

## PROVISION OF SERVICES

# Fifth report on the provision of services for patients with heart disease

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## EXECUTIVE SUMMARY

### Synopsis

- Services for cardiac patients are poorly provided in the UK.
- This problem has been recognised recently by the Department of Health (particularly in England) and much has already been done to rectify it.
- Despite this there remains much to do. The crucial areas that need to be addressed to secure the cardiovascular service that our patients deserve are as follows:
  - 1. Implementation of the National Service Framework (NSF):** conditions not included in the NSF should receive the same degree of attention as coronary heart disease (CHD). The NSF should be implemented consistently throughout the entire UK.
  - 2. Patient involvement:** In the past there has been very little patient involvement in the planning of cardiovascular services. Patients need to be brought into the process far more so that the service becomes truly patient centred.
  - 3. Staffing:** There is a severe shortage of all types of properly trained health care professionals and support staff that are needed to provide a modern and effective cardiovascular service. Unless proper numbers of staff are recruited and retained it will remain impossible to deliver the level of care required by cardiac patients. It is crucial that all the factors that lead to the present staff shortages are addressed as soon as possible.
  - 4. Information technology (IT):** Delivering modern care to cardiac patients is complex and the present level of IT must be improved if care is to be safe. Good IT is essential for education, training, medical records, telemedicine, and data collection. Furthermore IT is required for effective audit and reliable clinical governance.
  - 5. Reorganisation of working practices:** This is already taking place and there are great opportunities to use staff more efficiently particularly by reviewing and revising their roles. This will improve the service for the patient.
  - 6. Maintaining standards and quality:** Quality will only be maintained if levels of training and continuing professional development (CPD) for all staff are high and there is effective clinical governance. There must be time and resources allocated to this aspect of the service rather than squeezing it in to the existing service.

## EXECUTIVE SUMMARY

### The format of the report

1. This report is designed so that individual sections can be read and referred to alone with the minimum of cross-referencing. This inevitably leads to repetition. Many of the issues that are discussed in the report are common to all areas of medicine.
2. Major improvements in infrastructure including IT and personnel are needed in all areas of medicine in the National Health Service (NHS) to a similar degree. This report has focused on the infrastructure needs for the care of heart patients so as to produce a comprehensive plan for the delivery of this service.
3. The generic issues are pulled together in this summary. It starts by describing the purpose of the report and the important elements required of a service to treat cardiovascular disease in 2002. It goes on to outline the considerable progress made to date, summarise the problems that remain, and suggest what is required to bring the level of cardiovascular care in England and Wales up to an acceptable standard.
4. This report was produced as a joint initiative by many groups involved in the care of patients with heart disease and by also by patients (see box on this page). Patient and lay views are incorporated into every section and there are lay summaries with each section prepared by lay contributors. There is also a lay version of this executive summary.

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### The purpose of the report

1. The report seeks to define the present situation with regard to the provision of cardiovascular services in all areas of the health care system. It is also a description of what were, at the time of writing, thought to be the requirements to provide the service that our patients need and deserve. This information should prove useful to those who are involved in moving forward the service at all levels.
2. Summarising the present situation helped identify areas where real progress has been made in the last few years and areas of future need. Once these areas of need were known the wide ranging expertise of the contributors was utilised to suggest ways the problems can be remedied.
3. The report is not meant to be a blanket criticism of the present situation. Such an approach would be inappropriate as well as counterproductive, and would also fail to recognise the very important advances in the organisation and financing of cardiovascular care that have been made in the last years in the UK.

### What should be the aims of a service to treat heart disease in 2002?

1. The service must deliver what the patient needs—that is, it must be a patient centred service. This requires more involvement of patients in the planning of cardiovascular care. The service needs to be delivered to patients as close to where they live as possible, and there needs to be equality of access to all geographic, social, and ethnic groups.
2. The service must be responsive to changes in practice and cover the whole of cardiology rather than simply concentrating on those areas highlighted by the National Service Framework (NSF) for coronary heart disease (CHD).
3. The delays and patchiness in service delivery across the country need to be tackled. Care should be both safe and appropriate. This requires an expert, properly trained, and committed workforce with an adequate number of personnel that has the correct resources in terms of equipment, beds, information technology, and support staff. The NSF and NICE initiatives are intended to improve equity of care.
4. At present many patients with serious heart conditions are not seen by a specialist trained specifically in the care of patients with heart disease.
5. It is crucial that there is a major review of the processes by which care for heart disease is supplied throughout primary, secondary, and tertiary care. There are great opportunities to improve the way that health care professionals work together, the way their tasks are organised, and the roles that they perform.

