

Coronary Heart Disease

National
Service
Framework

Chapter Eight

Arrhythmias and Sudden
Cardiac Death

8



National Service Framework for Coronary Heart Disease

Chapter Eight: Arrhythmias and Sudden Cardiac Death

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Foreword

In the five years since the publication of the National Service Framework for Coronary Heart Disease, there have been impressive improvements in the way that the NHS tackles England's biggest killer. Mortality rates have fallen quickly and health inequalities are beginning to narrow. Waiting times for diagnosis, heart bypass surgery and angioplasty have reduced dramatically. Emergency care is quicker and more effective. Two and a half million people are receiving life-saving statins. New services are helping smokers to stop and we are investing in our children's future with the national school fruit scheme and a range of new measures in the public health white paper, *Choosing Health*.



The first seven chapters of the NSF concentrated primarily on disease in the arteries. The publication of this new chapter completes the set by addressing diseases of the heart's electrical systems. It provides new models of care and markers of quality to support further improvement in services for arrhythmias and better prevention of sudden cardiac death.

Arrhythmias, or irregular heartbeats, range in their severity – from a minor inconvenience or discomfort to a potentially fatal problem. The symptoms a person may experience include palpitations, dizziness or blackouts. They are very common, particularly among older people. They can have a profound effect on the quality of life of the people who suffer from them and there is a good deal that the NHS can do to tackle them.

This new chapter also gives special attention to sudden unexplained cardiac death. Where there is little or no warning of death in a young person, each family story is moving and each story is tragic. Experts estimate that there are up to 400 such deaths each year. With this document, we aim to prevent some of these tragedies and ensure that there is appropriate support for the families of people who die unexpectedly, many of whom are young.


This new NSF chapter provides a quality framework against which local services can secure improvements. It will enable the NHS to deliver the highest quality of care to people whose lives are affected by arrhythmias.

The standards based system heralded by *Standards for Better Health* makes it clear that National Service Frameworks are key to supporting improvements in service quality. Together with guidance from the National Institute for Clinical Excellence, they are integral to the new system. Some of the terminology is changing. From now on National Service Frameworks will establish 'Quality Requirements', underpinned by the best evidence available, which describe the principles of care that clinicians and others will use to guide their practice. Over the course of the three year planning period NHS

organisations' performance will be assessed not just on whether they are meeting national targets, but increasingly on whether they are delivering high quality services across a range of areas, including National Service Frameworks.

I would like to thank the members of the External Reference Group for their advice on this new National Service Framework chapter, including the Arrhythmia Alliance, the Cardiomyopathy Association, Cardiac Risk in the Young, SADS UK and the Syncope Trust and Reflex Anoxic Seizures (STARS). Dari Taylor MP and the patient and family groups worked tirelessly to ensure that this important area received the attention it deserves.

The NHS can take great pride in the way that it has delivered the first seven chapters of the NSF. I am confident that this new chapter will see a similar story of improvement for patients and their families.

A handwritten signature in black ink, reading "John Reid". The signature is written in a cursive style with a long horizontal stroke extending to the right.

John Reid
Secretary of State for Health

Section One: Setting the scene

Introduction

1. The National Service Framework for Coronary Heart Disease, published in March 2000, set out a blueprint for provision of fairer, faster high quality services for the prevention, diagnosis and treatment of coronary artery disease, based on 12 national standards.
2. This new chapter extends the scope of the NSF to include cardiac arrhythmias (electrical disorders of the heart), and the way in which the NHS responds to sudden cardiac death.
3. This section sets out the background and context for the quality requirements. Section two sets out the three quality requirements and 20 markers of good practice for implementation. Section three sets out how the Department of Health and other national bodies will support this work.

Arrhythmias

4. An arrhythmia is an abnormality of the heart's rhythm, either caused by an inherited problem or by an acquired condition that disturbs the electrical impulses which regulate the heart. The heart may beat too slowly, too quickly or in an irregular way. The symptoms a person may experience include palpitations, loss of consciousness, dizziness and breathlessness. In extreme cases, certain types of arrhythmia can cause sudden cardiac death.
5. Cardiac arrhythmia affects more than 700,000 people in England and is consistently in the top ten reasons for hospital admission, using up significant A&E time and bed days. Atrial fibrillation (AF), the most common arrhythmia, affects up to 1% of the population (rising to 4% in the over 65s) and absorbs almost 1% of the entire budget of the NHS.¹ The overall incidence of stroke is about 5% per year in people with AF so it is a significant cause of mortality in England.²
6. In recent years there have been significant improvements in both technology and clinical skills that are enabling improved prevention, diagnosis and treatment of these conditions. Implantable cardioverter defibrillators (ICDs) and sophisticated pacing devices have given cardiologists many more treatment options for these patients.³ For some conditions, catheter ablation, which treats malfunctioning parts of the heart, provides a cure so that patients no longer require medication or suffer from palpitations.
7. Delivering improved quality of initial and early care for patients with arrhythmia will lead to these cases being managed more quickly, more cost effectively and in appropriate settings with improved quality of life and survival outcomes. Many patients can be cured of troublesome or life-threatening arrhythmias. Others can be treated so

