a number of potentially modifiable risk factors which can be measured to estimate overall risk. SIGN Guideline 97 on risk estimation and the prevention of CVD therefore covers the prevention of other forms of CVD, not just CHD.

Smoking

3.5 The association between smoking and increased rates of CVD is well understood. Smokers are twice as likely to suffer a heart attack than non-smokers, and smoking is also linked to increased risk of stroke. The Scottish Government's historic ban on smoking in public places in March 2006 led to a reported reduction of 17% in hospital admissions for heart attack when comparing numbers observed 10 months before and after the ban, based on a sample of nine hospitals in Scotland. It is not clear whether there is similar research in relation to strokes. Adult smoking rates increase with increasing deprivation. In 2005-06, smoking rates in Scotland ranged from 11% in the least deprived 10% of areas to 44% in the most deprived 10% of areas. Recent research has also demonstrated that smoking is responsible for a significant reduction in survival after cardiac surgery (*British Medical Journal*, 2 April 2009 338; 902 *et seq.*).

3.6 A survey of Scottish GPs carried out in the autumn of 2008 by the charity HEART UK found that 24% of those who responded did not refer their patients routinely for lifestyle modification advice and therapy. That finding is confirmed by the EUROASPIRE Study, reported in *The Lancet* for 14 March 2009 (Vol 373) which suggests that more effective management of lifestyle risk factors is 'desperately needed' in patients with CHD. The study found that adverse lifestyle effects persisted in patients one year after a cardiac event. These trends included smoking. About one-fifth of patients continued to smoke and the proportion of young women smoking actually increased. *The Lancet* editorial made the point that cardiologists often overlook smoking as a risk factor for CVD when compared to hypertension and hyperlipidaemia, despite the fact that tobacco smoking increases the risk of acute myocardial infarction, sudden cardiac death, aortic aneurysms and peripheral vascular disease. It is likely that these findings would also apply to people who have had a stroke.

3.7 The lack of attention that smoking cessation receives in some primary care and specialist settings is clearly an issue that needs to be addressed, especially as US data suggest that smoking cessation is more cost effective than other preventive cardiology measures. Heart disease and stroke patients should be referred to and have access to community-based smoking cessation services following discharge from hospital.

Action:

All GPs and practice nurses should undertake training in brief intervention/health behaviours and inequalities change, to help them support their patients to make positive lifestyle changes. Greater use could be made of community pharmacists, who should also be included in brief intervention training programmes and trained in the use of CVD risk assessment tools. There is also a role for health coaches, as the Stroke Association work in England indicates.

3.8 In May 2008 the Scottish Government launched *Scotland's future is smoke-free, a Smoking Prevention Action Plan* with £42m being made available over the next three years (2008-09 to 2010-11) to support a wide-ranging tobacco control programme, including £33m for a range of smoking cessation services. The Action Plan signalled the Government's intention to bring forward new legislation to control the availability and promotion of tobacco by introducing a registration scheme for tobacco retailers and restricting the display of tobacco products in shops. These measures will be taken forward in the Tobacco and Primary Medical Services (Scotland) Bill (published on 26 February 2009) with the main aim of reducing smoking rates by stopping young people starting to smoke.

Alcohol

3.9 Excess alcohol consumption is related to a wide range of health harms. For those over the age of 40 drinking a small amount of alcohol may have a protective effect against heart disease and stroke. However, for those who drink beyond this low level, and for those under 40 years old who drink any amount, alcohol increases the risk of heart disease and stroke by increasing blood pressure, weight and levels of triglycerides in the blood. In March 2009 the Scottish Government published a discussion document *Changing Scotland's Relationship with Alcohol: A Framework for Action*, which outlines a range of measures to tackle alcohol misuse, including introducing a minimum price per unit of alcohol, tackling irresponsible promotions, limiting the use of marketing material, placing a duty on licensing boards to consider raising the age of off-sales purchases to 21, and introducing a social responsibility levy. This is backed up by a record investment of over £120m from 2008-09 to 2010-11, to reduce alcohol-related harm.

Action:

NHS Boards, through their cardiac and stroke MCNs, should ensure appropriate referral to community advice and support on alcohol use.

Hypertension

3.10 The Quality and Outcomes Framework of the GMS contract from April 2009 includes two new indicators for primary prevention of CVD in patients with hypertension without confirmed CVD. These require practices to complete a CVD risk assessment on newly diagnosed patients in this category and to give lifestyle advice on an annual basis to all patients diagnosed with hypertension from 1 April 2009. The importance of this issue is underlined by the recent meta-analysis of 150 clinical trials involving blood pressure medication, published in the *BMJ* (23 May 2009, vol. 338 p 1245 et seq.). The results indicate the importance of lowering blood pressure in everyone over a certain age.

Cholesterol

3.11 The report *Cholesterol and the ageing population*, published in 2008 by HEART UK claims that cholesterol is the single greatest risk factor for CHD, contributing to almost half the CHD-related deaths in the UK. Cholesterol is also a major risk factor in stroke, and it contributes to the increased risk of CVD associated with diabetes and obesity. The draft NHS QIS clinical standards for prevention and treatment of CHD, currently out for consultation, propose the following priority groups for prevention of CVD:

- Patients with:
 - Hypertension without confirmed CVD;
 - A first degree relative with premature CVD; and
 - A first degree relative with Familial Hypercholesterolaemia (FH);
- Patients with a personal history of:
 - Diabetes (Types 1 and 2) aged 40 and over; and
 - Familial Hypercholesterolaemia at any age.

3.12 Population-wide action on cholesterol seems to offer the biggest opportunity for health gains relative to the small scale of effort involved. Whole population approaches should therefore be borne in mind, as indicated in the CVD Guide to Primary Prevention, published in 2005 by Heart Health National Learning Network.

3.13 The specific issues around testing for Familial Hypercholesterolaemia are covered in paragraphs 4.95 to 4.97.

Obesity and Cardiovascular Risk

3.14 Individuals with a BMI $>30\text{kg/m}^2$ have a two- to threefold increased risk of CHD and stroke compared to individuals with a normal BMI. They also have a very dramatic (fortyfold) increased risk of developing diabetes. Central obesity, as measured by waist circumference, is a better predictor of cardiovascular risk than BMI (defined as waist circumference $\geq 102\text{cms}$ in men and $\geq 88\text{cms}$ in women). Scottish Asians are at greater risk of CHD and stroke at lower BMI and waist circumference than non-Asians ($\geq 90\text{cms}$ in Asian men and $\geq 80\text{cms}$ in Asian women).

3.15 *Healthy Eating, Active Living: An action plan to improve diet, increase physical activity and tackle obesity (2008-2011)* was published in June 2008. This document outlines commitments to invest £56m in initiatives aimed at supporting people to make healthier choices in what they eat, to build more physical activity into their everyday lives and to maintain or achieve a healthy weight. This action plan will build on, not replace, the continued delivery of the Diet Action Plan and Physical Activity Strategy.

3.16 The action plan also set out the Scottish Government's intention to develop a long term strategic approach to addressing the current obesity epidemic. This will require cross-departmental and cross-sector collaboration to make deep, sustainable changes to our living environment, from one that promotes weight gain, to one that supports healthy choices by all.

Diet

3.17 Currently, a wide range of actions is under way in relation to the provision of a healthier diet for the general population, all of which have the potential to make a positive long term and sustained impact on the incidence of CVD. Reductions in levels of salt, fat and sugar in food are particularly relevant to tackling CVD. Measures targeted at early years, such as a £19m investment over three years to improve the nutrition of women of childbearing age, pregnant women and children under 5 in disadvantaged areas, and measures to increase the proportion of babies who are exclusively breast fed at 6-8 weeks, are key to success in this area. The Schools (Health Promotion and Nutrition) Scotland Act 2007 will also ensure better access to nutritionally healthier foods in schools.

3.18 The National Food and Drink Policy for Scotland aims to create a healthier Scotland by changing individual behaviour and attitudes about diet and food choices by:

- improving the nutritional quality, safety and freshness of food on offer in institutions and the catering sector; and
- supporting Scottish food manufacturers and retailers to take the initiative in driving forward consumer demand for more affordable, healthier food options.

Physical Activity

3.19 The link between physical activity and health is now firmly established, with clear evidence showing that regular activity has both preventive and therapeutic effects on many chronic conditions, including CHD and stroke.

3.20 Scotland's physical activity Strategy *Let's make Scotland more Active*, published in 2003, remains the key Scottish Government policy document in this area. The Strategy sets a target for 50% of adults and 80% of children to meet recommended levels of physical activity by 2022. In recognition of the fact that these are challenging targets, over the three years (2008-11) the physical activity budget will double from £2m to £4m a year.

This is over and above spending in other Government areas which impact directly on physical activity, for example sustainable transport, the active schools programme, etc. The key implementation settings for the next three years will be schools, workplaces, communities and homes.

Equally Well

3.21 *Better Health, Better Care* emphasised the importance of identifying and prioritising practical actions to reduce 'the most significant and widening health inequalities in Scotland'. *Equally Well*, the report of the Ministerial Task Force on Health Inequalities, sets out the joint Government and local authority plan to tackle Scotland's health inequalities. Evidence shows that those individuals and families from our most deprived communities are most likely to have risk factors associated with poor health outcomes, including CVD. By offering tailored services, focussed on preventative action, which meet the specific and differing needs of our most deprived individuals, *Equally Well* aims to reduce the gap in health outcomes between most and least deprived.

3.22 Research suggests that CHD, hypertension and diabetes originate early in life during foetal development. If intrauterine growth is restricted, for example due to inadequate maternal energy intake, there is an increased risk of low birthweight which can have a permanent effect on long term health. Studies suggest that low birthweight babies are more likely to suffer from cardiovascular disease later in life.

Anticipatory Care: targeted high risk primary prevention

3.23 Improving rates of premature mortality from CHD in our most deprived areas is therefore a key objective for Government. This is reflected in the National Performance Framework indicator 'to reduce mortality from CHD among under 75s in deprived areas' and in the 'Keep Well' HEAT target, 'to deliver an agreed number of inequalities-targeted health checks with a focus on CHD'.

3.24 The 'Keep Well' and 'Well North' Programmes provide anticipatory care for those at higher risk of CHD, stroke and diabetes. They invite 45-64 year olds, initially within deprived communities, to attend a health check and offer those found to be at higher risk medical treatment and support to tackle smoking, poor physical activity and other health-related behaviour.

3.25 As the mechanisms for targeting and engaging with 'at risk' populations become more refined, Boards are expected to broaden out their focus to include other key groups that are vulnerable to premature mortality from CVD, such as the South Asian community, offenders, and deprived people living in remote and rural areas.

3.26 The delivery of this service has significant implications for the NHS, local authority services and the third sector, and 'Keep Well' will be fully evaluated with lessons/best practice learned used to influence the future shape of healthcare services.

'Life Begins' Checks

3.27 *Better Health, Better Care* committed the Scottish Government to developing a programme of 'Life Begins' checks. NHS 24 is therefore currently developing a robust online self assessment programme, complemented by telephone-based assistance. This programme will invite people reaching the age of 40 to conduct a web-based self assessment through which they can identify which, if any, personal, family and lifestyle issues could pose a risk for their future health and wellbeing. Where needed, people will be signposted to sources of help and given the option of a telephone consultation with a health adviser. There will be a facility to inform practices of the outcome of the self assessment, if the person agrees. The programme should be 'equalities checked' and it will be important to ensure that those who do not respond are followed up.

ASSIGN Risk Calculator

3.28 ASSIGN was developed as part of SIGN Guideline 97 on Risk estimation and prevention of cardiovascular disease. It is being implemented and assessed initially through GP practices involved in the *Keep Well* programme. While based on the Framingham risk score, it includes a measure of social deprivation – the Scottish Index of Multiple Deprivation – as well as family history. This means that for the first time Scottish people at risk of CVD can have a full assessment of that risk, taking account of the influence of both deprivation and family history (as a proxy for ethnic background). This is particularly important in terms of the Scottish South Asian population, who are at greater risk of CHD at lower BMI and younger age than the rest of the population.

3.29 ASSIGN is the preferred CVD risk calculator in use across Scotland. It is available throughout primary care as a web-based tool, and will be due course be integrated into primary care IT systems. In this context, it is helpful that in the new QOF indicators for primary prevention ASSIGN is one of the acceptable risk assessment scores for the achievement of the indicator.

Action:

ASSIGN should be promoted more actively within primary care by NHS Boards and their cardiac MCNs, and integrated with current GP systems (see paragraph 7.17). ASSIGN must be available easily, in a variety of formats, to all clinicians dealing with CVD.

3.30 The 'polypill', a tablet combining the different drugs available to treat many of the cardiac risk factors, is thought to be capable of reducing heart disease by 80% ('Can the polypill save the world from heart disease?', *The Lancet*, Vol 373 18 April 2009, pp 1313-14). The results of the Indian Polycap Study (TIPS) showed that each of the components of the polypill did what was intended: the statin reduced cholesterol, the three antihypertensives reduced blood pressure and aspirin reduced the clotting ability of blood. Tolerability for the polypill was good. The paper concluded, however, that a large trial with longer follow-up is however needed to assess the true feasibility of this strategy.

Health Promoting Health Service

3.31 NHS Boards are making good progress with implementing the seven actions outlined in CEL(2008)14 on the Health Promoting Health Service ('Every healthcare contact is a health improvement opportunity'). All of the actions, which are focussed on the acute sector, will make a contribution to further reducing rates of CHD and stroke in Scotland.

3.32 Given the proportionately greater use of acute services by patients from deprived communities, this initiative offers a major opportunity to improve health and reduce health inequalities across a whole range of disease areas, not just CHD and stroke. The Scottish Government, in conjunction with NHS Health Scotland, is planning a national conference in autumn 2009 to demonstrate and build on progress to date with the CEL actions.

Action:

The Scottish Government Health Directorates should use the outputs from the 2009 national conference to further develop the Health Promoting Health Service concept, and issue a follow-up CEL by spring 2010.

3.33 *A Force for Improvement: The Workforce Response to 'Better Health, Better Care'* further develops the role of NHS staff as ambassadors for improving health and promoting the benefits of preventative action and measures of self care for patients and the public across a range of health issues.

Mental Health

3.34 People with serious mental health problems are more likely to suffer from CVD before the age of 55, and once diagnosed have poorer survival rates. Those affected by anxiety and depression are less likely to engage in lifestyle change. Interventions to change behaviour will therefore have to address psychological issues. Further actions should include: better screening for depression; improved access to psychological therapies in acute settings and cognitive behavioural therapy; and motivational interviewing, all of which can help improve physical function, mood and treatment compliance. The QOF already incentivises annual screening for depression for those patients with diagnosed CHD and/or diabetes. Addressing anxiety and depression within 'Keep Well', through access to mental wellbeing supports for stress, and the *Living Better* programme (see box over) will have a positive impact on those with poor mental health.

'Living Better'

'Living Better' aims to improve the mental health and wellbeing of people with diabetes and Coronary Heart Disease. It is funded by the Scottish Government and runs from January 2008 to November 2010. Research indicates that approximately one in three people with diabetes and one in 5 with CHD experience depression. There is evidence that providing treatment and support for depression and other mental health problems can bring a range of physical and psychological benefits. It is estimated, however, that 50% of people with mental health problems go undiagnosed in primary care.

'Living Better' is being piloted on six sites, and starts from the position that people with diabetes or CHD deserve a holistic assessment of their needs, both physical and mental, matched by appropriate services. In order to achieve this, the project team is working with GPs, Community Health Partnerships, people with CHD and diabetes and their carers, to improve the detection of mental health problems and improve the support people receive.

3.35 If people are worried about their life circumstances, they will be less ready to change their behaviours. This is particularly relevant given the current recession, and could be tackled through initiatives such as direct NHS referral to welfare rights services, ideally in healthcare settings, assisting people with managing debt, improving their housing situation and reducing fuel poverty.

Action:

Once evaluated, the lessons from 'Living Better' pilots should be rolled out by NHS Boards and their cardiac and stroke MCNs.

3.36 A paper in *The Lancet* for 3 January 2009 (Vol 373, 82-93) reported that current data suggest that obstructive sleep apnoea (OSA) increases the risk of developing CVD and that its treatment has the potential to diminish such risk. Large-scale randomised trials are however needed to determine, definitively, whether treating OSA improves cardiovascular outcomes.

Inequalities in CVD Prevalence

3.37 As noted at [paragraph 2.1](#), over the past 10 years Scotland has seen a steady fall in the mortality rates of the cardiovascular diseases (CVD) of Coronary Heart Disease (CHD) and stroke. Behind these population trends, however, there remains a worrying gap in cardiovascular health between the more affluent and the more deprived people of Scotland. This is clearly illustrated by Figures 3 and 4, taken from the Chief Medical Officer's annual report for 2007.