### What has been done already?

1. Very major steps have already been taken in many different areas. This has been driven by the recognition by the Department of Health in recent years of the importance of CHD as a very major health problem in the UK.
2. This recognition has been turned into reality for the patient via the NSF for CHD. The NSF sets very precise figures for the treatment of CHD. These targets then provide a framework for the redesign of services and ensure that the important standards of care enshrined in this document are delivered to patients.
3. In practical terms the NSF has already been translated into a significant increase in the number of coronary revascularisations being performed in England. The NSF must be updated regularly since care of patients with heart disease is evolving quickly and the original NSF is inevitably out of date now.
4. The new local networks of care are rapidly developing and will provide the way to do this. This should be the first step in

a reorganisation of the method by which much cardiovascular care is delivered and will lead to integration of primary, secondary, and tertiary care.

5. Improving access for patients to the system has begun, predominantly in England, with the advent of rapid access chest pain clinics. These allow patients with new onset chest pain, but who are not in need of emergency treatment, to be seen in a specialist clinic with a minimum wait. These clinics have been set up in association with the NSF and they are now available in most areas of the UK. Other aspects of outpatient care are outdated and need to be radically rethought.
6. There has already been some progress towards better information technology (IT) and a move towards an electronic patient record; achieving this will be a major step towards complete integration of care. An NHS IT strategy has been published recently, as has information strategy for coronary disease.
7. It is also important to hear the voice of the patient as medicine moves towards becoming more patient centred. The newly established “NHS collaboratives” are a major move in the right direction.
8. There is now an emphasis on improving standards throughout the NHS. The emergence of “clinical governance” which extends audit and encompasses everything that affects the quality and safety of care is a major step forward. However it brings with it many real problems, which are discussed below, and in addition at present it applies almost exclusively to the medical profession and needs to be extended to all other health care workers.

### Problems that remain and ways of dealing with them

In this section of this executive summary the main problems in the delivery of cardiovascular care are highlighted. Some are already being tackled, at least in part, and many are common to all areas of delivery of patient care. Solving them requires a combination of new thoughts combined inevitably with increased funding. The cost of an ideal service is infinite and therefore this report prioritises the major areas. The needs for cardiac patients are of course mirrored across the spectrum of medicine, and there is an urgent need for greatly increased resources for all types of medical patients, who are being admitted to hospital in ever increasing numbers.

#### 1. Extension of the NSF

(a) The NSF has already had an enormous impact in England. However, because health care budgets and priorities are the responsibilities of devolved government departments the NSF has not been implemented in Wales, Scotland or Northern Ireland. The interest of these countries in a scheme equivalent to the NSF for CHD is variable and delayed. This has given rise to major differences in the provision of cardiac health care. These differences are especially obvious in border areas, especially where cross border referrals are commonplace. It is essential that more homogeneous services are provided.

(b) The NSF is designed to deal only with CHD, which is the single most important part of cardiology. However, there are many other important areas of cardiology and cardiac surgery, which also deal with important and life threatening conditions, for which there are effective treatments backed up by a good evidence base. These include heart muscle disease, complex heart rhythm problems, valvular heart disease, and congenital heart disease in both children and adults. These areas often generate problems that consume a large amount of time, expertise, and resource. These conditions need to be brought into focus and given the same attention as CHD. They also need funding in proportion to the demand they make on the service. This must be done soon and thoroughly otherwise there is a real danger that the whole service will be unbalanced by the emphasis on CHD to the detriment to large

numbers of other patients. Major capital schemes, planned as part of the NSF, will address some of these issues.

## 2. Involvement of the patient in cardiac care

(a) The whole medical profession has realised the need to involve patients in the planning of care. This is regarded as a high priority for patients with heart disease, many of whom need to cooperate with their doctors and vice versa to get the best care available. Attempts have already been made to do this and indeed this report has had a considerable amount of patient and lay input. However, there needs to be a better method of achieving this. The British Cardiac Society is spearheading the development of this type of consultation and has set up a working group to move this forward in conjunction with existing patient groups. This is a collaborative venture with the British Heart Foundation that already has a major presence in the community.

## 3. Staffing

(a) *Shortage of staff*—Trained staff are in short supply everywhere within the NHS. They are a precious and scarce resource in the NHS. This is largely because there are not enough trained people to fill such posts should they be available. This problem is common to all types of staff treating patients with heart disease—for example, cardiac surgeons, cardiologists, nurses, technicians, and support staff (for example, secretaries and clerks). The plans to double the number of consultants in most medical specialties over the next decade are likely to prove inadequate if cardiologists are to provide 24 hour care for all patients with heart disease.