their chances of long-term survival are greatly increased. Many of these treatments also improve quality of life and demonstrate value for money.

Sudden cardiac death

8. The substantial majority of the approximately 100,000 sudden cardiac deaths each year in the UK are caused by coronary heart disease, which is addressed in previous chapters of the NSF. However, most sudden deaths in people under 30 years old are caused by inherited cardiomyopathies and arrhythmias. An estimated 400 sudden cardiac deaths each year are unexplained and the majority of these have a genetic basis.
9. This chapter sets out a quality requirement and markers of good practice to support the NHS services in identifying people who are at increased risk and assessing them and their families to reduce their chances of dying from an arrhythmic condition. In addition to purely clinical care it sets out best practice for ensuring that, for those diagnosed with a potentially life threatening condition, and their families, there is appropriate counselling, advice, information and psychological support.

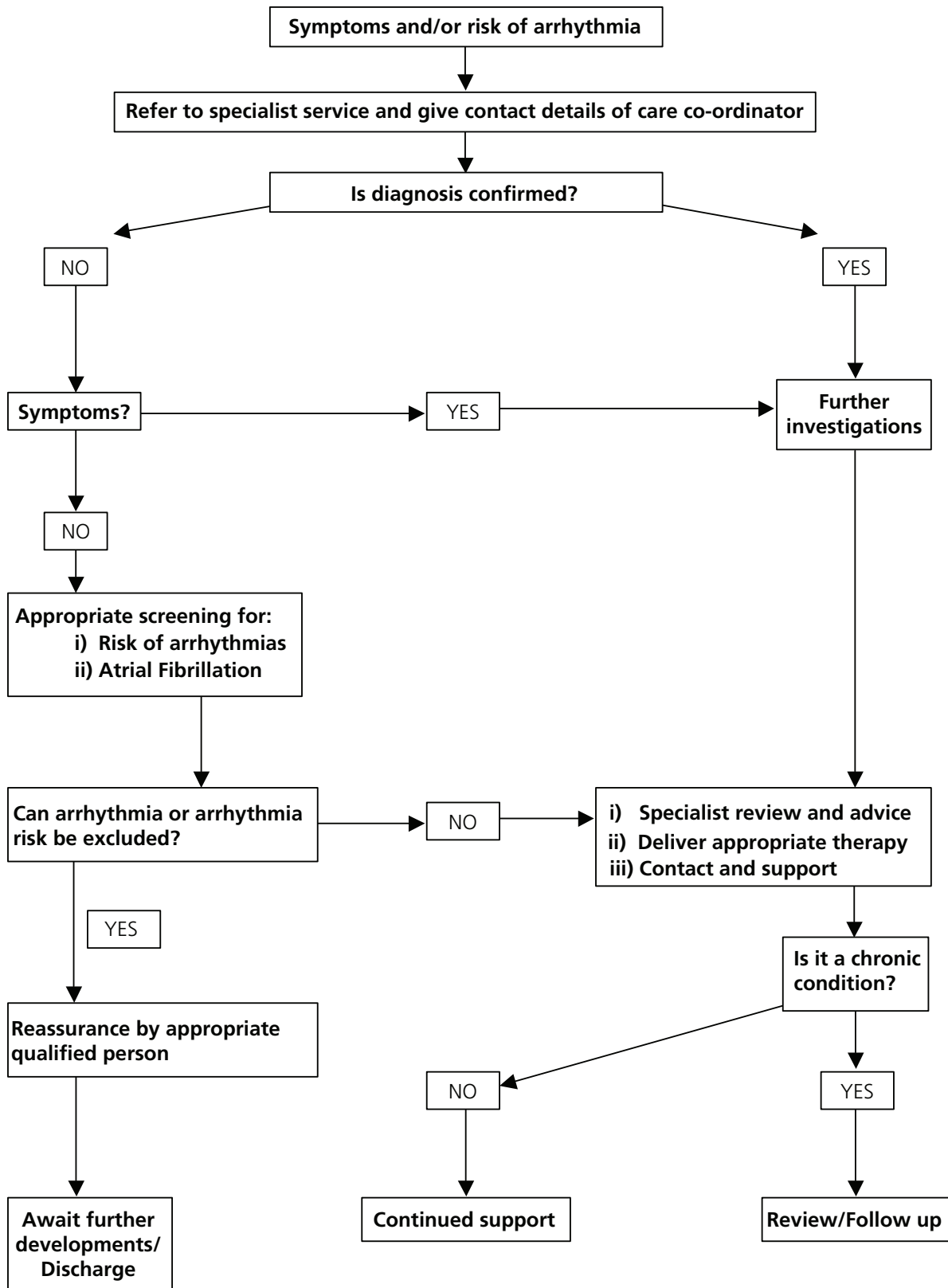
Where arrhythmias are treated

10. The setting for the care of arrhythmias varies according to the nature and severity of the condition. For many people, initial expert assessment and reassurance is all that is necessary. Others may need to be seen by a cardiologist or specialist nurse to ensure appropriate diagnosis and treatment. Some will require more specialist treatment or an operation. Regular follow up may be required, for example patients with pacemakers need check ups to ensure their device is functioning normally and that their condition is stable.

Further information

11. Further information on the conditions covered in this new chapter will be made available on the Department of Health website at www.dh.gov.uk/PolicyandGuidance. These documents include the evidence base for the quality requirements and markers of good practice set out in this document. They include a resource of further models of care and protocols that can be adapted locally to assist local planning and implementation. They also incorporate important testimony from patients and their families which provide valuable insights into ways in which services can be made more responsive to their needs.

Figure 1: Care pathway for arrhythmia patients



The quality requirements

12. The quality requirements set out in this chapter are:

Quality requirement one: Patient Support

People with arrhythmias receive timely and high quality support and information, based on an assessment of their needs.

Quality requirement two: Diagnosis and Treatment

People presenting with arrhythmias, in both emergency and elective settings, receive timely assessment by an appropriate clinician to ensure accurate diagnosis and effective treatment and rehabilitation.

Quality requirement three: Sudden Cardiac Death

When sudden cardiac death occurs, NHS services have systems in place to identify family members at risk and provide personally tailored, sensitive and expert support, diagnosis, treatment, information and advice to close relatives.