Figure 3:

Coronary Heart Disease standardised mortality ratios by SIMD deprivation decile, 2002-06

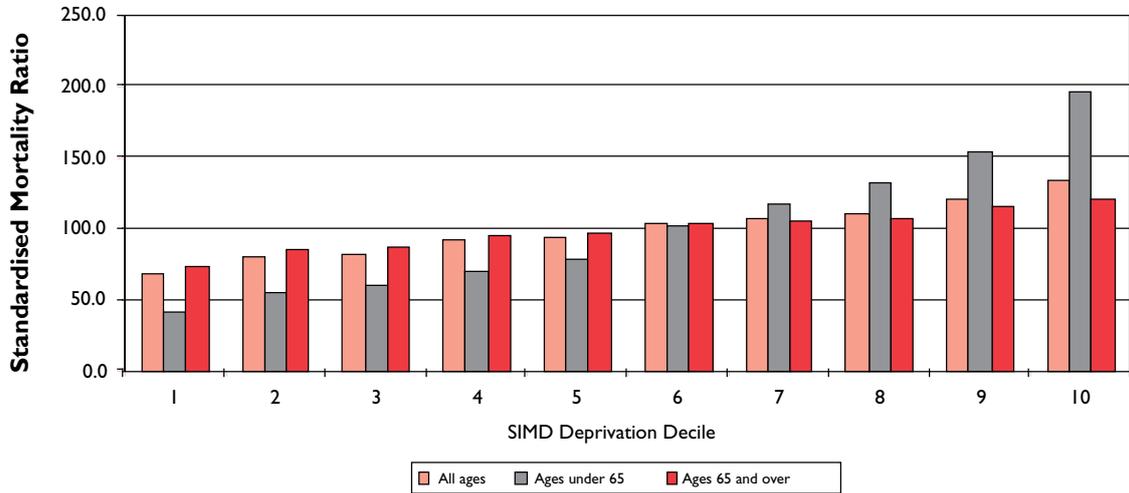
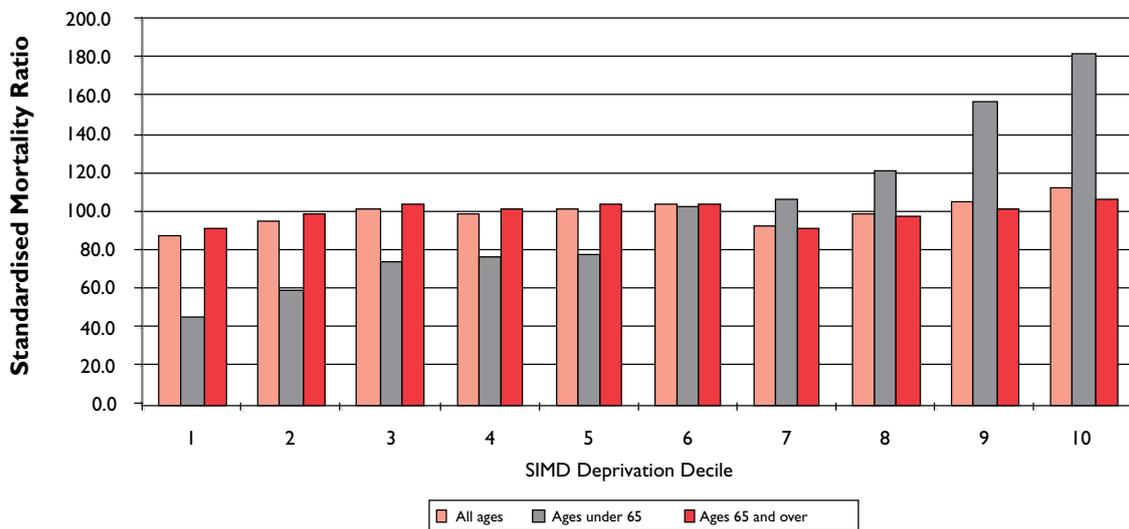


Figure 4:

Cerebrovascular disease standardised mortality ratios, by SIMD deprivation decile, 2002-06



3.38 According to recent published research ('Effect of financial incentives on inequalities in the delivery of primary care in England', *The Lancet* 2008; 372: 728-36), there has been a narrowing of differences in the QOF achievement for practices in areas of relatively high and low deprivation in the years following its introduction against a background of overall rising achievement. The QOF therefore has the potential to continue to contribute to the reduction of health inequalities.

3.39 The Public Health Service (PHS) component of the community pharmacy contract is being used to target resources to tackle inequalities. Community pharmacies, located where people live, are well placed to help provide patients and the public with personal care closer to home, including measuring weight, calculating BMI, measuring total and HDL cholesterol, blood pressure and blood glucose monitoring. Some NHS Boards have local initiatives to allow some community pharmacies to provide blood pressure monitoring. The introduction of the Chronic Medication Service may provide an opportunity for developing a national approach.

Action:

The Scottish Government should consider extending the community pharmacy contract to include blood pressure monitoring, phlebotomy and ECGs where appropriate.

'Hearty Lives'

The British Heart Foundation's 'Hearty Lives' is a programme of work across the UK in communities with high rates of heart disease. 'BHF Hearty Lives Dundee' will include extending the 'Keep Well' health checks to 40-44 years and to particular at-risk groups of staff, further exploiting the potential for opportunistic health checks and exploring new ways of delivering services to those who are reluctant to access them.

3.40 As noted at [paragraph 3.14](#), in the UK there is a high rate of CVD among South Asians (i.e. people who have ancestral origins in the Indian subcontinent). Compared with the rest of the population, mortality rates in Indian subcontinent-born populations are 50-60% higher than the standard population. The incidence of acute myocardial infarction in South Asians living in Scotland is 60-70% higher than in the standard population. Developing primary care programmes to identify and manage cardiovascular risk in high-risk populations such as these should be part of strategies to reduce CHD. People from specific ethnic groups such as Asian, black and Afro-Caribbean, are also at greater risk of experiencing a stroke.

3.41 Recording of ethnicity status of newly registering patients in the GP record has been part of the QOF since April 2006. In November 2008, a Directed Enhanced Service (DES) was introduced extending this to all registered patients, with the aim of 80% of patients having ethnicity status recorded by April 2011. This DES also included the recording of the need for an interpreter, including sign language.

3.42 A study on myocardial infarction in South Asians, reported in *Biomed Central Public Health* 2007, 7:142, concluded that it was worrying that South Asians in Scotland are at greater risk of heart attack than a Scottish population notorious for its susceptibility to heart disease. The clinical and epidemiological challenges for prevention, control and rehabilitation of CHD in South Asians are therefore formidable, although survival after AMI in South Asians seems to be comparatively good.

3.43 The *Kush Dil* (Happy Heart) project was set up in Edinburgh in 2002 to manage cardiovascular risk in South Asians. An assessment of its impact was published in the *Journal of Public Health* (Vol 29, No 4, pp 388-397) in August 2007. It developed and tested methods for a locally-based, culturally sensitive CHD prevention and control service for South Asians. The project led to a reduction in cardiovascular risk factors amongst participants, who also reported a shift in their motivational status, increasing the likelihood that diet and lifestyle changes are maintained. A further report on the project will be written up by Community Food and Health (Scotland) to share with others in the third sector learning on working with BME communities.

3.44 Future initiatives should adopt the key features of this programme: a targeted community approach that is grounded in a practical understanding of the high-risk group, and one that is culturally sensitive, flexible and accessible (run in a familiar environment) and which fosters good relationships with the at-risk community. For such services to be implemented nationally, on a larger scale, further evaluations are needed to provide rigorous data on effectiveness and cost-effectiveness.

'Community Heart'

The Tayside Cardiology unmet needs project, known as 'Community Heart', which ran from April 2006 to December 2008, aimed at improving access to specialist cardiology services which are normally hospital-based by offering cardiology clinics in deprived areas of Tayside. This was achieved by using a variety of venues including a mobile clinical unit, non-NHS anti-poverty centres and places of worship, such as the mosque. Some people were identified for specialist review from hospital database searches, but the majority were identified by self-presenting opportunistically for a heart health check. During this assessment, the specialist nurses considered symptoms which might be consistent with undiagnosed or sub-optimally managed CHD. The project illustrates the opportunities which can exist for cardiovascular assessment and specialist cardiology follow-up in community areas such as gala days, mosques, bingo halls and shopping centres.

Action:

Cardiac and stroke MCNs should jointly develop plans for adopting this type of flexible, culturally-sensitive approach in other areas of Scotland by March 2010.

Conclusion

3.45 Having considered these issues relating to prevention, in particular healthy lifestyles and health inequalities, we now look at the services needed by those with established heart disease, or who have had a stroke.

4: SERVICES FOR HEART DISEASE

4.1 People with heart disease and their families understandably want their healthcare needs to be met as locally as possible. *Better Health, Better Care* emphasises that resources should be directed to supporting local front-line services wherever possible and that these local services should be linked by technology to specialist centres to provide additional support and information where this is required.

4.2 People with heart disease also want to avoid admission to hospital wherever possible. Under HEAT Target T6 NHS Boards have set trajectories over the three years from 2008-09 for the reduction in hospital admissions of people with a primary diagnosis of a number of conditions, including CHD.

4.3 In broad terms, the description of services in the rest of this chapter begins with those delivered locally, then regionally and finally at national level. Where a service is provided at more than one level, the description of it is continuous.

Waiting Times

4.4 People want their investigations and treatment to be undertaken as rapidly as possible. Since December 2004, the Scottish Government's waiting time standards for CHD have meant that patients wait no longer than eight weeks between review by a heart specialist to diagnostic angiography, and no more than 18 weeks between angiography and cardiac revascularisation (either PCI or surgery) if required.

4.5 Since December 2007 there has been a maximum waiting time of 16 weeks from referral by GP to a rapid access chest pain clinic (RACPC), through to treatment. From 2011 there will be a maximum waiting time of 18 weeks from referral to treatment for all conditions, including cardiac. To begin the move towards achieving this new target, the maximum routine waiting time for cardiac outpatient clinics was set at 18 weeks in December 2007, reducing to 15 weeks or less at March 2009.

New Definition of Acute Myocardial Infarctions/Acute Coronary Syndromes

4.6 In recent years, a number of sensitive and specific diagnostic tests (biomarkers) have helped clinicians refine the way in which acute myocardial infarction (AMI) is diagnosed and treated. Increasingly, the term MI is now being replaced with Acute Coronary Syndrome (ACS). These tests of biomarker levels measure the amounts of troponin and creatinine kinase released into the blood when part of the heart muscle is damaged. A diagnosis of myocardial infarction has a range of potentially significant implications for patients and their families with respect to psychological effects, life insurance, careers and lifestyle. A more precise diagnosis, and recognition that even minor elevation in troponin is associated with poorer prognosis, means however that more appropriate initial and long term treatment can be offered.

Action:

Each cardiac MCN needs to ensure the following:

- Patient groups and charities are informed of the national consensus on the new definition of AMI/ACS, particularly in areas where this represents a significant change in the diagnosis rates of AMI/ACS;
- All clinical staff involved in caring for CHD patients understand the rationale for the change and promote it within their own hospital, participating in the education of colleagues outwith the specialist cardiology environment;
- Cardiac rehabilitation departments are aware of the change of definition and make sure service provision matches the likely increase in those diagnosed with non-ST elevation MI (NSTEMI);
- Hospital coding departments are informed of the change of definition;
- GPs are made aware that this may result in an apparent rise in the number of patients coded as having MI and that this could have an impact on their CHD registers; and
- Hospital biochemistry departments are asked to review their troponin assay to ensure a standardised approach across Scotland.

Action:

The National Advisory Committee on Heart Disease should monitor progress to ensure consistency of approach to ACS diagnosis and treatment across Scotland.

Recommended Terms and Coding for Myocardial Infarction and other Acute Coronary Syndromes

ICD10	READ code	ICD10 description	Discharge letter description
I200	G3111	Unstable angina	unstable angina (only use with negative troponin)
I210	G301z	Acute transmural MI of anterior wall	anterior STEMI
I211	G308	Acute transmural MI of inferior wall	inferior STEMI
I212	G304 posterior; G305 lateral,	Acute transmural myocardial infarction of other sites	posterior or lateral wall STEMI
I213	G30X	Acute transmural myocardial infarction of unspecified site	STEMI (site unspecified)
I214	G307	Acute subendocardial myocardial infarction	NSTEMI (any elevation of troponin with features of cardiac ischaemia without electrocardiogram ST elevation)
I240	G3110	Coronary thrombosis not resulting in myocardial infarction	Aborted MI
R074	R065z	Chest pain – unspecified.	Chest pain – unspecified

4.7 The Scottish Ambulance Service has looked into near patient testing in the recent past, and consulted senior clinicians. It was recognised that troponin testing equipment was currently designed to be used in fixed clinical settings, such as community hospitals, health centres and GP surgeries. The Scottish Ambulance Service will continue to monitor the evolution of near patient testing equipment to determine if there comes a point at which significant patient benefit may be achieved by adding this facility to front-line ambulances.

Optimal Reperfusion for ST Elevation Acute Coronary Syndrome (ACS)

4.8 SIGN Guideline 93 recommends that, where possible, patients with ST elevation ACS (also known as ST segment Elevation Myocardial Infarction or STEMI) should be treated immediately with primary percutaneous coronary intervention (primary PCI). This type of heart attack is caused by prolonged blockage of the blood supplied to the heart through the coronary arteries. Because STEMI affects large areas of the heart muscle, it causes changes on the ECG (electrocardiogram) as well as in levels of key chemical markers in the blood. Where patients are unlikely to receive primary PCI within 90 minutes of diagnosis, for example for reasons of geography, they should receive immediate thrombolytic therapy. The aim of optimal reperfusion therapy (ORT) for all patients requires close working between cardiologists, in partnership with the Scottish Ambulance Service and colleagues in Accident & Emergency medicine.

4.9 In summer 2006 NHS Lothian and the South East Division of the Scottish Ambulance Service received funding from the Chief Scientist Office for a feasibility study of a hybrid programme of pre-hospital thrombolysis and primary PCI in Lothian. The final report of the study was submitted in April 2008 and includes data analysis on the running of a 24/7 365-day-a-year primary PCI service.

4.10 The study demonstrated very positive results, including apparent reductions in mortality and length of hospital stay. Primary PCI is however only one of three components of the pragmatic approach needed to deliver optimal reperfusion to all eligible patients. The other elements are pre-hospital and in-hospital thrombolysis. All three elements must be delivered equally well to ensure equity of access to ORT. Regional Planning Groups are now considering the results of the Lothian pilot and the implications for roll-out of this service across the country.

4.11 Following approval by the West of Scotland Regional Planning Group, an enhanced reperfusion service was introduced across the West of Scotland in 2008. Patients with ST elevation ACS are brought by the Scottish Ambulance Service directly to either the Golden Jubilee National Hospital or Hairmyres Hospital for primary PCI if they are within the agreed travel time from one of the two intervention centres. Those outwith the agreed travel time receive thrombolysis (where appropriate) prior to being brought to the intervention centre for follow-up care.

4.12 The South-east and Tayside Regional Cardiac Planning Group is working to a phased implementation of an ORT service. The Primary PCI centre at the Royal Infirmary of Edinburgh is currently covering those patients within the agreed travel time in Lothian and Forth Valley. It is developing plans to roll the service out to Borders and Fife later in 2009, and is working with NHS Tayside to synchronise the development of services for residents of North Fife who are within the agreed travel time. The model reflects the approach adopted in the west of Scotland.

4.13 Comments from the North of Scotland Planning Group indicate that the major limitation to the optimal reperfusion service will relate to ambulance and cardiac catheterisation laboratory resources. The intention currently is to deliver Primary PCI at all three centres (Aberdeen Royal Infirmary, Raigmore Hospital, Inverness, and Ninewells Hospital, Dundee) within working hours. Outwith working hours, patients will be given thrombolysis and then taken to Aberdeen Royal Infirmary for angioplasty.

4.14 The recommendations in SIGN 93, addressing the whole patient journey in the emergency setting, have been incorporated into the draft NHS Quality Improvement Scotland (NHS QIS) clinical standards on the prevention and treatment of CHD developed by a multi-disciplinary project group involving representatives from all the cardiac Managed Clinical Networks (MCNs), including patient representatives. The draft standard is that patients with a suspected heart attack have an electrocardiogram (ECG) performed in the pre-hospital setting by a trained member of staff within 30 minutes of the call for help. This 30-minute window for diagnosis, which includes the ambulance response time and the time taken to perform and interpret an ECG, is then added to the previously quoted 90 minutes (diagnostic ECG to balloon time for Primary PCI) and 30 minutes (diagnostic ECG to needle time for thrombolysis) to give the following standards:

- the 'call to balloon' time is 120 minutes or less for patients with ST elevation ACS treated with primary PCI; and
- the 'call to needle' time is 60 minutes or less for patients with ST elevation ACS treated with thrombolysis.

4.15 For patients presenting directly to hospital, the following draft standards were developed by the NHS QIS project group:

- the 'diagnostic ECG to balloon' time is 90 minutes or less for patients presenting directly to hospital with ST elevation ACS treated with primary PCI;
- the 'diagnostic ECG to needle' time is 30 minutes or less for patients presenting directly to hospital with ST elevation ACS treated with thrombolysis; and
- patients with suspected ACS, with no ST elevation identified by ECG, are transported immediately to hospital for further assessment where trained staff are available to manage acute chest pain.

4.16 The final CHD standards document may be aligned further with international standards over the course of the next year.

4.17 Responses to the consultation on the revision of this Action Plan suggested that pre-hospital thrombolysis is under-used in some rural areas, and that front-line staff need more training on current treatments and the management of ACS patients. There is a role here for the Scottish Ambulance Service (SAS), which is responsible for the administration of thrombolytic therapy in the pre-hospital setting.

Action:

The SAS should review current arrangements for delivery of pre-hospital thrombolysis across Scotland, particularly in rural areas, including assessment of staff training needs, and submit a report to the National Advisory Committee on Heart Disease by March 2010.

4.18 Any ORT plan needs to have a robust decision support team in place which is clearly identifiable to paramedics, NHS 24 and others. Whether this should be at each centre offering primary PCI or whether it should be organised at regional or national level is an issue which needs to be debated with all the key agencies, including the Scottish Centre for Telehealth.

4.19 An inter-regional cardiac planning group met regularly until the beginning of 2008. This forum facilitated discussion and planning across the three regions. As we identify new diagnostic tools and interventions and receive new evidence which has the potential to impact on current services, this regular forum is essential, to give a pan-Scotland perspective.

Action:

The cardiac group which brought together representatives of the three Regional Planning Groups to provide a pan-Scotland perspective should be re-convened as a sub-group of the National Advisory Committee on Heart Disease, to promote consistency of approach across Scotland, for example in relation to ORT, through inter-regional discussion and planning.

Defibrillators in public places

4.20 Delays in performing defibrillation can be reduced appreciably if those in the vicinity of a sudden cardiac arrest outside hospital can use an automated external defibrillator (AED) before the arrival of the emergency medical services. The most recent evidence on public access defibrillation is set out in *A national scheme for public access defibrillation in England and Wales: Early results, Resuscitation* (2008), doi: 10.1016/j.resuscitation.2008.03.226.