(b) Present estimates of need show that the consultant workforce in most medical specialties will need to be doubled; in cardiology this would be an increase of the number of consultants from approximately 630 at present to 1200 (approximately 1 per 50 000 of the population).<sup>\*</sup> However, the need for 24 hour consultant cardiology care in all secondary and tertiary centres, combined with European working time directives, means that every district general hospital will need eventually (at least) five cardiologists and that tertiary centres will need more. The authors of this report believe that a target of 1500 consultant cardiologists in the UK by 2010 is not excessive.

(c) Similarly, in paediatric cardiology there are currently 59 consultants in the UK. The number needs to be increased to a target level of one paediatric cardiologist per 500 000 of the population, giving an overall figure of approximately 120 consultants in the UK.

(d) *Reasons for the shortage of staff*—These differ depending on which staff group is considered. However, it is clear that the futures of the different staff groups are tightly bound together. In some cases—for example, cardiologists and cardiac surgeons—the problem is not recruitment or retention but more one of inadequate provisions to train and employ the necessary number of people. In the case of other staff there are other major issues inhibiting recruitment. These are complex but the generally low level of remuneration and ancillary benefits for what are very responsible and demanding jobs are very important factors.

(e) *Changing roles*—The way that work and responsibility is divided up in the health care arena has changed very little over many years, but there are now attempts to alter if not break the mould. There are several examples of the way that responsibilities traditionally in the area of one group may be moved

into that of another—for example, the creation of general practitioner (GP) specialists, the extended role of nurses taking over many tasks previously carried out by doctors, and the multi-skilling of technicians so that they can do the jobs which, for example, previously needed a radiographer and a technician. These measures will not ease staffing problems unless there are adequate numbers of the group who are taking on the new responsibilities and at present this is clearly not the case. There are already too few GPs, nurses, and technicians, and therefore just shifting the work around will solve nothing. However, careful reassessment of these should lead in the long term to a much more economical and efficient delivery of service.

(f) *Chronic understaffing*—This has been present for years, and has led to overwork and low morale. This, linked with ever increasing expectations from better informed patients, has been a major factor in the upsurge of medical mistakes, patient complaints, and dissatisfaction. In a system, which involves human beings both as the givers and receivers of care, it will never be possible to eliminate error completely. However, it is essential that all the factors leading to the present situation are acknowledged and we must all work together to rectify the problems. This will require:

(i) Careful review of the systems underlying working practices. Since mistakes often arise from poor systems rather than individual mistakes, the introduction of appropriate, agreed protocols should help considerably.

(ii) Adequate time for the correct amount of continuing professional development (CPD) for the whole health care team, and adequate staffing to cover the absences of other staff for essential training.

(iii) Adequate allowance of funding and staff time to support the very important task of clinical governance.

(iv) The increased time needed for the very much more time consuming process now required of senior staff in obtaining patient consent to procedures and operations.

(v) The provision of time and resources for training and mentoring other members of the team and for running the basic elements of a scheme for revalidation.

(vi) The provision of staff skilled in counselling so that the increased amount of information needed by patients is properly provided.

(vii) Adequate staff to allow work rotas to comply with European working time directives.

All this extra work has usually been added on to an already full agenda and has received little or no additional funding or staffing despite the vast increase in the amount of work that has been involved. This should not continue.

(g) *What can be done regarding staffing?* These issues of staffing are fundamental to running an effective service for patients with heart disease. It is pointless to have excellent facilities and no one to work in them. An initiative is needed from within the specialty to look at the role of all health care professionals delivering the service and explore new and more efficient patterns of delivery. Eventually this will have to be in parallel with an overhaul of staffing in the whole NHS. Clearly this is easier to achieve within the specialty in the short term, particularly as there is general agreement that this is needed. The problems involved in such reforms are immense, but without them we will continue to fail to measure up to the growing needs and expectations of our patients. In the end this approach will only work if there is also a centrally driven reform of remuneration and working conditions to attract the people needed so urgently by the service.