Conclusion

13. The *NHS Improvement Plan* made clear that in future the NHS would have fewer performance targets, to enable greater local flexibility in tailoring services to local needs. In turn it gave a stronger emphasis on the standards and quality requirements by which patients can judge the performance of the services they receive. In keeping with this philosophy, the NHS will be able to use this chapter of the NSF to inform the delivery and redesign of local services.
14. Improvements to services in this area will make an important contribution to the delivery of the reduced set of national Public Service Agreement targets that have been agreed with the NHS, and will help narrow inequalities in health due to cardiovascular disease. Better management of atrial fibrillation will reduce mortality from stroke. Prompt treatment of arrhythmias will be an important part of the work to guarantee a maximum 18-week wait by 2008. Improved care for this large group of patients can also make a significant contribution to the delivery of the target for reducing unnecessary and costly emergency admissions to hospital for acute episodes of these chronic diseases.

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Section Two – The quality requirements

Introduction

1. Since the publication of the first seven chapters of this NSF, the Government has adopted new devolved approaches to the NHS, set out in *The NHS Improvement Plan* and *Standards for Better Health*. Together, these underpin the delivery of high quality services which are fair, personal and responsive to patients' needs and wishes. They recognise the importance of adopting a common framework for all matters related to performance and a common language, so that terms such as "standards" have a clearly understood and shared meaning. The Department of Health defines standards as a means of describing the quality that healthcare organisations are expected to meet or aspire to. "Quality requirements" will be established through National Service Frameworks. These describe the care and approaches which local services will use to guide their planning and clinical practice.
2. Chapter Eight of the NSF identifies three quality requirements covering patient support, diagnosis and treatment and sudden cardiac death. This section sets out the aims of each of the three quality requirements, their rationales and the markers of good practice to inform their local delivery and assessment. Quality requirements will also inform the Healthcare Commission in developing the criteria for assessment and inspection of arrhythmia care. The Healthcare Commission will undertake thematic reviews of progress towards meeting the quality requirements set out in this chapter.
3. The care pathway set out on page 5 will assist in planning implementation of these quality requirements. Further generic pathways and protocols to inform local delivery will be made available on the dedicated website.