4.21 AEDs operated by lay persons are used in England and Wales in a National Defibrillator Programme promoting public access defibrillation (PAD). Two strategies are involved: static AEDs installed permanently in busy public places operated by those working nearby; and mobile AEDs operated by community first responders who travel to the casualty. The conclusions in the article are based on 1,530 resuscitation attempts since the programme began. The key benefit of these strategies is an improved chance of survival for people suffering a cardiac arrest.

4.22 According to the report, the on-site (static) strategy has now proved to be very effective at places where there is an appreciable risk of cardiac arrest occurring, such as larger railway stations and airports. The level of such risk that would make implementation mandatory remains to be defined, nor is it clear exactly what level of 'footfall' should be used to determine the locations for static AEDs. For the on-site strategy to be effective, there must be a considerable number of AEDs in the vulnerable area. Current international guidelines support the establishment of AED programmes when:

- the frequency of cardiac arrest means there is a reasonable probability of an AED being used at least one in two years;
- the time from call-out of the conventional ambulance service to delivery of a shock cannot reliably be achieved within five minutes; and
- the time from collapse until the on-site AED can be deployed is less than five minutes.

4.23 The results for mobile AEDs were appreciably less good, and were particularly poor in the patients who arrested at home, the commonest place for cardiac arrests to occur. The report suggests, however, that the results achieved by community first responders should be regarded as a promising start to a strategy at an early stage of development.

4.24 The relative cost-effectiveness of the two approaches has not been defined. There has been no formal cost-effectiveness study in the UK, but a rough cost analysis suggests a figure of roughly £20,000 per life saved.

Action:

NHS Boards should seek advice from their cardiac MCNs in considering the introduction of both approaches to PAD, in particular whether there are suitable locations in their area in which the static approach might be beneficial. If recommended by the MCNs, NHS Boards should introduce these by the end of March 2010.

Cardiac Rehabilitation

4.25 Comprehensive cardiac rehabilitation (CR) consists of exercise training together with education and psychological support. The aim of these interventions is to help patients return to normal living and encourage them to make lifestyle changes to prevent further cardiac events. There is a wealth of evidence, including from 'Have a Heart Paisley', demonstrating the clinical and cost effectiveness of cardiac rehabilitation. It is an inexpensive treatment that saves lives.

4.26 Until recently, only those who had had a myocardial infarction or cardiac intervention (PCI or bypass graft) had access to cardiac rehabilitation services. It is now clear that people who undergo other 'step changes' in their conditions, for example unstable angina, new onset angina or the development of chronic heart failure, will also benefit from cardiac rehabilitation. The recent redefinition of myocardial infarction (see paragraph 4.6) will result in a significant increase in the number of those who will be formally eligible for cardiac rehabilitation in the future. The proposed widening of eligibility for CR is also detailed in the draft NHS QIS clinical standards for CHD.

4.27 The Scottish Campaign for Cardiac Rehabilitation, mounted by the British Heart Foundation (BHF) Scotland and Chest, Heart & Stroke Scotland, highlights figures from ISD suggesting that up to 60% of people who have had a heart attack or cardiac intervention receive cardiac rehabilitation. The campaign suggests that this could be increased to an 80% participation rate if services were tailored to suit each individual's needs and drew in under-represented groups such as those from ethnic minorities, and those in remote and rural and/or deprived communities. ISD figures also demonstrate that only 3% of people with angina and less than one per cent of those with heart failure received cardiac rehabilitation in Scotland in 2007.

4.28 The CR campaign has the following objectives:

- every heart patient who is suitable and wishes to take part is given access to a rehabilitation programme;
- patients are offered alternative models, such as home-based rehabilitation, if they prefer not to take part in community programme or attend hospital;
- programmes should meet the needs of carers and under-represented groups such as those in deprived or remote/rural communities;
- each programme should meet the minimum standards set out by British Association of Cardiac Rehabilitation and the SIGN Guideline on Cardiac Rehabilitation; and
- provision must be monitored through a national audit of cardiac rehabilitation.

4.29 It is clear that NHSScotland will need to increase capacity significantly, particularly in terms of staffing, for cardiac rehabilitation to be available to all eligible patients who wish to participate and benefit from resulting decrease in morbidity and premature mortality. The challenge for NHS Boards will be to fund CR, in line with the NHS QIS draft CHD clinical standards, into the future on a sustainable basis. The specific rehabilitation needs of those with heart failure also need to be borne in mind.

4.30 In addition, CR services will need to ensure that the introduction of optimal reperfusion services, with people experiencing shorter hospital stays and many receiving treatment outwith their home NHS Board, does not lead to a reduction in referrals to CR. The West of Scotland model seeks to address this by providing follow-up care after primary PCI within District General Hospitals (DGHs), to allow people to access CR and other local services.

4.31 The SEAT Cardiac Rehabilitation Group, a sub group of the Regional Cardiac Planning Group, is working to ensure that referral processes between the tertiary centre and district general hospitals will allow all eligible patients to receive CR and other appropriate services locally. The model adopted reflects that outlined in the West of Scotland.

Action:

NHS Boards should, through their cardiac MCNs, undertake a needs assessment of their cardiac rehabilitation process for all eligible patients, identify priorities and allocate appropriate resources, by end March 2010.

4.32 ISD has undertaken considerable work on cardiac rehabilitation data. This work is now an integral part of the overall NHS QIS CHD Improvement Management Programme (see paragraph 6.14), where arrangements for ongoing national audit are being put in place.

4.33 The 'Heart Manual' developed by NHS Lothian is a home-based self management programme used in many parts of Scotland and is a unique example of a psychologically-informed cardiac rehabilitation programme which promotes confidence in heart patients. Evaluation has shown that those using it require less contact with their GP, with fewer re-admissions to hospital in the first 6 months.

Action:

NHS Boards, through their cardiac MCNs, should implement the 'Heart Manual' or equivalent to ensure that people receive structured information, education and develop the skills needed to help them manage their own condition. This is in line with the Scottish Government's general thinking on the self management of long term conditions.

'Braveheart' Project

The 'Braveheart' project in Falkirk uses older people who have taken part in cardiac rehabilitation to mentor others who are just starting on the rehabilitation programme post MI. The project has proved extremely successful and produced wider than expected benefits for participants, mentors and health professionals.

Action:

NHS Boards, through their cardiac MCNs, drawing on the Network's patient representatives, should adopt the 'Braveheart' approach by end December 2009.

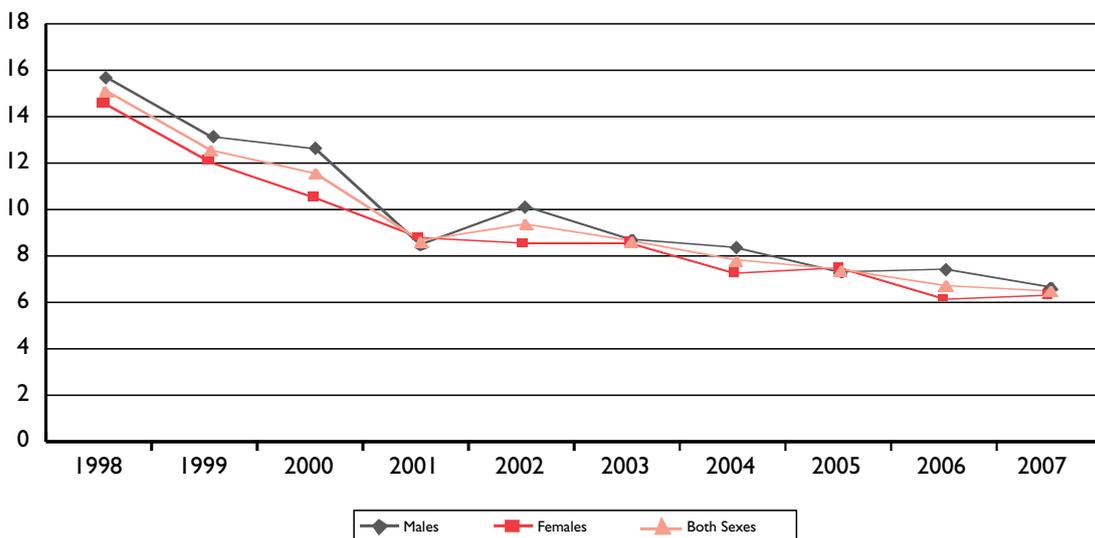
Heart Failure Services

4.34 Improved survival rates from acute myocardial infarction and the demographics of an ageing population mean that heart failure is becoming an increasingly prevalent condition, often associated with the presence of other diseases.

4.35 ISD data show that the standardised mortality rate for cardiac failure has fallen from 14.8 per 100,000 population in 1998 to 5.3 in 2007 (Graph 3). Non-elective admissions have also dropped very significantly over this period. However, elective admissions for cardiac failure show little in the way of decline, confirming this as a high prevalence condition in the Scottish population. It is thought that there may be as many as 100,000 people in Scotland living with heart failure at present, resulting in very significant increases in the numbers (and costs) of prescriptions for heart failure drugs over recent years. Costs in this area rose from ~ £27m in 2000-01 to ~ £44m in 2006-07.

Graph 3: Standardised Mortality for Heart Failure

Age-Sex Standardised Mortality Rate per 100,000 Population



4.36 The BHF Scotland Heart Failure Nurse Educator project, established in NHS Lothian in 2008, aims to help educate primary care teams about the needs of those with heart failure. A local physician with a special interest in heart failure should be identified in each secondary care setting to lead a heart failure team which will have a role in: direct management of people with heart failure; provision of specialist advice to other clinical colleagues; and links to regional and national heart failure services.

4.37 While the current post in NHS Lothian is fully funded by BHF, this level of support would not be possible across the country. The Foundation can however offer other support for the development of this role, such as expertise, networking, development of further education and, potentially, direct financial support for staff development through its 'adoption' programme for health professionals. The key is ensuring that the heart failure staff increase the knowledge of other health professionals working in primary care, to enable them to manage the more stable patients, freeing up the specialist heart failure nurses to see those with more complex needs.

Action:

NHS Boards, through their cardiac MCNs and CHPs, should adopt the approach taken in this project by March 2011.

4.38 Managed Discharge (from hospital to primary care) is crucial in the management of those with heart failure, and should aim to provide:

- hospital discharge instructions that address all of the following: activity level, diet, discharge medications, follow-up appointment, weight monitoring, and what to do if symptoms worsen (these items are being considered by the Scottish Patient Safety Programme as a key performance measure for discharge of patients with CHD);
- community support, for example through community-based heart failure nurses;
- outpatient multidisciplinary follow up, including pharmacy input;
- regular review of drug treatment to optimise pharmacological interventions and re-reinforcement of patient education on weight monitoring; and
- provision of information, including self management programmes, in language which can be readily understood.

4.39 Out-of-hours (OOH) support is vital for people with heart failure. It is important that information is available to clinicians during the OOH period to optimise heart failure patients' care. Currently the Emergency Care Summary (ECS), which includes information on current medication and allergies, is available for the vast majority of patients to OOH services, NHS 24 and A&E. For patients with heart failure with particular needs (which could include complex care arrangements, or where a patient has to be referred directly for specialist care), GPs can use the 'special notes' system to provide further information to these services. This is sent by the practice to the Board OOH Hub and, after electronic entry, is available to OOH services in NHS 24 and Boards should the patient make contact. Improvement and standardisation of this process are currently under way to ensure that heart failure patients, as well as others, can benefit maximally from this availability of information.

4.40 A short-life working group involving NHS 24 and the chronic heart failure nurses from Glasgow is considering ways of delivering a better service for people with heart failure, particularly in relation to the management of their medication and to encourage the use of its 'special notes' facility. Concerns exist about the capacity of the existing service to cope with additional demands, since current caseloads of specialist heart failure nurses are already very high.

Action:

The recommendations of the short life working group should be considered by NHS Boards through their cardiac MCNs as soon as available.

4.41 A review of specialist heart failure services in Scotland, published in the autumn of 2008 by Chest, Heart & Stroke Scotland and the British Heart Foundation on behalf of the Scottish Heart Failure Nurse Forum, highlighted areas in need of resources and investment to meet the rising number of those requiring specialist support.

4.42 A recent BHF research project indicated that those who received care from a heart failure specialist nurse valued the service very highly. Having one person with whom they could build up a relationship of trust and understanding noticeably improved their recovery rate and increased their own confidence in being able to cope with their heart condition. The fact that heart failure nurse specialists are often supplementary prescribers, working with medical and pharmacy colleagues to locally agreed medical therapy guidelines, contributes to the observed reductions in hospital admissions in these nurse-led services.

4.43 In remote and rural locations, where specialist heart failure nurses may be in short supply, the potential for a 'generic' cardiovascular nurse to undertake both heart failure and cardiac rehabilitation roles should be considered. Any nurse-led heart failure service, wherever it is based, needs to link to the exercise programme component of the local cardiac rehabilitation service. Heart failure nurses could also provide psychological support as part of routine management, with support and supervision by specialist psychologists. Consideration should be given to extending the working hours of heart failure nurses, so that they are able to provide a service out-of-hours, especially at weekends.

4.44 The current minimum service level requirement is 1WTE Specialist Heart Failure Nurse per 100,000 population. The ratio should be considered with caution when assessing the demands of remote and rural areas. The service at present manages only those who have heart failure secondary to left ventricular dysfunction, but this is only one cause of heart failure and the evidence suggests that many more people living in Scotland have heart failure due to other causes.

Action:

In preparation for the publication of the new CHD clinical standards, NHS Boards, through their cardiac MCNs, should undertake a needs assessment of cardiovascular nurse specialists delivering care to heart failure patients, including the potential for delivering out-of-hours cover through the education of primary care nurses, by the end of December 2009.

4.45 Social isolation is one of the most marked features of advanced heart failure. Chest, Heart & Stroke Scotland offers a heart failure support service in NHS Lothian, Lanarkshire, Greater Glasgow & Clyde and Highland. This has been awarded Approved Providers Standards and incorporates:

- a volunteer befriending service;
- forum meetings for patients, carers and health professionals; and
- a regular newsletter.

Action:

NHS Boards, through their cardiac MCNs, should work with Chest, Heart & Stroke Scotland to replicate these initiatives across Scotland.

4.46 In response to new evidence on the optimal management of patients with heart failure due to left ventricular dysfunction, from April 2009 a new indicator has been added to the QOF to encourage the prescription of Beta blockers in addition to ACE inhibitors or angiotensin receptor blockers in appropriate patients.

4.47 Palliative care is crucially important. In March 2008, the Scottish Partnership for Palliative Care (SPPC) and the BHF Scotland published *Living and dying with advanced heart failure: a palliative care approach*. The report responded to a recommendation in the CHD and Stroke Strategy in 2001 that provision should be made to meet the palliative care needs of people with end-stage heart failure. A succession of reports from the Scottish Audit of Surgical Mortality has highlighted the plight of those with end-stage heart failure dying in acute hospitals with a worse prognosis and poorer quality of life than many people with cancer; but with limited access to the benefits that a palliative care approach could bring both them and their families.

4.48 SIGN Guideline 95 on the management of chronic heart failure has a section on palliative care that includes a clear recommendation that a palliative care approach should be adopted by all clinicians managing people with chronic heart failure from the early stages of the disease. The recommendations in the Guideline have been incorporated into the draft NHS QIS clinical standards on the prevention and treatment of CHD. The relevant draft standard states that patients who remain symptomatic despite optimal treatment/maximum tolerated therapy are identified and offered a supportive and palliative care approach. It is essential that people with advanced heart failure are included on the palliative care register in each general practice, their care needs assessed and care planned to meet those needs.

4.49 An important recommendation in the SPPC/BHF report is that implementation of a combination of active and palliative care will be best achieved by a model of shared care and enhanced communication involving multi-professional teams across cardiology, primary care, specialist palliative care, general medicine, medicine for the elderly and social care. Care should be co-ordinated by a named individual such as a heart failure specialist nurse or other suitably trained health professional. This will help ensure that people with advanced heart failure are re-assessed regularly to confirm that palliation is the appropriate choice amongst an increasing number of management strategies.

4.50 The report highlights the role of both the cardiac and the palliative care Managed Clinical Networks in taking forward implementation of its recommendations locally, with support, as needed, from the National Centre for the Treatment of Advanced Heart Failure.

4.51 All NHS Boards have now submitted delivery plans against the Actions in *Living and Dying Well* which aim to provide services for those patients with palliative and end of life care needs, irrespective of diagnosis, and which incorporate the recommendations from the SPPC report *Living and dying with advanced heart failure: a palliative care approach*.

4.52 In November 2008, a Palliative Care Directed Enhanced Service (DES) was introduced in Scotland. This emphasised the importance of including all patients with palliative care needs (not just those with cancer) on the GP palliative care register. The DES also requires practices to compile a care plan for such patients and to ensure that a summary of this is made available to OOH services. This will initially be through the 'special notes' system (see paragraph 4.39) but an electronic Palliative Care Summary (ePCS) is currently being piloted, with anticipated roll out across Scotland later in 2009.

Action:

NHS Boards' cardiac and palliative care MCNs should jointly undertake an audit of practices' implementation of the palliative care DES, and collaborate to ensure implementation of Boards' *Living and Dying Well* Delivery Plans by end December 2009.

4.53 The creation by the British Heart Foundation and Marie Curie Cancer Care of a centre of excellence in Glasgow, and their investment in research and development for those with advanced heart failure, represents a major contribution in this area. A Marie Curie Cancer Care and British Heart Foundation collaborative project, working together with NHS Greater Glasgow & Clyde, aims to develop equity of access to palliative care services for cancer and cardiac patients.

Cardiac Interventions

4.54 Historically, cardiologists have been appointed to District General Hospitals (DGH), but with a regional responsibility to deliver specialist aspects of service on a sessional basis. In particular, cardiologists have been appointed to DGHs with sessions in coronary intervention, and more recently device therapy. There is definite scope to develop this model further to include the full range of regional services.