## 4. Information technology

(a) Good information technology (IT) is essential for the running of the whole NHS and, if properly provided, will make the

<sup>\*</sup> In England there is currently one cardiologist per 80 000 of the population, but with significant geographical variation.

service much more efficient. This should help to alleviate some of the problems regarding staffing which have been discussed above. It is particularly needed when caring for heart patients since accurate information may be required quickly when the patient's condition changes suddenly and life threatening problems develop. Thus it is essential that the data are quickly available to all the health care professionals who deal with the patient. It will be crucial in linking primary, secondary, and tertiary care and making the new networks of care effective. This is not the case in most areas at present.

(b) Clinical governance is linked closely to IT. There is a need for accurate data to be collected and recorded locally so that the results of treating heart patients are accurately known. This area has been assisted by the publication of treatment outcomes but the quality of the data needs to be improved, validated, and risk stratified.

(c) Every section of this report makes it clear that despite recent initiatives by the Department of Health there is a major problem because of the lack of IT. Although the problems are complex this needs very urgent rectification; this is an area where a substantial injection of funds would make an enormous difference, both to the ability to buy the systems, and also to employ enough clerical and computing staff to make the systems work. The British Cardiac Society intends to develop a comprehensive data set of heart disease and its treatment. This will be a collaborative effort in conjunction with the Department of Health.

(d) *Electronic patient record*—The development of the electronic patient record will, with appropriate safeguards on confidentiality, be immediately available to the health care professionals throughout the system. This will improve coordination of care and communication which are the cornerstones of medicine.

(e) *Telemedicine*—Developing computerised links at a distance is likely to allow complex follow up procedures such as checking pacemakers and implantable defibrillators to be done at a distance which will be much more convenient for patients.

## 5. Reorganising working practices

(a) The success of the rapid access chest pain clinics, which are a relatively new concept, shows that there are opportunities to reorganise the service to the benefit of all.

(b) In the last two years 30 collaborated networks in coronary disease have been established. Their aim is to redesign service so as to improve the patient experience throughout the patient journey.

(c) Outpatient clinics are time consuming and have been performed in the same way for decades. The need for many of the attendances must be very carefully examined and better ways found to look after some of these patients. This will need the kind of cooperation that is implicit in the setting up of the local networks of care.

(d) In addition to the change in the roles of various staffing groups it is essential that the way each group organises itself is carefully examined. Among the medical staff there is an under use of non-consultant and staff grades, particularly in the context of outpatient cardiology, rehabilitation, rapid access clinics, and investigations. In the USA there has been an increase in ancillary workers known as surgeon and physician

assistants. They carry out tasks in close cooperation with doctors. They assist at operations, obtain and collate test results, etc. This saves medical time and the cost per hour is much less than it would be if a doctor were carrying out these tasks.

(e) Patterns of inpatient care are also amenable to modification, but often constraints originate from outside the immediate health care system—for example, the availability for care in the community for a patient whose needs are not medical but social. There is already a strong interface with the social services and this should be improved.

(f) The expansion of the internet will have major impacts in this area in the future, but we do not have any real feel at present for the way this will develop. It will be a major educational resource for health care professionals and also patients. Its use to aid the interaction of the patient and the health care professional is very exciting but at present poorly developed.

## 6. Maintaining standards and quality assurance

(a) *Appropriate staffing*—The standard of care depends on the employment of high quality staff who are not overworked. Issues relating to the adequacy of staffing are addressed above (section 3).

(b) *Training*—High quality staffing is only achieved if initial recruitment attracts the right people and then the training is of high quality. This depends on having the appropriate curriculum and assessment of training. Curricula and training methods must be updated on a regular basis. This is happening in some areas and a good example is the curriculum for the training of cardiologists. This is produced under the aegis of the Royal College of Physicians and was recently completely rewritten.

(c) *Clinical governance*—Clinical governance in all aspects is pivotal in the quest to maintain the standard and quality of care.

(d) *Continuing professional development (CPD)*—This is essential to maintain standards, and the right quantity and type of CPD is central to this aspiration. This will only be achieved if time is allowed for this and there is adequate cover to permit people to attend training and also to have time to organise and provide training. This must be factored into the levels of staffing and needs to be funded accordingly.

### (e) *Research*

(i) The place of research in the service is often ignored and a short term utilitarian attitude has been adopted so that research is regarded as a luxury that does not have a major role in training or maintenance of standards. This is far from the truth. Ongoing research in all areas in which the heart patient is treated produces a questioning attitude and allows new data to be interpreted with caution and intellectual rigour. It also produces pride in teams doing research, which positively affect the quality of the clinical work that they do.