Quality requirement one: Patient Support

Aim: To improve the emotional and practical support offered to patients with arrhythmias and their families.

Quality requirement: People with arrhythmias receive timely and high quality support and information, based on an assessment of their needs.

Rationale

4. All patients require information about their condition and how best to manage it. Appropriate support early in the care pathway for people with heart problems has been shown to reduce anxiety and depression, encourage behaviour change and reduce the use of health resources.¹ For example, it is often helpful for patients scheduled to receive a cardiac intervention to receive a contact name and a phone number they can use to obtain advice. For younger people, families and carers are better able to cope with their health problems if they are empowered to become partners in the continuing care of children and young people by developing

individualised, non-prescriptive treatment plans in conjunction with the child or young adult as set out in the Children's NSF.²

5. Any illness related to the heart may cause anxiety to patients, even in the case of benign conditions. Numerous studies have shown that living with an arrhythmia places patients at greater risk of psychological problems and a poor quality of life. Appropriate information and support can relieve this.³
6. A standardised and formal assessment of needs, followed by the setting of agreed goals and ongoing support with active self-management, reduces the likelihood of patients missing out on the support they need. This would also prevent clinicians' possible preconceptions affecting how patients respond to offers of support, and ensure appropriate provision of services.
7. Some groups of patients are at significantly increased risk of anxiety, depression and a poor quality of life. These include those who are about to receive an ICD, or have recently done so. Routinely checking for these problems, and establishing appropriate protocols for providing suitable care, would increase quality of life for these people.

Markers of good practice

- People with arrhythmias receive a formal assessment of their support needs and those at significantly increased risk of anxiety, depression or a poor quality of life receive appropriate care.
- People with long-term conditions receive support in managing their illness from a named arrhythmia care co-ordinator.
- Good quality, timely information about arrhythmic conditions is given by appropriately trained staff.

For children and young people:

- Every child and young person receives age-specific preparation, treatment, support and follow-up.
- Transition to adult services does not automatically occur at age 16 but takes into account the individual needs and wishes of the young person.

Quality Requirement Two: Diagnosis and Treatment

Aim: To ensure expert assessment of a person in whom an arrhythmia is suspected, and that an appropriate and clinically effective care pathway is followed.

Quality requirement: People presenting with arrhythmias, in both emergency and elective settings, receive timely assessment by an appropriate clinician to ensure accurate diagnosis and effective treatment and rehabilitation.

Rationale

8. For many NHS professionals, awareness and understanding of cardiac arrhythmias is low. This can lead to some arrhythmias being undetected when patients present for the first time, particularly if the symptom has stopped by the time an examination can be made and an ECG recorded. For all patients with an arrhythmia or suspected arrhythmia, prompt recording and archiving of a 12-lead ECG, even if symptoms have

subsidised, improves the chance of accurate diagnosis and can help to prevent subsequent events and ensure appropriate further investigation and treatment.

9. All patients successfully resuscitated from cardiac arrest outside of hospital are at increased risk of recurrent, life-threatening arrhythmias. Immediate transfer to hospital and pre-discharge assessment by a cardiologist will enable more rapid diagnosis and treatment of their disease and reduce their chances of further life-threatening arrhythmias.
10. Service improvements can be achieved locally by several means:
 - guidance on making the initial diagnosis and on management by readily accessible approved algorithms;
 - improving access to a higher level of expertise by development of rapid access multidisciplinary arrhythmia and/or blackouts clinics;
 - focused education of key carers;
 - improving access to diagnostics at all stages; and
 - improving acquisition, storage and availability of clinical information such as ECGs and audit of all interventions.
11. Effective arrhythmia care allows many patients to be cured and discharged. Those with long-term conditions may be managed in primary care (after their initial assessment) and some will require hospital follow up. These steps require close collaboration at all levels of the health care service, for example in the development of innovative shared care protocols and patient education. A multidisciplinary approach is key to ensuring improved service to those with cardiac arrhythmias and to the delivery of interventional therapies. Better access to effective treatment in primary, secondary and specialist settings will reduce hospital admissions, reduce mortality and improve the quality of life for patients and their families.
12. A significant number of people suffer from blackouts of cardiac origin. Some of this group will require long-term medication, catheter ablation or the implantation of a pacemaker or ICD. Whether or not this is the case, all patients and their families need support and a detailed explanation of the cause and likely prognosis of their symptoms. It is particularly important that children and young people suffering from blackouts are expertly assessed.
13. As with any clinical intervention, it is important that staff carry out a sufficient volume of activity to ensure they are appropriately skilled to provide high quality care and meet appropriate standards.⁴