4.55 Coronary artery bypass grafting will continue to be delivered from the existing three centres in Scotland, with referrals from interventional cardiology hubs.

4.56 The establishment within DGHs of cardiac catheterisation facilities which are unable to deliver either elective or emergency coronary interventions is not the preferred model for Scotland, and existing DGH catheter laboratories must be involved in a wider interventional network at regional level to ensure high standards of care and optimal use of resources, particularly with the advent of primary PCI (see paragraph 4.8 onwards).

4.57 An assessment is needed of the current and future levels of elective interventional services in Scotland. Issues that might be addressed include: predicted patient numbers; the various types of procedure; the staff resources required and any associated workforce issues affecting cardiac service; how services will be configured; and how equity of access to regional and national services can be assured. The report *Access to Cardiac Care in the UK*, published in June 2009 on behalf of the Cardio & Vascular Coalition, sets out thinking on projected future need for cardiac interventions.

4.58 The newly-established Scottish Imaging Managed Clinical Network will be keeping a watching brief on developments relating to the future of non-invasive coronary imaging, as part of its horizon-scanning role and will make recommendations for their planned introduction as appropriate.

West of Scotland Heart and Lung Centre

4.59 The West of Scotland Heart and Lung Centre at the Golden Jubilee National Hospital (GJNH) became operational in 2007 and made a significant contribution to meeting the waiting time guarantee in cardiac activity by 31 December 2007. The migration of clinical services from Glasgow and Lanarkshire means that the Centre is now one of the largest in the UK, serving the residents of all six West of Scotland NHS Boards. The new Centre provides the following services:

- all adult cardiothoracic surgery and outpatient activity previously carried out at Glasgow Royal and Western Infirmaries;
- all adult thoracic surgery previously carried out at Hairmyres Hospital; and
- all interventional cardiology services previously carried out in Glasgow, including angiography/angioplasty, electrophysiology and complex pacemaker implantation

as well as providing a home to three of Scotland's national services:

- the National Centre for the Treatment of Advanced Heart Failure;
- the Scottish Pulmonary Vascular Unit (SPVU); and
- the Scottish Adult Congenital Cardiac Service (SACCS), previously known as the Grown-Up Congenital Heart Unit.

4.60 Patients will continue to be treated in their local hospital in the first instance. Those who need to have a planned surgical or interventional cardiology procedure are referred for treatment at the Centre, with the exception of interventional cardiology in Lanarkshire which continues to be provided at Hairmyres Hospital.

4.61 The issue of Percutaneous Aortic Valve Replacement/Transcatheter Aortic Valve Implantation (TAVI) has been the subject of a National Institute for health and Clinical Excellence (NICE) interventional procedure guidance (IPG266) which noted that:

'evidence on TAVI for aortic stenosis is limited to small numbers of patients who were considered to be at high risk for conventional cardiac surgery. It shows good short-term efficacy but there is little evidence on long term outcomes.'

4.62 This issue will need to be considered at regional level once there is clear evidence that the techniques proposed are safe and effective. Scoping work on TAVI being undertaken by NHS QIS will also help to inform future consideration. This will be an issue for the Scottish Health Technologies Group to consider in due course, as part of the development of better, more streamlined approaches to evaluating new devices and technologies in Scotland. Predicted numbers of procedures are low and suggest that the technique may be more appropriately commissioned as a national service.

4.63 Better mechanisms are needed to recognise and take account of the local, regional and national impact of the introduction of highly specialised new technologies, particularly given their potential funding implications, which inevitably fall on territorial Boards. There is also a clear need to link the aspirations of any given specialty at national level to regional developments and Boards' local planning and prioritisation processes. This can best be achieved through proper integration of MCNs with local and regional planning structures.

Action:

NHS Boards should continue to ensure that their MCNs are fully integrated with local and regional planning and prioritisation processes.

4.64 The process of planning services at regional level, and their links to local and national services, will be helped by the arrangements which each of the RPGs now has in place for cardiac services. It is essential, however, that the arrangements developed by each RPG should be consistent with the arrangements in other parts of the country, to ensure an equitable approach across the whole of Scotland. This process will be overseen by the inter-regional planning group referred to at [paragraph 4.19](#).

National Centre for the Treatment of Advanced Heart Failure

4.65 Data show that many young survivors of acute myocardial infarction and other life threatening cardiac events, such as viral myocarditis, never access the kind of circulatory support that would enable them to survive the acute injury long enough either to stabilise and recover, or to undergo urgent cardiac transplantation.

4.66 In recognition of this, and of the increasing number of people with chronic heart failure, the 2004 CHD and Stroke Strategy Update highlighted the establishment of a national centre for the treatment of advanced heart failure, with the associated additional resource of £450k allocated from Strategy funding. The National Centre is a nationally designated service which includes the original Scottish Heart Transplant Service. Donor rates and the development of new medical technologies such as cardiac resynchronisation therapy (CRT) for the management of chronic heart failure, mean that heart transplantation is increasingly seen as one of a range of treatment options.

4.67 The National Centre aims to improve management of the condition by:

- updating and educating professional and management colleagues throughout NHSScotland about the new service;
- acting as a tertiary source of advice to clinical colleagues at regional and local level;
- addressing the unmet needs of heart failure patients;
- establishing appropriate 'rescue' services for acute severe heart failure; and
- promoting the role of non-transplant cardiac surgery in heart failure patients.

The Centre also has a role in national and international research.

4.68 For the National Centre to fulfil its potential in these areas, it needs to work synergistically with the Scottish Adult Congenital Cardiac Service and Scottish Pulmonary Vascular Unit, both of which are also nationally designated and funded and co-located at the Golden Jubilee National Hospital.

4.69 The National Centre currently has no psychology provision, a situation that needs to be rectified. In particular, the National Centre must be able to offer psychological profiling prior to transplantation, and evidence-based psychological assessment and treatment of those who have had a heart transplant. The material on Cardiac Health contained in the 'Guide to delivering evidence-based Psychological Therapies in Scotland', published by the Scottish Government in December 2008, should be of assistance.

Action:

National Services Division of NHS National Services Scotland, as commissioners of the national service, should address the issue of psychological support as a matter of urgency, with any additional resources required obtained through top-slicing of NHS Boards' budgets.

Paediatric Cardiac Services

4.70 The national Paediatric Cardiac Services consist of 3 elements of care:

- paediatric cardiac surgery;
- paediatric interventional cardiology; and
- neonatal cardiology.

4.71 The worldwide incidence of congenital heart disease is approximately 8 per 1000 live births. Incidence rates in Scotland have varied between 8.29 - 11.02 per 1000 live births (ISD 1995-2004), which equates to around 450-600 children per year; being born with this condition. The survival of children born with congenital heart disease has improved dramatically over the past 30 years, through improvements in diagnosis, medical and surgical management as well as anaesthetic care.

4.72 It is estimated by the Scottish Adult Congenital Cardiac Service (see paragraphs 4.77-4.78) that 78% of children will survive into adulthood and that approximately 135 patients each year make the transition from the paediatric services. This means that by 2010, there will be an estimated 15,600 adult patients in Scotland living with adult congenital cardiac disease.

4.73 All surgical procedures are carried out at the Royal Hospital for Sick Children in Glasgow (Yorkhill Hospital). The Service will move to the site of the Southern General Hospital, when the new children's hospital is complete, providing an integrated paediatric and neonatal service. A number of outreach clinics are carried out by the cardiologists across Scotland, covering all Board areas with the exception of NHS Orkney and NHS Western Isles.

4.74 Outwith the services provided at Yorkhill Hospital, there are a small number of children born with hypoplastic left heart syndrome who receive surgery at Birmingham Children's Hospital. This is a very complex condition with an associated risk of high mortality. Plans are currently under way to re-introduce hypoplastic left heart syndrome surgery to Yorkhill Hospital, providing complete service provision for children in Scotland by 2010.

4.75 NHSScotland is currently participating in a Department of Health review of paediatric cardiac surgery.

4.76 There are very close working links between Paediatric Cardiac Services and the Scottish Adult Congenital Cardiac Service (SACCS), with joint teenage clinics to help the transition between the paediatric and adult services. The paediatric surgeons also carry out the adult congenital surgery. In addition, the SACCS clinicians provide outreach clinics to pregnant women with congenital cardiac disease at the Queen Mother's Hospital in Glasgow. There are plans to expand the existing outreach clinics in Edinburgh and Inverness to cover more areas of Scotland, and improve the links with other local clinicians.

Scottish Adult Congenital Cardiac Service

4.77 SACCS has been developed in response to the needs of those with congenital heart disease who are now surviving into adulthood. The service has recently introduced cardiac MRI scanning as the most up-to-date diagnostic tool available, and is in the process of developing its outreach arrangements, aiming to provide appropriate local support for those living with congenital heart disease, with ready access to the specialist centre.

4.78 It is essential that the service should reflect the indicators of high quality care included in the commissioning guide published by the Department of Health in May 2006. NSD, as commissioners of the Scottish service, is working with the service providers to meet these indicators. Further work also needs to be done on raising awareness of the service among both patients and local clinicians (whether in primary care or secondary care), including the need for the development of clear referral pathways. In addition, robust data on the number of people with congenital heart disease need to be compiled across Scotland.

Action:

NSD and the Golden Jubilee National Hospital should work towards achievement of the DH commissioning standards for adult congenital heart disease and address the other issues of awareness raising, development of referral pathways and data collection identified above.

Inherited Cardiac Conditions

4.79 Inherited cardiac conditions often carry a large psychological burden and have a significant impact on quality of life. The main concern expressed by patient support groups is the lack of organised care, support and investigation. In response to this, a combined cardiac genetic service has been established and funded in the west of Scotland. The key to the service is the multi-disciplinary team, with cardiological and clinical genetic medical expertise, imaging and access to appropriate genetic testing.

4.80 There are three main categories of inherited cardiac disease:

- arrhythmias;
- cardiomyopathies; and
- multi-system genetic diseases with a significant cardiac involvement such as the muscular dystrophies and connective tissue disorders.

All have the potential to cause sudden cardiac death, though this is more frequently associated with the cardiomyopathies and arrhythmias.

Familial Arrhythmia Network Scotland

4.81 Inherited cardiac diseases are a common cause of sudden unexplained death (SUD) in young people. A recent published study found an inherited cause for 40% of SUD below the age of 40. In 2008, the national Managed Clinical Network, the 'Familial Arrhythmia Network Scotland' (FANS), was established to coordinate the management in Scotland of families with a proven or suspected familial arrhythmia. The MCN comprises cardiologists, clinical geneticists and pathologists who are involved in assessing such patients and their families. Patients or families can be referred to the regional network clinic for assessment, specialist cardiological investigation and genetic testing and for co-ordination of cascade family screening and counselling. Affected patients and affected relatives identified and treated through cascade screening will in due course be entered into a national registry and will, if appropriate, be referred back to their local cardiology, medical or paediatric services for follow up, with further support or advice available from the MCN. A recommendation for referral of patients at risk of, or diagnosed with, hereditary arrhythmias to a cardiology specialist who is part of FANS, is included in NHS QIS draft clinical standards for CHD.

4.82 The MCN aims to raise awareness of familial arrhythmias, define and agree referral protocols, develop national guidance for clinical and genetic testing and establish a national register in conjunction with ISD. The register will support long term follow-up, including testing for the late onset of a condition, administration of new therapies and scope for identifying new genes and genetic tests as they become available.

Action:

ISD should work with FANS towards developing a national register of familial arrhythmias.

4.83 As with all MCNs, it is essential that those living with the condition concerned, or voluntary organisations that speak on their behalf, should be fully integrated into their work. In the case of FANS, that input is provided by Scottish HART (Heart at Risk Testing), the Cardiomyopathy Association in Scotland and GIG (the Genetic Interest Group).

4.84 The funding of the genetic counsellors required by the Network comes from the resources which have been made available for strengthening NHS genetics services through implementation of the Review of Genetics in Scotland (2006). The additional genetic tests required are similarly funded through strengthening the Scottish Molecular Genetics Consortium. FANS needs to have strong links with local cardiac Managed Clinical Networks, with relevant regional services and the SACCS.

4.85 The service's tertiary activities (clinical and genetic diagnostic testing, risk stratification and initiation of arrhythmia management) are centred in cardiac genetic services and specialist arrhythmia services run in Aberdeen, Dundee, Edinburgh and Glasgow, with subsequent follow up remaining with local cardiology services. A familial arrhythmia NHS internet-based clinical record system is being developed, and this will allow selected participants secure access to record key clinical information for families throughout Scotland, and access diagnostic information about families to assist in individual case assessment and management. The materials currently being developed by the Network include referral pathways for familial arrhythmia, familial cardiomyopathy, and in particular sudden unexplained death and sudden cardiac death, through collaboration with the forensic pathology network and the Crown Office and Procurator Fiscal Service.

Cardiac Assessment of Young Athletes (CAYA) Pilot

4.86 The UK National Screening Committee (NSC) has on a number of occasions considered the evidence base for the introduction of a population screening programme for conditions such as hypertrophic cardiomyopathy or other causes of sudden cardiac death. The Committee's advice, which the Scottish Government has accepted, is that such a programme is not justified, in part because of the lack of an agreed definition of hypertrophic cardiomyopathy and the lack of a diagnostic test that could accurately predict the outcome for an individual. There are also concerns about wrongly labelling someone as being at risk of sudden death, since this might unnecessarily restrict the activities of many children who would never develop clinical problems, and cause difficulties in adult life, for example in relation to insurance, mortgages and employment. The Committee has however advised that close relatives of those diagnosed with a condition such as hypertrophic cardiomyopathy should be offered tests and advice, and the Scottish Government fully accepts that advice.

4.87 The Committee has now asked for further research to be undertaken on the specific issue of pre-participation screening of young athletes for hypertrophic cardiomyopathy or other causes of sudden cardiac death.

4.88 The Cardiac Assessment in Young Athletes programme at the Sports Medicine Centre at the National Stadium, Hampden Park, was launched in August 2008 by the Cabinet Secretary for Health and Wellbeing as a joint project involving the Scottish Government, the Scottish Football Association and the University of Glasgow. It is a two-year pilot which will offer cardiovascular assessment on a voluntary basis to young Scots over the age of 16 who take part in any organised amateur sports.

4.89 The programme at Hampden is based on an internationally-recognised questionnaire, the use of ECG and, in addition, ultrasonography. Ultrasound, which has not been used before in such a programme, is intended to improve the overall accuracy of the assessment. Although cardiomyopathy is one of the assessment targets, other abnormalities of the electrical tissue, structural problems of the heart and circulation will also be sought.

4.90 It is likely that the programme will produce a very small number of positive cases, perhaps two in total during its two years' duration. If a problem is found, the athlete will be directed to the appropriate clinical service for full assessment and care.

4.91 There needs to be a greater focus on meeting the needs of relatives following sudden cardiac death. The British Heart Foundation has recently launched a UK-wide Genetic Information Service to help relatives deal with the consequences of losing a loved one to an inherited heart condition. The new Helpline service will support the need for bereaved families to have an assessment in a specialist clinic. This could save potentially hundreds of lives by detecting and treating an inherited heart condition in other family members. The Helpline's information about specialist clinics in Scotland has been updated with the help of cardiologists and clinical geneticists.

Neuromuscular disorders

4.92 Cardiac involvement occurs in a variety of inherited neuromuscular disorders, for example clinically-apparent cardiomyopathy, is observed in about one-third of those with Duchenne and Becker muscular dystrophy. In the long term, many develop cardiac abnormalities and many require permanent pacemakers or implanted defibrillators.

4.93 FANS (*see paragraph 4.81*) is developing links with the Scottish Muscle Network, which covers cardiac problems related to inherited neuro-muscular conditions such as myotonic dystrophy or Duchenne Muscular Dystrophy. FANS is only a partial solution to problems associated with sudden cardiac death, in that it addresses deaths related to inherited arrhythmias but not those related to abnormalities such as hypertrophic cardiomyopathy. The reasons for this focussed remit are that, unlike the cardiomyopathies and the multi-system genetic conditions, the inherited familial arrhythmias can be diagnostically challenging, and specialist input, usually from cardiologists with an arrhythmia background, is required for diagnosis, risk stratification and treatment. Currently, arrhythmia specialists are committed to a role in FANS, but a number would be unable to commit to a wider remit covering all inherited cardiac conditions.

4.94 FANS, once fully established, should expand to cover cardiomyopathies, with the recruitment of cardiologists with a sub-specialty interest in these conditions. Inherited cardiac connective tissue disorders (Marfan's syndrome and related conditions) already have pathways in Scotland, based on the Scottish Clinical Genetics Guidelines project 1996-2000. However, they should, with the other categories of disease above, in the future be incorporated within a single national Network which includes all forms of inherited cardiac disorders. This development would enable closer co-ordination of clinical services for these patients across Scotland.

Action:

Over time, there should be a single national Managed Clinical Network covering all inherited cardiac conditions.

Familial Hypercholesterolaemia

4.95 Familial Hypercholesterolaemia (FH) is a form of inherited high cholesterol which affects over 10,000 people in Scotland and which can cause heart attacks or strokes at a young age, even in the 20s and 30s.

4.96 Despite the continual downward trend in rates of cardiovascular mortality over the past 10 years, as noted at [paragraph 2.1](#) rates of decline of mortality for men and women aged 35 to 54 years have flattened out. A significant proportion of these individuals could have FH. The risk of myocardial infarction in carriers of the FH gene is extremely high and it is estimated that 50% of men will have an MI by the age of 50 and 30% of women by the age of 60.

4.97 When an individual is diagnosed with FH, it is essential that all close relatives have their cholesterol levels measured so that they too can start lifestyle modifications, and preventive treatments if necessary. This approach is supported by the NHS QIS draft clinical standards for prevention and treatment of CHD. Children of people with FH should be tested before the age of 10. There is a need to raise awareness of FH among primary care professionals, to prioritise the need for diagnosis, to define and agree referral protocols, and to develop good practice for clinical investigations, genetic testing and cascade screening within families.