(ii) At present the curriculum for training in cardiology recommends a year in research. This is insufficient to develop independent academic skills. There is a great need within British cardiology to strengthen academic cardiology. This needs more creative and innovative training programmes for both clinicians and academics with longer periods of research than is presently provided for.

**LAY SUMMARY: FIFTH REPORT ON THE PROVISION OF SERVICES FOR PATIENTS WITH HEART DISEASE**

*This report is a guide to what is needed to bring care of heart patients in the UK up to a good overall standard. It is designed to help set up new services for treating heart disease and improve existing services. The term cardiac or cardiovascular care covers all aspects of diagnosis and treatment of patients with heart disease. This report has been written by a team of doctors, nurses, other health care professionals, and also patients and lay members of the public. It is inevitable that in any area as complex as the provision of cardiac care there will be rapid progress which may be hard to keep up with. Furthermore keeping up with progress is expensive. Treatments change and hopefully improve, with new methods replacing old. The roles of the staff and hospitals providing care will also change. Two good examples are the shift of many forms of cardiac care, previously confined to specialist centres, to local hospitals and the very important expansion of the role of the nurse in the delivery of general and specialist health care. There are many other areas where similar important changes that improve care for patients are evolving. It is important that the way care is delivered is centred on the individual needs of patients. Contrary to the belief of some, this is not a new ambition among health care professionals who care for patients with heart disease. However, in the past it was not as well developed, prominent or universal as it should have been. Patients' views need to be considered more carefully and included in the planning of the way in which cardiovascular services are delivered. This report aims to reflect this goal and lead to a more patient centred service. The other key to providing modern effective services that suit the patient is multidisciplinary working at all levels. There is a strong will among all health care professionals, including doctors, nurses, technicians, ambulance, social service workers, and administrative staff, for this to occur. The new local networks of care currently being developed will provide the basis for this. A network of care is a formal structure, which allows primary care (the GP practice or local clinic), secondary care (the local hospital), and tertiary care (the specialist heart centre) to cooperate closely so that the patient receives good and appropriate treatment.*

*There have been huge advances in the diagnosis and treatment of heart disease over the last decade. The provision of care for patients with heart disease in the UK has not managed to keep up with the increased demand that these advances have created because they have occurred against a background of limited expenditure on all areas of health care. Consequently, the availability of modern care in the UK has not moved forward as fast as it should have and now compares badly with what is available in many other countries in the developed world. However, there are now very encouraging signs that this situation is being remedied. The introduction of the National Service Framework (NSF) for coronary heart disease (CHD) has been a major step forward, and secondly there has been a substantially increased allocation of funding to allow the aims of the NSF to be met. The NSF is a series of carefully thought out standards of care for patients with CHD, which if met will greatly improve the care of heart patients nationwide. They are based on scientific evidence and it will be necessary to perform checks to assess whether they are being achieved. The NSF has already led to a significant increase in the number of heart bypass operations carried out. Despite these improvements there is still a significant shortfall in the provision of care for cardiac patients. The NSF is being implemented in England, but devolved government departments in Scotland, Wales, and Northern Ireland have not shown the same level of interest in this initiative. Although the NSF for CHD is a welcome advance it deals*

*only with part of the problem. There are many other types of important heart disease not covered by the NSF—for example, heart failure, heart rhythm problems, and diseases of the heart valves. These require the same degree of attention as is now being given to CHD as a result of the NSF. Inevitably such shortcomings can only be corrected if adequate resources are available, but resources have to be used appropriately to solve the problem. This report sets out to explain in detail what is needed to provide the service that our patients need.*

**Trained staff**

*There is a shortage of all types of health care professionals required to provide modern and effective cardiac care across the board. This ranges from a shortage of general practitioners to a shortage of cardiac surgeons, and is particularly acute as far as nurses and cardiac technicians (now known as CCSOs) are concerned. The shortage of nurses, which is severe in very specialised areas such as intensive care, is occurring at the same time as the role of the nurse is being extended. This extended role of nurses is extremely important to the provision of cardiac care. New roles are being created for nurses and to some extent they are taking over many jobs that in the past have been reserved for doctors. Clearly there is a major difficulty when there is a lack of nurses available for their traditional roles at the same time as more nurses are needed to fill new posts within an extended role. The same problems occur throughout the service, but the other main area where there are major problems is in the provision of cardiac technicians. Cardiac technicians who perform many of the tests heart patients need have not in the past had a proper career structure, although very belatedly one is now being developed. The major staffing problems faced by the National Health Service (NHS) can only be overcome if there is a radical review of the way that staff are used, and of the recruitment, training, retention, and remuneration of all health care professionals. It is true to say that there is no point in building and equipping new facilities in primary, secondary or tertiary care if there are no suitably trained staff available to run them.*