Markers of Good Practice – Initial Treatment

- All patients receive a hard copy of the ECG documenting their arrhythmia and a copy is placed in their records.
- Patients who survive out-of-hospital cardiac arrest and patients presenting with pre-excited atrial fibrillation are assessed by a heart rhythm specialist prior to hospital discharge.
- The following patients are assessed urgently by a heart rhythm specialist:
 - a. Patients with syncope or any other symptom(s) suggestive of an arrhythmia and a personal history of structural heart disease or a family history of premature sudden death
 - b. Patients with recurrent syncope associated with palpitations
 - c. Patients with syncope and pre-excitation
 - d. Patients with documented 3rd degree AV block (not associated with acute MI)
 - e. Patients with recurrent syncope in whom a life-threatening cause has not been excluded
 - f. Patients with documented ventricular tachycardia
- The following patients are referred to a heart rhythm specialist:
 - a. Patients with a presumed diagnosis of ventricular tachycardia
 - b. Patients with Wolff-Parkinson-White (WPW) syndrome or asymptomatic pre-excitation
 - c. Patients with symptomatic regular recurrent supraventricular tachycardia which is unsuccessfully treated with one type of medication or who would prefer not to take long-term medication
 - d. Patients with recurrent atrial flutter
 - e. Patients with symptomatic atrial fibrillation despite optimal medical therapy
 - f. First degree relatives of victims of sudden cardiac death who died below the age of 40 years
 - g. Patients with recurrent unexplained falls

For children and young people:

- Any child with recurrent loss of consciousness, collapse associated with exertion, atypical seizures with a normal EEG or with any documented arrhythmia is referred to a paediatric cardiologist.

Markers of Good Practice – Ongoing Treatment

- Mechanisms are in place for urgent referral of patients with sustained or compromising arrhythmias for prioritisation of appropriate treatment.
- Implantable cardioverter defibrillators (ICDs) are considered in patients presenting with life-threatening ventricular arrhythmias and in those without demonstrable arrhythmia but identified as being at high risk.
- Catheter ablation is considered as the treatment of choice in patients presenting with sustained supraventricular tachycardia (SVT) other than atrial fibrillation, and cardioversion of recent onset atrial fibrillation (AF) is considered as early as is clinically safe.
- Where further hospital treatment is not recommended, a care plan is agreed between the patient, GP and the arrhythmia care team, including follow up and support as required.

For children and young people:

- Treatments and service delivery for children, and adults with congenital heart disease, are tailored to meet their needs.⁵

Quality Requirement Three – Sudden Cardiac Death

Aim: To reduce mortality from sudden death and improve services for families who have lost a close relative.

Quality requirement: When sudden cardiac death occurs, NHS services have systems in place to identify family members at risk and provide personally tailored, sensitive and expert support, diagnosis, treatment, information and advice to close relatives.

Rationale

14. Sudden cardiac death in younger people is often indicative of inherited cardiac disease. There is real potential to prevent further tragedies by the appropriate care of family members in these cases.
15. Unexpected death of a family member is deeply traumatic for those who experience it. Appropriate support from professionals as well as other people who have experienced similar tragedies helps people to cope with such events.
16. Good awareness in primary care of conditions which can lead to sudden death is an important part of preventing some of these deaths. Examples of these conditions are hypertrophic cardiomyopathy, right ventricular cardiomyopathy, Long QT syndrome, Brugada syndrome and Wolff-Parkinson-White (WPW) syndrome. More information about these conditions can be found at www.dh.gov.uk/PolicyandGuidance.
17. When sudden unexplained cardiac death occurs, close relatives are at potential risk of also having a fatal cardiac condition. A coroner's post-mortem is vital to determine the cause of death and (subject to appropriate consent) provides the opportunity to assess the potential risk to the family. More information about the role of the coroner can be found at www.dh.gov.uk/PolicyandGuidance. Effective evaluation of relatives, guided by genetic testing, can prevent further deaths in the family.
18. A standard post-mortem, which specifically looks for the commonest causes of premature sudden death, has been drawn up by the Royal College of Pathologists. This includes preservation of appropriate tissue if required for subsequent DNA extraction and histological review. Consent from the family must be obtained for any samples to be held for future testing. Appropriate involvement of the coroner, pathologist and family doctor in the management of these cases helps to ensure appropriate case identification.