Action:

A national forum for FH should be established by the Scottish Government Health Directorates to address the issues identified above by end 2009.

4.98 The UK National Screening Committee (NSC) endorses cascade screening within the families of affected individuals. This approach is cost-effective because it allows the identification of the sub-group of patients who require treatment with more powerful statins.

4.99 The clinical consensus is that patients with FH and cascade screening within families should be handled through lipid clinics, with the input of genetic expertise, probably in the form of genetic counsellors from the local genetic service. Through the 2006 review of genetic services in Scotland, money has been allocated to increase the number of such counsellors.

4.100 The NICE guideline on FH published in August 2008 advocates cascade screening within families, using both lipid and DNA testing as a confirmatory test, and the Scottish Molecular Genetics Consortium has asked the Aberdeen molecular genetics laboratory to look at how it might provide the necessary laboratory tests in Scotland.

Action:

The Aberdeen molecular genetics laboratory should develop a funding proposal for a pilot project of cascade testing for FH, for submission to CSO.

4.101 The 2002 Strategy highlighted the limited opportunities for nurses in postgraduate training in the care of those with CHD. The BHF has since funded the post of BHF Lecturer in Cardiac Care at the University of Glasgow and this has supported the development of courses 'Managing Cardiovascular Risk' and 'Managing Cardiac Care'.

5: SERVICES FOR STROKE

5.1 Stroke services, shaped by the local Managed Clinical Network in each NHS Board, need to provide evidence-based and high quality care at all stages, from identification and treatment of a transient ischaemic attack (TIA) to prevent a stroke, through to the long term support of those with multiple impairments recovering from a stroke (and their unpaid carers) in the community.

Action:

NHS Boards, through their stroke MCNs, should ensure that their stroke services are comprehensive and include each of the essential elements identified in this chapter.

5.2 A revised SIGN guideline (108) was published in December 2008 focusing on the most recent evidence on optimal management of patients with acute stroke and TIA. This builds on previous SIGN guidelines covering stroke rehabilitation and swallowing problems which emphasise how modern management can improve outcomes by preventing further stroke, reducing disability and promoting recovery. SIGN 64, which deals with stroke rehabilitation and complications, is currently under review.

5.3 The level of public understanding about stroke is low and confused, with many believing that stroke is a heart condition, not a 'brain attack', a fact re-inforced by a recent *Lancet* editorial (Vol 373 May 2, 2009, p 1496). Both the revised SIGN Guideline 108 on acute stroke and the revised NHS QIS clinical standards on stroke emphasise that a stroke is a medical emergency on a par with a heart attack. To address these issues, the National Advisory Committee on Stroke has been encouraging the FAST Campaign, the dissemination of which has been supported by Chest, Heart & Stroke Scotland, and by the Stroke Association in England. Details are given in the box below.

Think FAST & save a life

A stroke is a medical emergency.

It can happen to anyone and it happens fast.

By calling 999 you help to ensure that someone gets diagnosis and treatment as quickly as possible.

This will improve their chances of recovery.

To check if someone is having a stroke, use the **F-A-S-T** test.

Face: Can they smile? Does one side droop?

Arm: Can they lift both arms? Is one weak?

Speech: Is their speech slurred or muddled?

Time: to call 999.

If you see these signs call 999 FAST.

The faster you react, the better their chances of recovery.

5.4 The NHS/Chest, Heart & Stroke Scotland campaign is running in NHS Grampian and Highland (June 2009), NHS Lanarkshire and NHS Greater Glasgow & Clyde (October 2009) and NHS Lothian and NHS Fife (February 2010). The National Advisory Committee on Stroke (NACS) has provided funding of £30,000 to support the evaluation of the campaign. The intention would then be to roll it out to all parts of Scotland. In rolling out and evaluating FAST, consideration should be given to the following issues:

- the fact that FAST was originally developed for paramedics;
- that it does not include some signs of stroke, such as disturbance of vision;
- that up to 20% of those identified through FAST are confirmed with a diagnosis other than stroke; and
- the potential impact in different localities, socio-economic and demographic groups.

Action:

The Scottish Government Health Directorates and NHS Boards, through their stroke Managed Clinical Networks, should continue to support the ongoing public awareness campaigns run by Chest, Heart & Stroke Scotland, taking account of the evaluation of the Stroke Association campaign in England.

Action:

The National Advisory Committee on Stroke should consider how best to develop a national strategy for the evaluation and delivery of FAST by end March 2010.

Action:

NHS Boards, through their stroke MCNs, in conjunction with CHPs and the voluntary sector should develop a local communications strategy to raise public awareness of stroke by end March 2010.

5.5 FAST campaign awareness should be included in First Aid training, as this would raise awareness in the workplace, schools, community groups and wider NHS services. The Scottish Ambulance Service and NHS 24 should work together to provide a co-ordinated response to calls for help from people with possible stroke symptoms, and to work with the stroke MCNs to ensure that protocols reflect local stroke services' capabilities.

5.6 The SAS has developed a strategy for the management of stroke in the pre-hospital setting. FAST training and recognition are in place for all front-line staff.

Action:

NHS 24 staff, primary care staff, ambulance crews and A&E department staff should all receive appropriate stroke awareness training, including FAST.

5.7 A Key Performance Indicator (KPI) for ensuring rapid transfer and assessment of patients presenting with acute stroke is being developed. This gives target times for each stage in the process of reaching a decision on whether the patient is suitable for thrombolysis from first presentation to unscheduled care. The Scottish Stroke Care Audit (SSCA) Steering Group will monitor NHS Boards' performance in relation to this indicator.

5.8 The collection of data which will allow monitoring of performance against the new NHS QIS standards is crucial. They will be reviewed regularly to ensure they reflect the most up-to-date evidence, based on clinical guidelines. Increasingly, there will be a need to capture data from both the pre- and post-hospital stages of the patient pathway which can then be linked to data from the hospital phase to ensure the whole pathway is monitored and improved. The tools to allow this to happen include: the development of SSCA; integration with ISD data; incorporation of KPI for pre-hospital care; and QOF developments in the future, to reflect ongoing management in primary care.

Action:

ISD will integrate audits of pre-hospital and hospital-based stroke care, building on SSCA work, and provide a minimum dataset to reflect performance against NHS QIS standards by end December 2009.

5.9 Stroke and transient ischaemic attacks (TIAs) are sufficiently common that most stroke services can and should be provided locally. This makes both early access to specialist care and discharge from secondary care back to the community easier.

5.10 About one-fifth of those who suffer a stroke will have had warning symptoms in the form of a TIA in the days or weeks before the onset of a stroke. This offers a unique opportunity to prevent a disabling or even fatal stroke using health behaviour change as well as interventions such as anti-platelet drugs, anticoagulants, cholesterol and blood pressure lowering medication. In some cases surgery on the carotid artery will also reduce the risk of subsequent stroke (see paragraph 5.53).

5.11 Daily TIA clinics and TIA Hotlines are two models of service which offer the necessary immediate access to clinical assessment and treatments to reduce the risk of future stroke.

TIA Hotline in NHS Lothian

From 1 March 2007 GPs across Lothian have been able to ring a dedicated number to speak directly to a Stroke Consultant and obtain immediate advice regarding the diagnosis, immediate management and further assessment of the patient. If the GP is still with the patient, the consultant can even ask the patient directly about their symptoms to reach a clearer diagnosis. Suitable patients are offered immediate admission for thrombolytic therapy. Others are offered routine admission or given an appointment for outpatient assessment within a few days. The Consultant keeps in close phone contact with the Neurovascular Clinical secretary at the Western General Hospital who uses a secure shared spreadsheet on the web to allocate available clinic slots. Following the introduction of the hotline, waiting time for TIA assessment dropped from 11 days to an average of three days. Importantly, the hotline ensures early appropriate treatment, with specialist assessment completed within seven days in virtually all patients.

Unscheduled Care TIA & Stroke Telemedicine Service to Orkney

Current evidence suggests TIA patients should be seen by the specialist within 24 hours and commenced on the necessary secondary prevention treatment immediately. By using video consultations, stroke specialists in Aberdeen can see all TIA patients on Orkney within this time scale. Following this video link assessment patients are then transferred to the stroke unit for further investigations and treatment can then take place as soon as possible after the event, which has been shown to greatly improve patient outcomes. The service went live at the end of July 2008. By end of March 2009 16 patients had been seen. Of the 16 patients, 13 were transferred and three avoided transfer to Aberdeen after the specialist telemedicine consultation. This project won the Improvement and Innovation Award at the Scottish Health Awards in November 2008. Numbers will never be large with an Orkney population of 18,000, however there is potential to replicate this service in other areas. For example Grampian, with a population of 526,000, could use the existing video conferencing equipment in the 12 community hospitals and link into the specialists in Aberdeen, reducing the need to travel to medical outpatients prior to referral for further radiology or vascular investigations. A pilot of this is being considered in this area.

5.12 Using the model described above the patient would go to their GP with symptoms and be given an appointment within 24 hours for the nearest telemedicine consulting area, which could be their GP practice or the nearest minor injury unit. Either way they would link up with the TIA specialist on call.

Action:

NHS Boards, through their stroke MCNs, should engage with the Scottish Centre for Telehealth in the first instance, to ascertain whether this is a viable option for TIA outpatient redesign in their area.

Thrombolysis

5.13 As with TIAs, those experiencing symptoms of stroke need to seek immediate medical advice and get rapid access to services at local or regional level. This is particularly important if treatment with thrombolytic drugs is under consideration, as this needs to be given within at most 4.5 hours of first symptom onset. Much better joint planning between primary care, NHS 24, the Scottish Ambulance Service and Emergency Admission Units is needed to ensure that all eligible patients across Scotland will be able to access specialist assessment and early treatment. As a result of discussions with NHS 24, SAS and the stroke MCNs, protocols and training are being developed and an impact assessment is under way. The Scottish Stroke Care Audit will monitor the performance of the pre-hospital services for stroke patients. It will look at delays from the time of first call (999 or NHS 24) to arrival of paramedics, alerting of local stroke services, and then in-hospital delays in the pathway to thrombolysis, including delays to brain imaging. These data will be used by NHS Boards, working with their stroke MCNs, to drive reductions in delays and maximise the number of those who can benefit from thrombolysis.

5.14 Treatment with recombinant tissue plasminogen activator (rt-PA) within 4.5 hours of symptom onset is known to improve the outcome for some stroke patients, but only a minority is suitable for this treatment. It should not be seen as a 'cure' for ischaemic stroke, rather that for some patients successful therapy can reduce severity, including the level of disability or impairment which can accompany this type of event.

5.15 In those patients where the time of symptom onset can be established definitely, emergency medical services need to be configured to allow delivery of thrombolytic therapy within the required time period. The receiving unit must be in a position to rapidly assess and confirm suitability to start treatment as soon as potentially eligible patients arrive at the front door, and to give the treatment within an hour, both in and out of hours.

5.16 For thrombolysis to be given safely, the patient must be assessed by an experienced clinician and have an immediate brain scan. There are too few stroke specialists in Scotland to provide an on site specialist round-the-clock service in each hospital admitting acute stroke patients, resulting in major inequalities in access to thrombolysis. Those living close to a major teaching hospital have some access, while those living more remotely have none. A nurse-led first assessment of potential patients for thrombolysis has been set up in West Lothian, to supplement the single consultant and part-time associate specialist. This model could be used elsewhere in the country, to help broaden access to stroke thrombolysis for eligible patients.

5.17 At the request of the National Advisory Committee on Stroke's MCN sub-group, Chest, Heart & Stroke Scotland is presently co-ordinating a programme of multi-disciplinary training in thrombolysis, based on the three Regional Planning Groups.

Action:

NHS Boards, with advice from their stroke MCNs, should consider appropriate models to facilitate access to thrombolysis for stroke patients, particularly in areas with limited medical cover.

5.18 The draft revised NHS QIS stroke standards stipulate that thrombolysis services should be aiming to treat more than five stroke patients per 100,000 population and to ensure that the door to needle time is less than one hour in at least 80% of patients treated. To meet these standards, NHS Boards will need to provide round-the-clock access to thrombolysis, if necessary with clinical advice being provided through telemedicine networks. The stroke MCNs are clear that to ensure equity of access to thrombolysis across Scotland, there will need to be a move to a regional model of service delivery.

5.19 The Scottish Centre for Telehealth is working with NHS Boards to introduce Telestroke networks which seek to develop pathways and protocols for the most effective administration of thrombolysis in each part of Scotland, to reduce delays and avoid long ambulance journeys.

5.20 There is a clear role here for the Regional Planning Groups, especially as stroke care moves towards intervention within 2 hours of diagnosis. Lessons learned from the redesign of cardiac services to meet optimal reperfusion therapy requirements could be valuable to this emerging service. Other aspects of stroke care that require a regional approach include interventional neuroradiology, neurosurgery and vascular surgery.

Action:

The Regional Planning Groups, in conjunction with the local stroke MCNs, the Scottish Ambulance Service and the Scottish Centre for Telehealth, should consider how to deliver optimal hyper-acute stroke care, including thrombolysis.

Telestroke networks

There are some examples of good practice already in place. NHS Grampian provides 24/7 face-to-face thrombolysis cover at Aberdeen Royal Infirmary (ARI) and 24/7 thrombolysis cover for Elgin via telemedicine from ARI. In the first three months of the network's activity, 10 telestroke consultations took place, with three people being thrombolysed as a result.

NHS Lanarkshire has face-to-face thrombolysis pathways and protocols in place and a telestroke network covering all Lanarkshire acute hospitals within hours. Out-of-hours cover via telemedicine links to stroke consultants' homes is in the final planning stage.

Stroke Unit Care

5.21 In the seven years since publication of the original Strategy, access to stroke unit care has improved. In 2002 there were 31 stroke units and 583 stroke unit beds in Scotland. By 2007 this number had increased to 38 units with a total of 768 designated stroke beds. More patients are being admitted to stroke units and being managed according to agreed standards, which undoubtedly improves outcomes. However, many hospitals are still not meeting the NHS QIS standard that at least 70% of patients with stroke should be admitted to a stroke unit within the first day. The updated standards, published by NHS QIS in June 2009, include the following essential criteria:

- 60% of all patients admitted to hospital with a diagnosis of stroke are admitted to the stroke unit on the day of presentation at hospital, and remain in specialist stroke care until in-hospital rehabilitation is complete; and
- 90% of all patients admitted to hospital with a diagnosis of stroke are admitted to the stroke unit on the day of admission, or the day following presentation at hospital, and remain in specialist stroke care until in-hospital rehabilitation is complete.

5.22 Access to stroke unit care is the single most important aspect of services, and is the key to meeting many of the other NHS QIS clinical standards for stroke care. NHS Boards have struggled to meet the existing standards on a sustained basis, and the revised draft standards will present an even greater challenge.

5.23 NHS Boards, in conjunction with their stroke MCNs, will need to seriously consider the aspects of service redesign required to achieve the new access target. Stroke unit beds need to be protected from other pressures, by giving them the same status as CCU beds, and by recording them on SMR data as distinct units.

Action:

A short life working group of the National Advisory Committee on Stroke should be established, to include representation from the Directors of Planning Group, to draw on NHS Boards' existing experience to explore the service and other implications of developing a HEAT target relating to stroke unit admissions.

5.24 The SSCA provides data on the performance of each hospital which admits acute stroke patients. The table below shows that, averaged over Scotland, the proportions of patients receiving care in line with current NHS QIS standards and with best evidence has improved in a number of areas between 2005 and 2007. However, there is still plenty of scope for continued improvement.

Standard of care	2005	95%CI	2007	95%CI
I.1.1				
Admitted to Stroke unit	72	71-73	77	76-78
Admitted to Stroke unit <1 day	51	50-52	56	55-57
I.1.6				
Swallow screened performed	64	63-65	69	68-70
Swallow screened <1 day	44	43-45	50	49-51
I.1.11				
Brain scan performed	94	93-95	96	95-96
Brain scan within 2 days of admission	78	77-79	87	86-88
I.1.16				
Given aspirin within 2 days of admission	57	56-58	69	68-70
Discharged on blood pressure lowering medication	61	59-61	64	63-65
Ischaemic Stroke discharged on antithrombotics	88	87-89	92	91-92
Ischaemic Stroke discharged on statins	77	76-78	80	79-81
Ischaemic Stroke in Atrial fibrillation discharged on anticoagulants	36	33-39	40	39-43

Source: www.strokeaudit.scot.nhs.uk/Downloads/files/SSCA_NationalReport_2008.pdf

5.25 The audit loop is closed through an annual letter to NHS Boards from the Scottish Government Health Directorates drawing attention to those aspects of services where good progress has been made, and those where further progress needs to be made. That process should continue, taking account of the revisions to the stroke standards.

Action:

The Scottish Government Health Directorates should continue to highlight NHS Boards' performance in the SSCA on an annual basis and NHS Boards should provide action plans to address any shortcomings.

5.26 One very positive outcome of this process is that it has prompted consideration by NHS Boards' Directors of Planning of ways in which Boards' performance against the clinical standards could be improved. The barriers to more consistent achievement of the standards which have been identified include:

- the number of acute receiving sites in Scotland;
- the overlap between stroke medicine and medicine for the elderly;
- the comparatively under-developed nature of stroke medicine; and
- the crucial importance of admitting those who have had a stroke to a dedicated stroke unit as a *sine qua non* of achieving many of the other standards relating to hospital care.

5.27 Stroke units need better nursing staff levels to allow them to provide early assessment, observation, monitoring swallow screening and early activation of stroke rehabilitation. Close attention should be paid to diet and nutrition of those being cared for in stroke units, especially those with communication and swallowing difficulties. The effects of a stroke are wide ranging, and as well as the physical impact, can include cognitive and mental health problems which have a profound effect on everyday activities. Currently, only a third of stroke units have access to clinical psychology services (see paragraph 5.48).

Action:

NHS Education for Scotland should establish a method for nurses working in a stroke unit to demonstrate that they have achieved the defined level of specialist knowledge and competence by December 2011.