Markers of good practice

- Individuals who experience episodes of sustained palpitation and/or unexplained impaired consciousness, particularly if repeated or triggered by exercise, have rapid access to cardiac evaluation, including 12-lead and continuous ECG monitoring and 2D echocardiography.
- Suitable bereavement services are available for those who have lost a family member.
- An expert post mortem is carried out and appropriate tissue retained if informed consent is given.
- Evaluation of families who may have inherited cardiac disease takes place in a dedicated clinic, with staff who are trained in diagnosis, management and support for these families. Genetic counselling and further testing is available if appropriate.

For children and young people:

- Children and young people who have lost a family member receive suitable bereavement support and, if potentially at risk themselves, appropriate clinical assessment and treatment.

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Section Three: National support to local implementation

Introduction

1. The *NHS Improvement Plan* and *Standards for Better Health* make it clear that in future, the NHS will have fewer performance targets, but a stronger emphasis will be placed upon core and developmental standards by which patients can judge the performance of the NHS. *Shifting the Balance of Power* has seen money, control and responsibility pass to local health services so that the communities they serve have greater influence over the way local resources are spent and the way local services are run. Delivery models that have worked well in the past may continue to do so; however, some may need to change. The Department of Health is working with Strategic Health Authorities and others on initiatives to support the NHS in implementing this NSF.
2. SHAs and PCTs can choose how they phase the process of implementing the quality requirements over the next five years.
3. Section Two set out three quality requirements and 20 markers of good practice aimed at better services. This section sets out how national action will support local implementation.

Investment

4. The last five years have seen historic and unprecedented levels of investment in cardiac services. The NHS is currently delivering a £600m programme of capital investment in specialist cardiac services to expand existing hospitals and build new hospitals for cardiac care in which capacity for electrophysiology services for arrhythmia patients has been an important component of local planning. This has been supplemented by a jointly funded Department of Health and Big Lottery programme of £125m investment in catheterisation laboratories which will increase capacity by at least 50%, enabling better access to electrophysiological diagnostic and treatment procedures. Wider investment in revenue, through general allocations to the NHS, for delivery of the 18 week wait target and NICE guidelines includes provision for these procedures. Historic levels of consultant growth and increases in other essential parts of the cardiac workforce will continue to be supported.

Modernisation and Service Redesign

5. With that investment, the key to implementation will largely centre on redesign of services rather than additional investment beyond that required by existing PSA targets on access. From April 2005 the bulk of the central resources for the Coronary Heart Disease Collaborative is being devolved to the 32 cardiac clinical networks to support service redesign and the Department of Health will work closely with the national collaborative team to provide targeted and evidence-based support to local service design to implement this chapter, where SHAs and cardiac networks request it.

The CHD Collaborative is already engaged in this area and can provide tried and tested models and approaches which improve patient care as well as efficient provision of services.

6. In addition, good practice guidance has been developed and published by the NHS Modernisation Agency. *10 High Impact Changes for Service Improvement and Delivery* sets out a range of highly effective approaches to NHS provision which are all applicable to the implementation of this chapter's aims.
7. Over time, an increasing amount of NHS services will be delivered by independent organisations such as NHS Foundation Trusts, which are not performance managed by Strategic Health Authorities (SHAs). This places particular importance on the role of Primary Care Trusts as commissioners in securing improvements in service.

Information

8. To support implementation and local clinical governance, the Department of Health will work with professional bodies, the NHS and the Healthcare Commission to test the feasibility of national clinical audit of arrhythmia care through the Secondary Users Service being developed as part of the National Programme for Information Technology.
9. A dedicated website will provide detailed information and support on implementation of the new chapter. This is available at www.dh.gov.uk/PolicyandGuidance. Further information and definitions are contained in this document at Annex A.

National Leadership

10. To provide ongoing national leadership and support, a new Arrhythmias and Sudden Cardiac Death board, reporting to the National CHD Taskforce, will enable continued patient, family, clinical, managerial and voluntary sector oversight of delivery of the chapter.

Measuring success

11. Health organisations will want to review local arrangements for people with arrhythmias and identify gaps in service provision that need improvement to meet the quality requirements set out in this NSF chapter. This will be done in the context of *National Standards, Local Action*, incorporating *Standards for Better Health*, which sets out a standards-based framework for all NHS organisations to use in planning. That document operationalises the Government's Public Service Agreement targets for the NHS and contains broad, overarching core and developmental standards for the NHS to use in planning, commissioning and delivering services.
12. In order to reduce health inequalities between areas with the worst health and deprivation indicators and the population as a whole, it is important that progress in tackling arrhythmias is made in the spearhead PCTs. This chapter will help secure these improvements, particularly through better identification and treatment of atrial fibrillation.
13. The Government will not set further national targets beyond the key Public Service Agreement targets. Local health organisations are being given greater autonomy to

take local action to improve services for the individuals and communities they serve. This will allow greater scope for locally determined targets and priorities to be matched to local needs. To be successful this will require effective health commissioning, managed through local deliver planning processes, monitored and accountable through the PCT and SHA chain.

14. In addition, the Healthcare Commission has an important role in monitoring and reviewing quality requirements across the NHS, with reference to national standards and National Service Frameworks, and in providing information to local communities about how their local services are doing. The Healthcare Commission is a new organisation and will need to develop processes for inspection and assessment. In monitoring progress towards implementation of this chapter, the Commission may wish to work in collaboration with those providing cardiac services in determining key measurables for service performance.

Annex A: Glossary

Ablation – intentional destruction of a small amount of cardiac tissue to permanently isolate, interrupt or destroy a tachycardia focus or circuit.

Anti-coagulation – thinning of the blood with drugs, usually warfarin.

Anti-tachycardia pacing – the ability to terminate tachyarrhythmias through pacing the heart at a rate faster than the tachyarrhythmia.

Arrhythmia – an abnormality of the heart beat. The heart may beat too fast, too slowly or in an irregular way.

Arrhythmogenic right ventricular cardiomyopathy (ARVC) – see ARVD below.

Arrhythmogenic right ventricular dysplasia (ARVD) – an inherited condition in which heart muscle may be progressively replaced by fatty and fibrous tissue. Areas of muscle where this occurs can set up short-circuits and lead to ventricular tachycardia (VT) or ventricular fibrillation (VF).

Atrial Fibrillation – a disorganised activation of heart muscle with loss of the normal electrical activation of the atria, which is replaced by many electrical circuits activating over the surface of the muscle in a rapid and disorganised way. This will usually result in a rapid irregular rhythm.

Atrial flutter – an arrhythmia related to atrial fibrillation, but where just a single abnormal circuit is found.

AV block – see Heart block.

Cardiomyopathy – a disease of the heart muscle, which may cause thickening, thinning and weakness, or replacement of muscle with fibrous tissue or fat. Patients with cardiomyopathies are at increased risk of arrhythmias and sudden cardiac death.

Cardioversion – the process of converting the heart back to a normal rhythm. This may involve drugs (chemical cardioversion) or with an electric current delivered across the chest (direct current cardioversion) or inside the heart (internal cardioversion).

Catheter ablation – use of catheters to pass energy into the heart to destroy abnormal tissues that are giving rise to arrhythmias.

Collapse – Sudden loss of posture with or without loss of consciousness.

Congenital heart disease – heart disease caused by deformed development of the heart in the womb.

Echocardiography – use of ultrasound to provide moving images of the heart muscle and valves, and make measurements of the functions and any damaged tissues.

Electrocardiogram (ECG) – electrical tracing of the heart's activation recorded on the body's surface.

Heart block – Abnormally slow or absent transmission of electrical impulses through a part of the conduction system of the heart.

Heart Rhythm specialist – a cardiologist who has taken a special interest in the management of heart rhythm disorders.

ICD (implantable cardioverter defibrillator) – a self-contained device implanted under the skin or muscle of the upper chest wall and connected to electric leads passing through the veins to be fixed to the heart muscle of the atrium and/or ventricles.

Myocardial infarction – coronary thrombosis causing blockage of a coronary artery resulting in a heart attack.

Pacemaker – System consisting of a pacing generator and lead(s) which regulates the electrical activity of the heart, usually to prevent the rhythm falling below a preset level.

Reflex Asystolic Syncope (Reflex Anoxic Seizures, RAS) – episodes where the patient has what looks like a seizure, but in fact has an arrhythmia. Occurs mainly in young children – any unexpected pain or shock can cause the heart and breathing to temporarily stop. Because the heart stops there may be abnormal movements of the arms and legs due to the brain being deprived of blood and oxygen.

SVT (Supra Ventricular Tachycardia):

Supraventricular – heart beats starting in the upper part of the heart, which are in general troublesome but not dangerous.

Tachycardia (tachyarrhythmia) – a fast heart beat at over 100 beats per minute.

Syncope – Fainting due to the brain being deprived of oxygen. Differs from epilepsy because in syncope the primary disturbance is cardiovascular, resulting in inadequate brain blood flow to maintain consciousness. In epilepsy, the primary disturbance is inappropriate activity of brain cells, with preserved blood flow to the brain.