Imaging

5.28 Imaging is a key part of stroke care, and there are constant advances, for example in MRI. Daily TIA clinics and hotlines mean that there is a need for immediate access to both brain and carotid imaging as well as other investigations such as ECG and echo. Consideration should be given as to whether duplex ultrasound, CT and MRI services can be delivered on a 24-hour basis in all hospitals admitting those who have had a stroke. NHS 24 and the SAS are currently piloting the feasibility of achieving a 55-minute call-to-CT scan time.

5.29 Expanded neuroradiology capacity will be required to allow an on-call rota in tertiary centres providing out-of-hours thrombolysis. Priority needs to be given to increasing the number of consultant radiologist PAs (Programmed Activities) and the number of radiographers to support the significant workload associated with stroke and TIA. Enhanced roles for radiographers (e.g. CT head reporting) should also be considered as part of the solution to imaging service pressures.

Action:

The newly-established Scottish Imaging Managed Diagnostic Network, in conjunction with the SAS and NHS 24, should address the neuroradiology issues identified in this section as a matter of urgency.

Younger People and Stroke

5.30 Younger patients with stroke can have specific and complex needs, such as support for return to work. Stroke training should be offered to all disability employment workers, to ensure they understand the issues involved in working with younger people who have had a stroke and who wish to return to work. The Delivery Framework for Adult Rehabilitation was launched in February 2007 and has a focus on rehabilitation for those wishing to return to, or remain in, employment after a period of ill health.

5.31 Chest, Heart & Stroke Scotland has published work on the services available to younger people (18-49) affected by stroke, and their families and carers. Key recommendations in that report include:

- GPs should be aware that stroke can affect younger people;
- in localities where, due to population density and socio-economic circumstances, there is a relatively high incidence of younger people experiencing strokes, designated 'younger' stroke units should be created, for example by concentrating these younger people in one site in the larger cities;
- where younger people who have had a stroke are treated in wards with a mixed age profile, health professionals should be aware that being treated in close proximity to very elderly people is a major concern for younger people experiencing a stroke, and their families. They should be informed, in a sensitive manner, that the best care can be provided by admission to a stroke unit that caters for people of all ages;
- issues relating to employment should be addressed immediately following a stroke. Occupational therapists should ensure that they are aware of the previous employment history of the young person who has had a stroke, in order to address possible alternatives at an early stage;
- all younger people who have had a stroke should be visited by a stroke nurse within two days of discharge from hospital, to identify and address any difficulties and provide a timetable of what is likely to happen in terms of service input in the following weeks; and
- younger people who have had a stroke, and their families, should be offered the option of Self Directed Support which would enable them to organise their own services.

Chest, Heart & Stroke Scotland and NHS Lanarkshire have developed a service which addresses issues such as access to education and training, vocational rehabilitation, employment, family relationships and the economic impact of stroke. Chest, Heart & Stroke Scotland, in partnership with the Citizens' Advice Bureaux in Lanarkshire, provides specialist advice on benefits.

Action:

NHS Boards should adopt the model developed by Chest, Heart & Stroke Scotland and NHS Lanarkshire to help younger people deal with the wider social consequences of stroke. Access to vocational rehabilitation support should also be provided.

5.32 One specific issue affecting those under 65 discharged from hospital after a stroke is that they are not eligible for free personal care. Two forms of support can however be provided. Nursing care payments are available to care home residents who fully fund their care home costs, and people who have dementia or any other degenerative illness and who require care, and who live in their own homes, can claim Disability Living Allowance.

Early Supported Discharge

5.33 There is now reliable evidence from clinical trials that early supported discharge from stroke units can achieve not only shorter lengths of stay, but also better clinical outcomes. The National Advisory Committee for Stroke (NACS) MCN Sub Group conducted an 'Early Supported Discharge for Stroke Survey' in April 2008 which attempted to estimate access to post-discharge stroke rehabilitation services in terms of the number of MCNs, hospital services and the percentage of the population which could access such services. The survey found that 52% of the Scottish population was covered by an Early Supported Discharge team. It also found that specialist community rehabilitation for the longer term management of stroke patients was available in seven NHS Board areas of which none were 'stroke specific'. Overall, 45% of the population was covered by a community rehabilitation team. Currently, access to specialist stroke rehabilitation services outside hospital is patchy. CHPs need to work with the stroke MCNs and local Rehabilitation Co-ordinators to make such services more available, consistent with Scottish Government policy.

5.34 The Rehabilitation Co-ordinators have been provided with a copy of the Early Supported Discharge survey results. Stroke services will be incorporated in the mapping and redesign of rehabilitation services which the Rehabilitation Co-ordinators are carrying out. Updates on this work will be monitored by the Delivery Framework for Adult Rehabilitation Implementation Group on a quarterly basis.

Action:

NHS Boards with their local planning partners must ensure that early supported discharge and community rehabilitation teams are integrated and easily accessible to assist people who have had a stroke to become as fully independent as possible.

Rehabilitation and Recovery

5.35 People who have had a stroke want above all to return to independent living. The focus of services should therefore be on empowering them and supporting them through the process of recovery. Across much of Scotland, Chest, Heart & Stroke Scotland, in partnership with local stroke services, provides a stroke nurse service which offers advice, information and support for up to 12 months following discharge from hospital.

5.36 Half of those who survive a stroke have some level of impairment:

- one-third have a communication impairment such as aphasia;
- over a third have cognitive problems and stroke is the second major cause of dementia after Alzheimer's;
- between 20-50% experience depression;
- between 60-70% experience a visual problem; and
- many rely on spouse or other family member for essential support and care, causing difficulties in turn for the carer.

With improved acute stroke care, the prevalence of those with a neurological impairment is likely to increase, with significant implications for health and social care. Up to 80% of those who survive a stroke with impairments are amenable to rehabilitation. With the right support, some degree of recovery is possible for most people. There is therefore 'life after a stroke'.

5.37 Long term care and support should include:

- access to information in suitable formats from NHS and voluntary organisations;
- access to rehabilitation, through the NHS, employers and the voluntary sector;
- access to psychological support in the community;
- secondary prevention support;
- annual check-ups through primary care;
- social care support provided by the statutory and voluntary sectors, including home care support, personal care, telecare, equipment and adaptations, supported housing and residential and nursing care;
- access to self management support;
- access to exercise through leisure services; and
- support for family and carers through the NHS, social care and the voluntary sector.

It should be provided through a multi-disciplinary team involving, as necessary:

- physiotherapy;
- occupational therapy;
- speech and language therapy and communication support;
- vision support;
- dietetics support;

- psychological support;
- vocational rehabilitation; and
- long term voluntary sector support, for example through patient support groups and volunteer outreach services.

Action:

NHS Quality Improvement Scotland should consider the wider standards that could be developed to reflect the most up-to-date evidence once the revised SIGN Guideline 64 on Stroke Rehabilitation is published, and discuss options for taking this work forward with the National Advisory Committee on Stroke and the stroke Managed Clinical Networks.

5.38 Allied Health Professionals (AHPs) are key agents in the delivery of rehabilitation services, including early discharge and outreach. They have a vital role to play in all stages of stroke patient pathway, and while some are already very skilled, all should have access to specialist training. It is particularly helpful if there is a single point of contact and ongoing support post-discharge. People should be offered specialist information and advice which is appropriate, accessible and timely, including that provided by the voluntary sector. The care plans of people who have had a stroke must include recognition of the needs of their unpaid carers.

5.39 Physiotherapy. Access to physiotherapy remains patchy. Physiotherapy at home after stroke improves outcome and increases independence. Specialist physiotherapy should be available at all stages of the patient pathway, to maximise independent functional recovery. Allowing self-referral to AHP services would enable stroke survivors to access timely and appropriate services to promote increased personal control.

Action:

NHS Boards, through their stroke MCNs, should investigate the implications of allowing self referral to AHP services by those recovering from a stroke.

5.40 'Exercise After Stroke: Physical Activity and Health' is a unique training course designed for specialist exercise instructors. It has been developed and validated through a collaboration between Queen Margaret University, Edinburgh, and the University of Edinburgh, with funding from the Scottish Government. The modular course is based around the most up-to-date and highest quality evidence available, and involves 200 hours of study comprising lectures, tutorials, practical sessions and self-directed learning. The course design may become available in due course for development in other parts of Scotland. Representatives of the leisure industry in the participating NHS Board areas are working in partnership with health colleagues to establish patient pathways into exercise and fitness training to maximise recovery for people who have had a stroke.

Action:

NHS Boards, through their stroke MCNs, should continue to work with leisure industry representatives to make best use of this new training course to improve access to exercise and fitness training for people with stroke in their area.

5.41 Occupational Therapy. The systematic review by Stroke Therapy Evaluation Programme at Glasgow Royal Infirmary (published in Cochrane Library, 2006) showed that occupational therapy (OT) significantly reduces risk of deterioration after stroke. Those who took part in after-stroke rehabilitative therapy proved better able to perform self-care tasks and were more likely to maintain these abilities.

Action:

NHS Boards, through their stroke MCNs, should prioritise the provision of OT services for stroke rehabilitation, given the strong evidence base in this area.

5.42 NHS QIS is working on an Ankle-Foot Orthoses (AFO) Best Practice Statement which aims to provide doctors, AHPs and nurses with practical advice and guidance on the use of ankle-foot orthoses following stroke to promote a consistent, cohesive and achievable approach to care. The Best Practice Statement is expected to be published and distributed across NHSScotland by September 2009.

Action:

NHS Boards, through their stroke MCNs, should ensure implementation of the Best Practice Statement on AFO, once available.

5.43 Speech and Language Therapy and Communications support. The survey *Back to a Life after a Stroke*, published in December 2008 by the Royal College of Speech and Language Therapists, Speakability, Chest, Heart & Stroke Scotland and the Stroke Association in Scotland, reviewed the experience of 280 people who had communication difficulties following a stroke. The report includes the following key points:

- communication difficulties after a stroke are significant for people who have them, and act to exclude them from public services;
- communication difficulties have an overwhelming impact on the lives of individuals and their families;
- people who have had a stroke value speech and language therapy and other communication support services, but they need much more of these; and
- direct speech and language therapy and voluntary communication support services make a real difference to the things that matter to people.

5.44 The report therefore makes the following recommendations to Government:

- improve provision of speech and language therapy and voluntary communication support to services in hospital and the community;
- raise healthcare professionals' awareness of the impact stroke can have on communication;
- improve the quality and communication accessibility of information;
- raise public services' awareness of the impact stroke can have on communication; and
- collect incidence and prevalence figures of people who have communication difficulties after a stroke, and data on current provision of communication services and needs of people with communication difficulties after stroke, to inform service planning and evaluation.

5.45 The Volunteer Stroke Service operates across 90% of Scotland, offering communication support through group activities, support to people in hospital, outreach one-to-one support and long term maintenance. It operates with funding from the NHS and in partnership with local speech and language therapy services, and makes extensive use of trained volunteers. Its effectiveness has been demonstrated by independent, peer-reviewed research.

Action:

NHS Boards, through their stroke MCNs, should ensure that provision of speech and language therapy services is included in the mapping exercise being undertaken by the Rehabilitation Co-ordinator in each NHS Board, and that services are supported appropriately, including voluntary sector communication support services.

The Stroke Manual by Connect – The Communication Disability Network

The stroke manual published by Connect is a useful tool which can support people with stroke and aphasia in asking questions, having discussions and conversations, and making choices and decisions. It includes easy-to-understand information on all aspects of life following stroke, from the early days, to picking up the threads months and even years after the event. The manual has been developed in direct response to the experiences and needs of people living with stroke and aphasia and validated by people who have first-hand experience of stroke and aphasia, as well as medical and social services experts.

Chest, Heart & Stroke Scotland has developed a range of aphasia-friendly publications, including:

- Conversation support book;
- Stroke journey (three booklets: *Early days*, *Rehabilitation after stroke*, *Moving on*);
- Aphasia identity card.

5.46 Support for visual problems. Visual impairment can affect up to 70% of stroke survivors, but many do not have their vision adequately assessed in hospital, causing significant problems for recovery and quality of life. Routine visual assessment should be carried out for all those who have had a stroke as soon as possible after the stroke. Where problems are identified, appropriate therapeutic support should be available.

My Stroke Book

NHS Greater Glasgow & Clyde developed a patient information resource called *My Stroke Book* to provide information and support to patients who have had a stroke and their carers. A large print version has been developed for the visually impaired and the book is being translated into Punjabi, Urdu and Cantonese in audio format. Every patient is given one of these books either just after admission to the hospital Stroke unit or – for patients whose stroke was some time ago – from their practice nurse through the Chronic Disease Management programme.

The Chief Scientist Office funded a randomised control trial on a Stroke Workbook based on the Heart Manual. The study showed modest functional improvement and maintenance of confidence amongst those who participated.

Action:

NHS Boards, through their stroke MCNs, should encourage the use of the Stroke Workbook.

5.47 Dietetics. The expertise that dieticians bring to stroke care is set out in detail in *The Value of Nutrition and Dietetics for Stroke Survivors* (December 2007). To maximise the effectiveness of rehabilitation, people who have had a stroke should have a nutritional assessment and access to advice and support in meeting their nutritional needs.

5.48 Psychological support. It is important to recognise the impact that the cognitive effects of stroke can have on the success of early supported discharge and community integration. Those from deprived areas who have had a stroke experience greater emotional impact and can require support for longer. Clinical Psychologists are ideally placed to provide evidence-based interventions in response to the emotional impact of stroke, but, as noted previously, currently only a third of stroke units have access to clinical psychology services. The 'Guide to delivering evidence-based Psychological Therapies in Scotland' (Scottish Government, December 2008), known as 'The Matrix', has been developed to help NHS Boards provide such interventions in key Government priority areas.

5.49 Vocational rehabilitation has been shown to be highly effective in supporting individuals to stay in, or return to, employment, voluntary or educational activities. The Delivery Framework for Adult Rehabilitation recommends that this is underpinned by integrated vocational rehabilitation services, and a number of programmes are under way in Scotland. A Vocational Rehabilitation pilot in Tayside has been established in collaboration with 'Healthy Working Lives' and was launched February 2007. Further funding has been provided by the Health Improvement Directorate and pilots are now also under way within NHS Lothian and NHS Borders.

Care Homes

5.50 People moving into care homes should have access to the full range of AHP services. Support systems and health monitoring for people in care homes or long term care institutions who have had a stroke must be addressed, with access to stroke services for re-assessment and further rehabilitation. The National Care Standards relating to care homes require providers to ensure that residents continue to receive healthcare services that meet their needs, and that these should be reviewed regularly, and at least every 6 months. Care homes need access to specialist rehabilitation services and training.

5.51 The Chief Health Professions Officer has also been working closely with the Care Commission to establish an AHP Consultant to address the need to improve meaningful activity in care homes for adults of all ages as well as supporting access to rehabilitation and early identification of dementia. This appointment is being funded for two years.

Palliative Care

5.52 There are specific issues for stroke patients in palliative care, including issues over nasogastric or pegylated feeding and when to withdraw these. The Scottish Government has provided funding of £40,000 to enable the University of Glasgow, with assistance from NHS Quality Improvement Scotland, to develop best practice statements on palliative care, including symptom control following severe stroke, and pain management post-stroke. These complement the work of the STARS e-learning modules. The role of palliative care in end of life stroke care should be considered further by the stroke MCNs in conjunction with the palliative care MCNs, taking account of the content of these best practice statements.

Action:

NHS Boards' stroke and palliative care MCNs should collaborate to implement the objectives in NHS Boards' *Living and Dying Well* Delivery Plans.

Carotid Surgery

5.53 About 500 patients each year undergo carotid endarterectomy to treat narrowing of their carotid artery and reduce the risk of subsequent stroke. If this operation is performed within a week or two of a TIA or minor stroke, there is very good evidence that at least 20 strokes would be avoided for every 100 patients treated. Currently most operations in Scotland are not done within the optimal waiting time of 14 days described in SIGN guideline 108. The patient pathway to carotid surgery needs to be greatly speeded up, to achieve reduced delays in:

- patients seeking medical help (the FAST campaign will help here);
- access to specialist assessment and appropriate investigation;
- referral to surgeon;

- assessment by surgeon; and
- time to surgery.

In order to meet the revised clinical standard that 80% of patients undergoing carotid endarterectomy should have the operation within 14 days of their stroke. The Scottish Stroke Care Audit will monitor delays in the patient pathway.

Reducing delays to carotid surgery in Lothian

In Lothian the stroke physicians, radiologists and vascular surgeons have met regularly over the last five years with the aim of reducing delays in patients accessing carotid endarterectomy. Changes to services have included:

- TIA Hotline and reduction of wait for neurovascular clinic
- same day Duplex scanning and confirmatory scan by another radiologist
- faxed referral to surgery with agreed information
- involvement of more surgeons to spread the load – avoidance of referral to named surgeon
- booking of date for surgery on receipt of referral, even before surgical assessment
- continuous monitoring of delays through audit and feedback to staff.

5.54 Similar, significant service redesign of the type undertaken in NHS Lothian will have to take place at most regional centres if the required reductions in delays to carotid surgery are to be achieved.

Action:

NHS Boards and Regional Planning Groups should urgently implement the kind of service re-design undertaken in NHS Lothian and elsewhere to reduce the current unacceptable delays in time to carotid endarterectomy for eligible patients.

Workforce Planning

5.55 Currently there are too few nursing and AHP staff to support acute stroke unit care, including stroke rehabilitation, which means that many units struggle to maintain adequate staffing levels. In addition, there is recognition of the difficulty of attracting and retaining staff with the appropriate skills and knowledge in many areas. These issues also apply to the numbers of staff who provide longer-term care and support in the community.

5.56 The relatively recent recognition of stroke medicine as a subspecialty for medical training purposes, and the establishment of specialty registrar posts should help to address the shortage of stroke specialists in Scotland. However, there is a clear lack of higher level specialist training for nurses and therefore of a career path which would help with retention. The lack of higher level training is being addressed by:

- NHS/Chest, Heart & Stroke Scotland stroke training programmes (see paragraph 2.12);
- phases 2 and 3 of STARS (see below), which incorporate specialist areas including thrombolysis; and
- the national programme of thrombolysis training being developed by Chest, Heart & Stroke Scotland.

5.57 The Stroke Association has already provided stroke awareness training to the social care workforce of one local authority and plans to offer this Scotland-wide. It also hopes to support stroke training in primary care, working with Education for Health, a UK education charity which already has an Open University-accredited training programme for stroke in primary care.

Stroke Training and Awareness Resources (STARS)

5.58 In 2002 the CHD and Stroke Strategy identified the need to provide a set of Core Competencies for professionals working with people with stroke. NACS commissioned NES to take this work forward and the Stroke Core Competencies were published in April 2005.

5.59 In May 2007 funding was secured from the Scottish Government Health Directorates to develop an e-learning training resource based on the Competencies. The key stakeholders involved in the project are Chest, Heart & Stroke Scotland, the University of Edinburgh, NHS Education for Scotland as well as a national steering group which includes expert stroke clinicians.

5.60 All NHS Boards in Scotland were asked to select members of the community and acute healthcare and social care teams to participate as case authors, with responsibility for the content and design of the website. Twelve NHS Boards and a wide range of professions were represented.

5.61 The website (www.Strokecorecompetencies.org) provides a multidisciplinary resource which focusses on a wide range of core knowledge and skills required by all staff delivering stroke care. It was launched in May 2008 and is freely available to all on the worldwide web. The project, is continuing, with further support from the Scottish Government, to develop training resources aimed specifically at staff working in acute stroke unit care. These modules are being launched in September 2009.

Action:

NHS Boards should ensure that their stroke MCN is providing in-service training opportunities such as STARS to staff involved in stroke care. NHS Boards should also ensure that staff have access to on-line training through their hospital IT systems by March 2010. This may require reconfiguration of security settings and installation of certain computer software on those computers used by staff.

Scottish Stroke Research Network (SSRN)

5.62 The SSRN is funded by the Chief Scientist Office and was set up to complement developments in the rest of the UK. It works through a devolved four regional structure and has 21 active research sites with plans to develop a further three to four sites. Recruitment to trials has risen in 2007-08 by 50% over the previous two years. Scotland is currently the second highest recruiting region in the UK (with over 500 participants per year) despite having a relatively more demanding portfolio of studies. The Network will continue to consolidate and build upon this progress and begin focussing on supporting activities such as development of the study portfolio, staff training, and service development. Renewed funding of £1.93m has been agreed for three years from April 2009. The SSRN has a key role in training staff to participate in clinical research.

Action:

CSO should be able to demonstrate increasing year-on-year recruitment to clinical stroke studies through the SSRN.

5.63 CSO has also allocated £15m a year to support the development of a 4-Board:4-University Scottish Academic Health Sciences Collaboration. This was launched on 17 June 2009 by the Cabinet Secretary, and aims to establish a world-leading platform of research infrastructure to attract external investment and economic development, strengthen the evidence-based culture in NHS and stimulate recruitment, training and retention of staff. The Collaboration is key to Scotland's ability to remain internationally competitive and involves the creation of some 250 new posts and infrastructure to support imaging, biorepositories and informatics. In addition, it will support clinical research facilities and functions, e.g. research nurses, pharmacy, governance, monitoring. Many of the Collaboration's activities will be relevant to stroke research.

5.64 CSO also funds the Stroke Research Programme at the Nursing, Midwifery and Allied Health Professionals Unit at Glasgow Caledonian University.

5.65 Opportunities for further research in relation to stroke include:

- public health research into stroke epidemiological research;
- health economics research into the non-NHS costs of stroke; and
- social research such as that proposed for FAST and into the needs and experiences of those who survive a stroke.

6: IMPROVING THE QUALITY OF CARE AND SUPPORT

Information and Communication

6.1 One of the major concerns from the British Heart Foundation's research project to explore the practical, social and emotional implications of living with CHD was a considerable lack of communication and information-giving on the part of the medical profession, leaving patients feeling disempowered, confused and anxious at a time when they particularly need strength, re-assurance and confidence.

6.2 One of the key messages from a survey carried out by Chest, Heart & Stroke Scotland and NHS Tayside during 2006-07 into the emotional impact of stroke was that stroke has a major emotional impact, with feelings of anxiety, frustration and fear of recurrence being common. If not addressed, these can intensify to clinical depression, with substantial detrimental effects on long term recovery and family relationships. Those who had had a stroke recognised the need to be able to talk to someone. One-to-one support from a knowledgeable health professional appeared to be the most widely acceptable intervention.

6.3 These findings are consistent with those in the generic work on long term conditions being undertaken by the Chief Medical Officer and the Long Term Conditions Alliance Scotland. It is essential that the approaches being developed through the Long Term Conditions Action Plan should be applied to people with heart disease and those who have had a stroke, from the time of their first contact with the NHS onwards. That information should include making sure that people have a clear understanding about what has happened to their heart on a physical level, in order to dispel misconceptions. It is also essential that people should be given a satisfactory explanation of the cause of their illness, to pave the way for discussions about the role of their own lifestyle and the acceptance of a degree of responsibility for their own health. People must be signposted to the information and support available from voluntary sector organisations.

6.4 The British Heart Foundation research project referred to above showed that within the medical profession there were weak links of communication between GPs and hospital consultants. This resulted not only in a lack of continuity of care, but also in patients feeling a sense of having been abandoned after discharge from hospital. People were, for example, often surprised at the apparent lack of interest shown by their GP in relation to their hospital treatment. Participants also commented on the compartmentalised nature of the medical system and the lack of the continuity of care necessary for a more patient-centred approach. The same issues have been raised by patients with stroke, and their carers.

6.5 The National Advisory Committee for CHD has supported the development of 'Heart Scotland' a website that contains a patient portal. When completed, it will direct patients and carers to nationally applicable, quality-assured information about all forms of heart disease, their causes, diagnosis, treatment, rehabilitation, and on living with specific manifestations. In addition, 'Heart Scotland' has created a series of 'virtual visits'. These illustrate what to expect in general terms when going for a consultation, test or treatment in a range of care settings, and at the same time highlight the growing role that community care settings such as the GP surgery and community pharmacy are playing in tackling heart disease.

Action:

NHS Boards, through their cardiac and stroke MCNs, need to make concerns about communication issues for heart disease and stroke patients one of their priorities, and develop plans to tackle these concerns locally.

6.6 NHS Education for Scotland has a patient eLibrary for stroke. NHS 24's website includes information on both heart disease and stroke. Chest, Heart & Stroke Scotland, the British Heart Foundation and the Stroke Association provide public information on their websites also.

6.7 In line with the Scottish Government approach to working in partnership with the voluntary sector, as set out in *Better Health, Better Care*, the key voluntary organisations – the British Heart Foundation in Scotland, Chest, Heart & Stroke Scotland and the Stroke Association in Scotland – will be fully involved in taking forward the actions in the revised strategy through their representation on the relevant National Advisory Committees. The Scottish Government Health Directorates (SGHD) will also continue to work with other organisations active in relation to CVD, such as HEART UK, Diabetes UK Scotland, Scottish HART, the Cardiomyopathy Association and the Arrhythmia Alliance. In addition, SGHD will also maintain close links with the recently-formed Parliamentary Cross Party Group on Heart Disease and Stroke.

Self Management

6.8 As with any other long term condition, self management has an extremely important part to play in relation to heart disease and stroke. The principles of self management as set out in the national strategy, *Gaun Yersell!*, developed by the Long Term Conditions Alliance Scotland (LTCAS) therefore apply here. They are:

- I am the leading partner in management of my health (I am involved in my own care. I, those who care for me and organisations that represent me, shape new approaches to my care);
- Be accountable to me and value my experience (Evaluation systems should be ongoing and shaped by my experience. They should be non judgemental and focus on more than medical or financial outcomes);

- I am a whole person and this is for my whole life (My needs are met along my life journey with support aimed at improving my physical, emotional, social and spiritual wellbeing);
- Self management is not a replacement for services. Gaun yersel' doesn't mean going it alone (self management does not mean managing my long term condition alone. It's about self determination in partnership with supporters);
- Clear information helps me make decisions that are right for me (Professionals communicate with me effectively. They help ensure I have high quality, accessible information. They also support my right to make decisions).

6.9 It is essential that people with a heart condition or who have had a stroke are made aware of all the relevant sources of information and support that could be made available to them, whether provided by the NHS, local authorities or the voluntary sector. Much of this work will be achieved through the NHS Health Information Service being launched formally in autumn 2009.

6.10 Voluntary organisations active in the area of CVD will be able to apply for grants from the Self Management Fund administered by LTCAS in order to promote the development of self management amongst those with a cardiac condition or who are recovering from a stroke. The Fund is being supported through £2m funding from the Scottish Government in each of 2009-10 and 2010-11. Details are available from the LTCAS website (www.ltcas.org.uk).

Managed Clinical Networks

6.11 The 'Voices Scotland' project supports the Scottish Government's vision of a mutual NHS by ensuring that chest, heart and stroke patients' and carers' views are represented, and their voices heard, and that they have the opportunity to be involved in a meaningful way in the work of NHSScotland. 'Voices Scotland' aims:

- to provide people affected with chest, heart or stroke conditions, and their carers, with the skills and confidence to work alongside the NHS;
- to empower patients and carers through access to information, training and support;
- to develop a supportive network of chest, heart and stroke patients and carers; and
- to encourage partnership working between the NHS and the voluntary sector.

6.12 The project, which is run by Chest, Heart & Stroke Scotland and the British Heart Foundation, has trained more than 250 people so far, across all but one NHS Board. Those who have been through the training have been able to take part in relevant work by SIGN, NHS Quality Improvement Scotland, NHS Education for Scotland and the 'Living Better' project, as well as taking part in the consultations on the revision of the CHD and Stroke Strategy and the Patients' Rights Bill.

6.13 One of the core principles of all MCN developments is that they should include strong patient and voluntary sector participation. 'Voices Scotland' helps to strengthen the patient and carer voice in the work of the cardiac and stroke MCNs. Given the central role intended for these Networks in taking forward this Action Plan, it is essential that the 'Voices Scotland' project should continue to provide the training needed. It is particularly important that those with communication difficulties following a stroke should be able to make their voices heard, and the development of training suited to their specific needs should form part of the next phase of the project. 'Voices Scotland' will also help to provide representation on the National Advisory Committees from those with a heart condition or who have had a stroke.

Quality and safety of care

6.14 The NHS Quality Improvement Scotland CHD Improvement Management Programme, issued in June 2009, represents the first nationally co-ordinated quality improvement programme for heart disease in Scotland. It complements and builds on existing work of the cardiac MCNs. The programme provides linkage between evidence-based practice, patient safety and patient-centred care. It is based on genuine partnership with health professionals and voluntary organisations involved in heart disease.

6.15 NHS QIS will work with the NHS, principally the cardiac MCNs and patient representative groups, to:

- harness the individual discrete functions of NHS QIS to deliver a proactive, integrated and supportive approach;
- ensure alignment and integration of work with the Scottish Patient Safety Programme (SPSP);
- work with other agencies as required;
- provide the appropriate resources, tools and mechanisms that will support the service in ongoing improvement;
- build capacity and capability to support service improvement;
- provide a structured approach and support for a sustained programme of implementation; and
- demonstrate the quality of care throughout NHSScotland.

Measurement for Improvement

6.16 A national audit programme is under way which is directly linked to the NHS QIS standards. The work is overseen by a Clinical Audit and Indicators Steering Group and supported by sub-groups covering heart failure, acute coronary syndromes, atrial fibrillation and cardiac rehabilitation. Audits will begin in 2009. Formal reporting mechanisms are also being put in place to ensure that local and national results are communicated widely, to drive improvement.

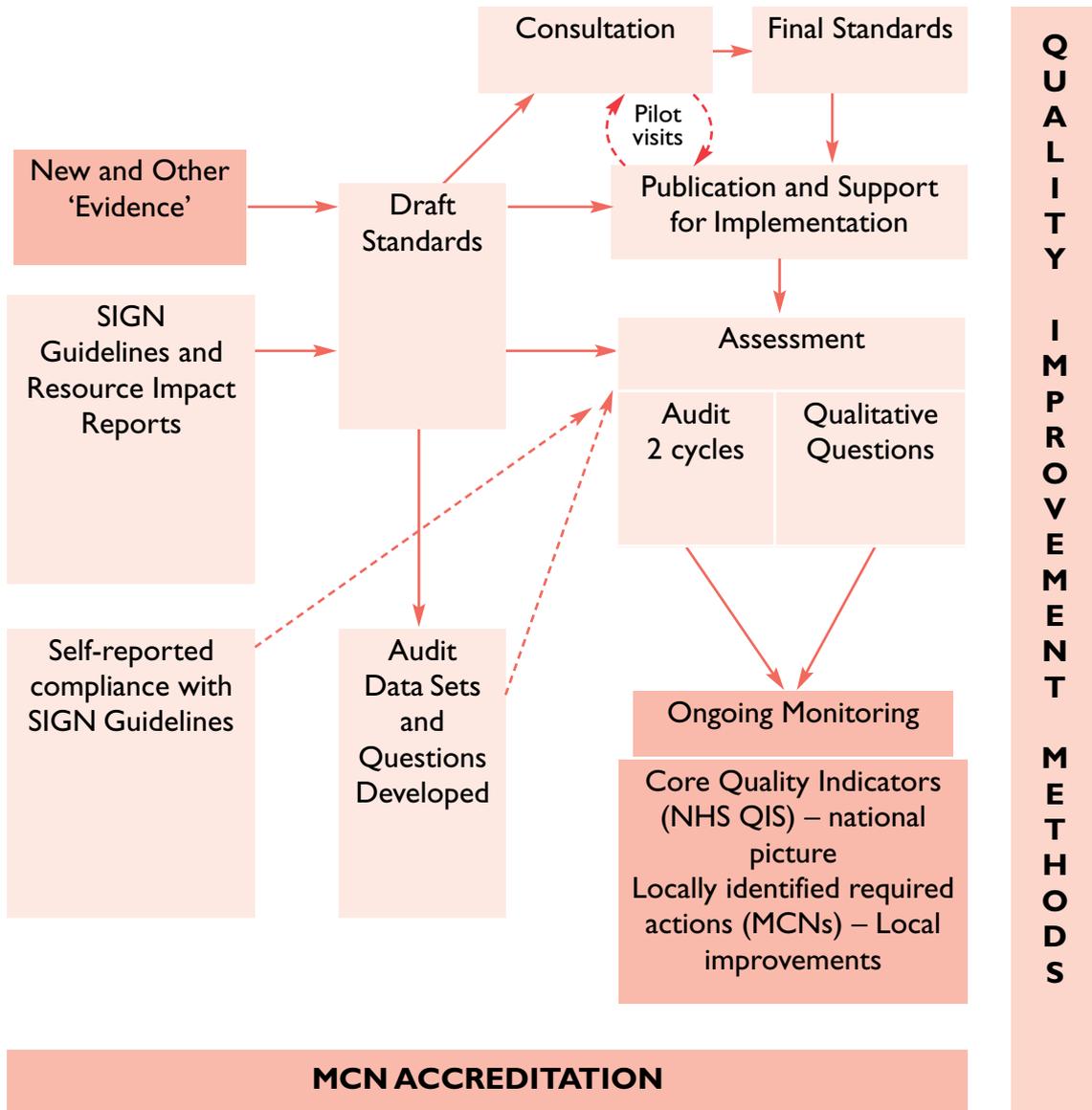
6.17 Clinical indicators will be developed, within the programme for CHD, informed by the results of audit activity. Work on developing measures of quality and safety in primary care will also be included within this work stream. It is envisaged that a small, focussed suite of indicators will provide the ongoing mechanism by which NHS Boards can monitor local activity and highlight where improvement may be required. Responsibility for this element of the CHD work programme falls within the remit of the Clinical Audit and Indicators Steering Group.

6.18 NHS QIS will ensure that emerging results and issues associated with this programme of work are shared between parallel work programmes, e.g. long term conditions and primary care to capitalise on the 'knowledge brokering role' and to ensure that the maximum benefits for people with or at risk of heart disease are realised.

6.19 NHS QIS will be developing and piloting Patient Reported Outcome Measures as part of the programme. This work will commence in late summer of 2009.

6.20 The Managed Clinical Networks (MCNs) are pivotal in taking the CHD Improvement Management Programme forward. NHS QIS will work closely with a range of key stakeholders but particularly the MCNs to ensure the success of the Programme. Accreditation of local cardiac MCNs will form part of this work, and the Programme will support MCNs to achieve accreditation.

**NHS Quality Improvement Scotland
CHD Improvement Programme 2007-2010**



Stroke

Clinical Guidelines

6.21 SIGN 13, 'Management of patients with Stroke I: Assessment, investigation, immediate management and secondary prevention', and SIGN 14, 'Management of patients with Stroke II: Management of carotid stenosis and carotid endarterectomy', have been updated and amalgamated into a single guideline entitled: 'Management of patients with Stroke or TIA: assessment, investigation, immediate management and secondary prevention'. This was published in December 2008 as Guideline 108 on the Management of patients with stroke or TIA: assessment, investigation, immediate management and secondary prevention. A patient version of the Guideline has been developed in collaboration with Chest, Heart & Stroke Scotland.

6.22 SIGN is currently working on a selective update of SIGN 64, 'Management of patients with Stroke: rehabilitation, prevention and management of complications, and discharge planning'. This will cover the issues involved in longer term support in the community following discharge from hospital dealt with in [Chapter 5](#).

Clinical Standards

6.23 NHS QIS first developed stroke standards in 2004, covering the care of the patient in the acute setting. As a result of the publication of SIGN Guideline 108, NHS QIS has revisited and updated the 2004 standards on a selective basis. The revised standards were published in draft form in December 2008 and will be finalised, following consultation, later in 2009.