T-LOC – Transient Loss of Consciousness/Fainting/Blackout with spontaneous recovery.

Vasovagal syncope – loss of consciousness caused by fall in blood pressure and slowing of heart rate due to relaxation of blood vessels and stimulation of the vagus nerve.

Ventricular Tachycardia (VT) – ventricular tachycardia is an abnormal heart rhythm arising from the muscle of the ventricles, rather than arising through the normal mechanism in the atrium.

Wolff-Parkinson-White (WPW) syndrome – a heart condition with an electrical 'short-circuit' causing the heart to race. In some patients WPW can be potentially life threatening.

Annex B: Expert Group Membership

Co-chairs

Dr Wyn Davies, St. Mary's Hospital

Professor Bob Lewin, University of York

Professor William McKenna, The Heart Hospital

Dr Edward Rowland, St. George's Hospital Medical School

Subgroup members

Dr Mark Anderson, Morriston Hospital, Swansea

Professor David Bates, Royal Victoria Infirmary

Mrs Winifred Bell, Manchester Royal Infirmary

Dr Edward Blair, John Radcliffe Hospital

Dr Tim Bowker, British Heart Foundation

Dr Christine Bundy, University of Manchester

Mr Michael Burgess, HM Coroner, Surrey

Dr Richard Charles, Cardiothoracic Centre Liverpool

Professor Stuart Cobbe, Scotland

Dr Michael Colquhoun, Resuscitation Council (UK)

Dr Derek Connelly, Arrhythmia Alliance

Miss Fiona Cooke, Southampton University Hospital

Ms Judith Cooke, Home Office representative

Mr Mark Cooke, Ambulance Service Association

Ms Alison Cox, Cardiac Risk in the Young (CRY)

Mr Steve Cox, Cardiac Risk in the Young (CRY)

Ms Thelma Dutton, Clinical Nurse Specialist in Heart Failure

Professor Patrick Doherty, York St. John College

Dr Iain Findlay, Scotland

Dr Adam Fitzpatrick, Arrhythmia Alliance

Dr Michael Gammage, University Hospital of Birmingham

Mr Robert Hall, Cardiomyopathy Association

Dr Guy Haywood, South West Cardiothoracic Centre

Dr Helen Hosker, GP, Manchester

Ms Debbie Hughes, British Association for Nursing in Cardiac Care (BANCC)

Mr Keith Johnston, John Radcliffe Hospital

Mrs Anne Jolly, SADS UK

Mr John Jolly, SADS UK

Ms Sue Jones, St. George's Hospital

Dr Gerry Kaye, Castle Hill Hospital

Mr Sidney Kaye, Patient representative

Professor Rose Ann Kenny, Newcastle University

Mr Steve Large, Papworth Hospital

Ms Stefanie Lillie, British Heart Foundation

Mrs Trudie Lobban, Arrhythmia Alliance and STARS

Professor Stuart Logan, National Screening Committee

Dr Jonathan Mant, University of Birmingham Medical School

Dr Vias Markides, National Heart and Lung Institute

Dr Pascal McKeown, Northern Ireland

Dr John Morgan, Southampton General Hospital

Ms Jayne Mudd, James Cook University Hospital, Middlesbrough

Prof Stanton Newman, Royal Free & University College Medical School

Mr Pete Nicholas, Patient representative

Dr David Oakley, British Cardiac Society

Dr Peter O’Callaghan, University Hospital of Wales

Dr David Pitcher, Resuscitation Council (UK)

Ms Louise Power, Patient representative

Dr Andrew Reid, HM Coroner, Inner North London

Mrs Pip Robinson, University Hospital Lewisham

Dr Richard Schilling, St. Bartholomew’s Hospital

Dr Sanjay Sharma, Cardiac Risk in the Young

Dr Mary Sheppard, Royal Brompton Hospital

Ms Sue Simpson, Queen Elizabeth Hospital NHS Trust

Dr Graham Stuart, Bristol Royal Hospital for Children

Dr Neil Sulke, Eastbourne District General Hospital

Ms Jenny Tagney, Bristol Royal Infirmary

Dr Malcolm Walker, University College Hospital

Professor Nigel Wheeldon, Northern General Hospital

Mr Mark Whitbread, London Ambulance Service

Dr William Whitehouse, Nottingham University

Dr Gregory Whyte, Cardiac Risk in the Young

Dr Chris Wren, Freeman Hospital