Practice Development

6.24 The NHS QIS Practice Development Unit (PDU), which forms part of the new Implementation and Improvement Support Directorate, conducted a scoping exercise in 2007 with allied health professions (AHPs) to identify potential contributions to improving practice to patients with a stroke. Following this scoping, different programmes of work have been completed, including programmes of improvement support and NHS QIS reports, as follows:

- a 'Stroke' Master Class for AHPs in 2007 to share best practice and update knowledge;
- the NHS QIS response to the *Aphasia in Scotland* report including a self-assessment tool to facilitate local evaluation of aphasia services (published 2008);
- an Easy Access Version of the NHS QIS Response to *Aphasia in Scotland* (published in February 2009) and specifically developed for people with aphasia;
- a programme of implementation and improvement support provided by the NHS QIS Practice Development Unit at six demonstration sites, The report *Road to Recovery – Easier to Swallow* (published April 2009) describes the programme which was given to nurses and AHPs in the management of the patient with dysphagia; and
- *The Road to Recovery – One Step at a Time* report (2007) outlines a review of issues relevant to AHPs and nurses in the management of ankle-foot orthoses following acute stroke. As a result of this work a Best Practice Statement on Ankle-Foot Orthoses Following Acute Stroke has begun, and will be completed in July 2009.

7: IT INFRASTRUCTURE

7.1 The Scottish Government's eHealth Strategy covers the period 2008-11. It outlines how eHealth can support the overall goals for NHSScotland highlighted in *Better Health, Better Care*. To date, Scotland has taken an incremental and pragmatic approach to developing eHealth solutions, and this will continue. However, the need for national coordination and collaboration at all levels is fully recognised, alongside the need for space for local flexibility and innovation. The developments for heart disease and stroke outlined below are entirely consistent with, and will support, the national direction of travel for eHealth.

Heart Disease Developments

7.2 Greater focus is needed by NHSScotland on the collection and collation of information related to the care of patients with cardiac conditions across Scotland. Emphasis should be placed on the use of information to improve patient care. Information should also be made available to key stakeholders at planning, managerial and clinical levels within the NHS to support service development.

Data Collection

7.3 A culture of data collection and reporting has been developed and strongly encouraged throughout secondary care, using information from established databases for cardiac surgery, PCI and the more recently implemented acute coronary syndrome register (SCI-CHD ACS). Clinicians and other CHD staff have a responsibility to support data collection at local, NHS Board, regional and national levels. Local data collection should be co-ordinated by Managed Clinical Networks. While specific CHD data officers have been key to this process, clinicians and other CHD staff have been directly involved in agreeing quarterly reports of data which reflect activity, and more importantly the quality of care being delivered in each centre. Plans to improve the accuracy and consistency of cardiac data recorded using the SMROI system are being linked to this process.

7.4 A directly relevant project, the NHS QIS CHD Improvement Management Programme (see paragraph 6.14) addresses the challenge of Guideline implementation and the establishment of processes which can assess quality of clinical care on an ongoing basis. This new approach to improving patient care, aligned with the Patient Safety Programme and Waiting Times standards, provides a sound basis for developing local templates.

7.5 A review in November 2006 of the role of current staff recognised that they needed to have wider involvement in CHD data collection than revascularisation audits. In January 2008, the Data and IT Sub-Group agreed that a wider programme of audit was required which provided measures of quality of care while also providing ongoing support for waiting times and quantitative data for service planning. In the light of these developments, NHS Boards, through their cardiac MCNs, should take the opportunity to clarify future staffing and funding arrangements for cardiac data collection within their local areas, in order to realign the focus of data collection towards the support for NHS QIS, ISD and local reporting mechanisms, rather than continuing the inputting of extensive data to registers.

7.6 In undertaking this exercise, NHS Boards are encouraged to make best use of the time-limited funds that have been made available by the Scottish Government, and NHS QIS, to support the move towards a new model for data collection in Scotland.

7.7 MCNs should work with local colleagues who have responsibility for the implementation of core work programmes such as I8 weeks and the Scottish Patient Safety Programme to ensure that relevant information relating to patient care for cardiac conditions is being captured and utilised. There is now a growing consensus as to the core information that is required to monitor patient care. The new model proposes focussing on the collection of a smaller number of key indicators to assess the overall performance of cardiac services. At a national level, work is required to develop an overall reporting framework that monitors clinical activity and patient care. The framework should build on HEAT principles summarising indicators from existing data sources and QIS standards. Further work is required to identify potential gaps in data collection which may need to be addressed.

Action:

NHS Boards, through their cardiac MCNs, should ensure that information systems are in place in order to meet the requirements of NHS QIS and ISD for the reporting of information relevant to cardiac care drawn from a range of core indicators that will be determined by May 2010.

Action:

NHS QIS, ISD and other relevant bodies, including the SAS, are required to establish mechanisms for reporting and publishing these data.

National Clinical Datasets Development Programme

7.8 A large body of work has been completed through the National Clinical Datasets Development Programme (NCDDP), hosted by the Information and Statistics Division (ISD), in developing and agreeing a comprehensive dictionary of data items for patients with CHD. Datasets are now available for heart failure, pacing and electrophysiology, cardiac rehabilitation, core cardiac information and acute coronary syndromes, and are currently being developed for chest pain clinics, cardiac catheterisation/angioplasty and cardiac surgery. Since Familial Hypercholesterolaemia is included in the NHS QIS clinical standards for CHD, the NCDDP should be extended to include FH.

Action:

The cardiac MCNs, and staff collecting information, should ensure that data definitions meet NCDDP criteria.

The NCDDP should be extended to include familial hypercholesterolaemia.

eCardiology

7.9 The National Advisory Committee's Data and IT Sub-Group has developed a high level specification document for an electronic patient record which aligns with the national eHealth agenda. This aims to build, in a modular fashion, a comprehensive clinical electronic record for patients with heart disease.

7.10 A range of IT solutions which allow routine, prospective clinically relevant data to be collected and reported are required as a matter of some urgency. An eCardiology Strategic Group should be established through the merger of the eHealth Implementation Group and the SCI-CHD ACS Steering Group. It will be charged with developing an eCardiology action plan for consideration by the eHealth Programme Board. Proposed developments must be aligned to the national priorities for data collection. Particular focus will therefore be placed on finding solutions to support the monitoring of NHS QIS clinical standards, the Scottish Patient Safety Programme and audit indicators, routine reporting by ISD, together with the ability to exploit future tracking systems for monitoring referral to treatment times for cardiac patients. Given this set of priorities, serious scrutiny needs to be given to the range of data collection systems currently in operation, with a view to determining whether these are fit for purpose.

Action:

The Scottish Government will establish an eCardiology Strategic Group to develop an action plan for consideration by the eHealth Programme Board by end December 2009.

SCI-CHD Acute Coronary Syndrome (ACS)

7.11 SCI-CHD ACS is an audit system with substantial clinical functionality that enables web-based collection of NCDDP compliant data on the management of ACS patients. The first version was released in January 2006 and the system is now switched on in 28 hospitals, with another four currently working through the implementation process, including the Golden Jubilee National Hospital and the hospitals in NHS Lanarkshire.

7.12 Current functionality includes:

- **NCDDP ACS dataset:** the system utilises and has extended the nationally agreed NCDDP ACS dataset, ensuring that consistency of data is maintained across NHSScotland;
- **Link to National CHI:** this ensures that all patient data has a validated CHI number attached to it where possible;

- **Production of discharge letters:** data collected throughout the patient's admission are compiled to produce pdf Immediate and Final discharge letters. The letters are compliant with the relevant SIGN Guideline and contain the fields required to send discharge letters through SCI Gateway. Robust sign-off mechanisms for junior doctors, consultants and pharmacists have been incorporated, and a support mechanism for secretaries to manage the printing and filing of letters is also available. For the moment, a hard copy of the discharge letter will be sent to the patient's GP, but in due course will be transmitted through SCI Gateway.
- **Reporting:**
 - **National STEMI Standards:** the ability to instantly produce predefined reports for submission of the Scottish Quarterly STEMI standards, subsequently allowing benchmarking across NHSScotland;
 - **MINAP:** in conjunction with ISD, work is in hand to transfer data from SCI-CHD to MINAP, to allow UK benchmarking. This link has been successfully piloted and live data will be transferred in the near future.
- **National Networking Model:** this incorporates a new security model to allow the viewing of records between hospitals across NHSScotland. Links between hospitals within the same region can be activated to freely share episodes on a view-only basis, e.g. Raigmore Hospital can activate a link with Western Isles Hospital. The regional model has been extended for those major receiving/interventional centres to allow links across NHSScotland rather than just within regions. Hospitals in which links have not been activated, or are outwith the region, can still share records, but this is done using a 'break glass' function where a reason for accessing the record must be given.

Demonstrations of the functionality of the system have been given to the three Cardiology Regional Planning Groups. The Scottish Government, the SCI-CHD ACS chair and the NHS QIS Clinical Advisor are working closely with NHS Boards' Caldicott Guardians to ensure data transfers meet required information governance standards.
- **SIGN Guidelines integration:** elements of SIGN Guideline 93 have been incorporated into SCI-CHD ACS to allow clinicians easy access to relevant guidance.
- **Risk Score Calculation:** risk calculators have been incorporated into the system and will be used to select patients for urgent in-patient transfer to regional centres for investigation and/or intervention in accordance with NHS QIS standards.

7.13 Over the coming year, SCI-CHD will build on the National Networking Model, moving away from the ACS orientation that the system has followed up until now. It will increasingly look at bringing together data on cardiology patients from varied sources into a central location through improving clinical care and improving speed of access to data by clinicians.

Action:

The eCardiology Strategic Group should look at extension of this CHD information gathering to primary care.

7.14 Discussions are ongoing with NHS QIS to fully embed the production of the NHS QIS CHD standards into SCI-CHD ACS. SCI-CHD ACS will develop a multi-functional tool, allowing use as:

- an ACS registry;
- a tool to collect the NHS QIS sample audit data;
- a tool to monitor the Scottish Patient Safety Programme performance measures for ACS; and
- a clinical system embedded in the clinical environment, producing 'real time' data.

The need for duplicate data entry and collection will be minimised, and the system used to deliver regular reports for quality improvement.

Action:

NHS Boards, in conjunction with their cardiac MCNs, need to establish mechanisms to collect the NCDDP ACS data set through SCI-CHD ACS (or a compliant alternative system) by March 2010.

The eCardiology Strategic Group, working closely with representatives from the Scottish Government, will ensure development priorities are delivered within the agreed funding arrangements and timetable.

7.15 The Wellcome Trust has recently funded (£3.6m) the Scottish Health Informatics Programme (SHIP), a Scotland-wide platform to enhance the use of patient records for research. The programme builds on ISD's ongoing development of a secondary uses service for NHSScotland to establish a research portal to test new ways of linking health service records with external research datasets.

Links to Scottish Ambulance Service

7.16 SCI-CHD ACS will continue to work with the Scottish Ambulance Service (SAS) on ways of transferring data from the central SAS system to SCI-CHD. These data are key to the optimal reperfusion service. Currently the SAS does not record the patient's CHI number against the ambulance record, which eliminates the possibility of linking records within SCI-CHD. Work is taking place within the SAS to rectify this in the coming year.

Action:

The Scottish Ambulance Service, working with other national bodies, should continue to explore mechanisms to link their databases with SCI-CHD, to improve national data collection on the delivery of optimal reperfusion services.

ASSIGN

7.17 As part of the eHealth strategy, there will be a national contractual framework in the near future for Board procurement of GP IT systems which will require such systems to meet certain criteria. To increase usage of ASSIGN (see paragraphs 3.28-3.29), functionality to embed the tool in the clinical system will be considered for inclusion as a highly desirable feature in this contractual framework, which is currently being developed by a consortium of NHS Boards.

Stroke Developments

7.18 Several strands of work have been proceeding in the area of stroke eHealth, which have already brought minor improvements in patient care but which promise to yield important benefits over the next five years.

7.19 As in the case of heart disease, the National Clinical Dataset Development Programme (NCDDP) coordinated by ISD, has developed agreed clinical terms which can be used in Clinical Information Systems. The clinical stroke community has worked with the NCDDP to produce several datasets including those relating to inpatient care, outpatient care, nursing and allied health professionals (AHPs). This work is an essential step in introducing electronic patient records (EPR) to stroke services.

7.20 The Scottish Stroke Care Audit was developed under the auspices of NHS QIS. Currently it comprises a separate audit based in each NHS Board area which uses comparable methods and software to collect, store and analyse a standard dataset which reflects the performance of services' delivery of evidence-based stroke care in Scotland. Each MCN employs audit coordinators who extract audit data from clinical casenotes, enter it into their database and analyse it. Each year the data from these audits are pooled to provide a National Report which is the main tool for monitoring progress against the NHS QIS standards for stroke service, the targets set in the Strategy and also MCNs' own targets for service improvement. The audit has demonstrated improvements across many aspects of stroke services, but there is still a long way to go.

7.21 The stroke audit is now being integrated within ISD as part of the coordination of all National Audits. Data which reflect quality of care will be transferred from electronic patient records (EPRs) to an audit system which will increase both the efficiency and accuracy of data collection. Increasingly, audit data will reflect current, rather than past, performance, and will help to identify service areas in need of improvement. A central database is now being developed at ISD which will allow integration with other datasets, such as SMRI and General Registers of Scotland.

7.22 Several stroke MCNs have developed and implemented EPRs to support their stroke services.

EPR use in local stroke services

The stroke unit in Ninewells has introduced an electronic patient record which allows the multidisciplinary team to record their work and to produce daily job lists for team members, and immediate and final discharge summaries. Team members enter information on laptops with wireless connections to hospital intranet.

In the neurovascular clinic at the Western General Hospital, doctors and nurses enter patients' history and examination directly into a purpose built web-based system. This allows the doctor to generate a letter to the patients' general practitioner during the consultation. The patient can take the letter to the GP the same day which ensures that they are started on appropriate treatment as early as possible. The system also produces typed requests for investigations and tailored information packs for patients and has markedly reduced the time spent dictating letters and typing them.

7.23 Although these local EPR systems work well in the services which developed them, there are significant hurdles to rolling them out across the country, including the fact that they do not currently communicate with each other; or other local IT systems such as laboratories and radiology. The Scottish Government has therefore provided project funding to:

- amalgamate the work already done on EPR in various NHS Boards, in particular Glasgow, Tayside and Lanarkshire as well as GCS modules in Lothian;
- build a detailed specification for a national generic EPR for stroke; and
- liaise with the Scottish Government eHealth Team to agree the way forward nationally.

The detailed EPR specification is being developed in NHS Lothian using TRAK software. It is hoped that the specification will provide NHS Boards with the necessary support to develop a national EPR for stroke within their individual Patient Management Systems.

7.24 The Scottish Government initiative of rolling out the national Picture Archiving and Communications Systems (PACS) system to all hospitals in Scotland is directly relevant to stroke patients. Plain X-rays and scans are now captured digitally and can be stored on computers, allowing doctors from across Scotland to see images, even if these were taken at another hospital.

7.25 The roll-out of the PACS system will bring particular benefits in the case of stroke patients, where doctors are very reliant on brain scans to make an accurate diagnosis. The system will enable clinicians to get a specialist opinion on the scan very rapidly, from another expert working in a different hospital, with obvious clinical benefits.

7.26 Telemedicine is also being used in a number of settings across Scotland to allow stroke patients to receive earlier and therefore more effective treatment with thrombolysis at their local hospital, even when a local stroke specialist is not available (see Chapter 5).

8: NATIONAL ADVISORY COMMITTEE STRUCTURES

8.1 The National Advisory Committee on Stroke will continue to act as the main forum for advice to the Scottish Government Health Directorates on all aspects of stroke, chaired by the Lead Clinician for Stroke. Its existing Sub-Groups will also continue. The National Advisory Committee on Heart Disease will also continue, chaired by the Lead Clinician for Cardiac Conditions, with a remit that reflects the range of cardiac conditions now covered by the Strategy.

8.2 The membership of these Committees will reflect that range of interests, including direct involvement of people with cardiac disease or who have had a stroke. The Committees will continue to have a Sub-Group that brings together at regular intervals the Lead Clinicians of the cardiac and stroke MCNs. In terms of CHD, the main function of the Intervention Sub-Group has been taken over by the Scottish Health Technologies Group, which, through its horizon-scanning and facilitating independent remit, provides assistance to the NHS in relation to upcoming technologies and their evidence base, including those relevant to cardiology. The functions of the Data and IT Sub-Group have been taken over by ISD and NHS Quality Improvement Scotland's audit programme. It is therefore being discontinued and replaced by the eCardiology Strategic Group. Both the National Advisory Committees will be supported by such short-life working groups as they see fit to set up (such as that which is currently looking at inherited cardiac conditions).

8.3 The inter-regional cardiac planning group (see paragraph 4.19) should function as a sub-group of the National Advisory Committee on HD, as should the eCardiology Strategic Group referred to in paragraph 7.10.

8.4 The cardiac and stroke Managed Clinical Networks in each NHS Board will remain the vehicles which NHS Boards should use to assist them with the planning and development of relevant services. The Networks have a central role in assessing Boards' performance against the new clinical standards for CHD and the partially revised clinical standards for acute stroke published by NHS Quality Improvement Scotland and in the audit arrangements being put in place by NHS QIS.

8.5 It will also be the role of the Networks to monitor implementation of the actions in this Action Plan and to provide regular updates on progress to the National Advisory Committees on Heart Disease and Stroke. The degree to which NHS Boards involve their cardiac and stroke MCNs in taking forward actions in this Action Plan will form an essential aspect of NHS QIS's accreditation of these Networks.

8.6 In taking forward work on the revised strategy and action plan, SGHD will also work closely with the various professional bodies in this area such as the Scottish Cardiac Society, the British Association of Stroke Physicians, the Scottish Stroke Nurses' Forum and the Scottish Heart Failure Nurses.

8.7 The key voluntary sector organisations will be involved in the work of these National Advisory Committees and their working groups.

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