**Information technology (IT)**

*Good communication has always been the cornerstone of good clinical care. This can only be achieved if good IT—that is, computerisation—is available, which allows information to be shared by all health care professionals dealing with the individual patients wherever they are being treated in the health care system. Central to this aspiration is the creation and introduction of an electronic patient record, which all health care workers can access. This is being developed but is not yet available. Progress is already being made in the development of the national Central Cardiac Audit Database (CCAD). At present this deals only with children with heart disease, coronary angioplasty, and with a national audit of heart attacks, but it should be extended for use in all areas of cardiac care. Accurate recording of investigations, treatment, and outcomes is also urgently needed nationwide so that the quality of care delivered to all patients can be monitored and where necessary improved. Collecting information for this essential task is very time consuming. Trained clerical staff must do this in order to relieve technicians, nurses and doctors who are already in short supply. Adequate computer hardware and software must be made available. Good IT systems are essential for the whole NHS but are particularly important in the technically complex area of cardiac care. A great deal of new financial investment and reorganisation is needed to provide IT of sufficient standard to support modern effective cardiac care.*

## CHAPTER 1: INTRODUCTION

### Synopsis

- The report is a template for service provision
- It is a multidisciplinary report for a multidisciplinary specialty
- Coronary heart disease (CHD) remains the single biggest killer in the UK
- Patients' views are incorporated into this report
- Care when needed must be made accessible to patients without significant delay
- Present inequalities of care, be they economic, geographical, racial or sex based, need to be tackled urgently
- The National Service Framework (NSF) for coronary heart disease (CHD) is a major advance
- Workforce recruitment and retention is a pressing issue in the new National Health Service (NHS), particularly in cardiology
- Information technology (IT) is crucial to all areas of clinical activity
- Continuing professional development (CPD) must be available for all
- Many more personnel are needed to do the clinical work and allow time for effective clinical governance and CPD
- Research is a vital part of a vigorous clinical service but there is insufficient funding and time available

### Lay summary: introduction

*This report is a guide to what is needed to bring care of heart patients in the UK up to a good overall standard. It is designed to help set up new services for treating heart disease and improve existing services. The term cardiac or cardiovascular care covers all aspects of diagnosis and treatment of patients with heart disease. This report has been written by a team of doctors, nurses, other health care professionals, and also patients and lay members of the public. It is inevitable that in any area as complex as the provision of cardiac care there will be rapid progress which may be hard to keep up with. Furthermore keeping up with progress is expensive. Treatments change and hopefully improve with new methods replacing old. The roles of the staff and hospitals providing care will also change. Two good examples are the shift of many forms of cardiac care, previously confined to specialist centres, to local hospitals and the very important expansion of the role of the nurse in the delivery of general and specialist health care.*

*The provision of care for patients with heart disease has been seriously handicapped by chronic shortage of resources. The most important resource that is in short supply is that of trained staff across the whole range of health care professionals involved in providing care for the heart patient. In addition to this, care for heart patients needs to be backed up by modern information technology which will aid communication between health care professionals and in addition allow proper selection of information regarding the type of disease being treated, and the outcomes. Furthermore information technology would allow the integration of primary, secondary, and tertiary care which is essential for first class services to be provided to the patient. Implementation of the National Service Framework is a major step forward in the care of patients with heart disease, and the appointment of a National Director of Heart Disease who is an experienced consultant cardiologist working at the Department of Health has greatly improved planning for heart disease treatment nationally and the implementation of these plans.*

1.1 This report is intended to:

- describe the present situation and act as a benchmark against which progress can be measured
- act as a template for new service developments
- identify areas of need and prioritise them

- suggest ways that shortfalls and problems can be overcome so that recent successes following the introduction of the NSF can be retained and extended.

1.2 CHD remains the single most common cause of death in the UK; in 1998 there were 137 153 deaths in the UK from CHD, out of an all cause mortality of 626 151. Thus CHD deaths constituted 22% of all deaths in the UK. As such CHD has recently been declared a major priority of the Department of Health. The European Union has recently issued a statement of intent to reduce risk factors for coronary artery disease. These are welcome developments and as a result many improvements in the resourcing and organisation of cardiac care have occurred within the last two years.

1.3 Despite this there are many shortfalls in the service and this report attempts to analyse the situation in a realistic and constructive way. It is clear that the service is not sufficiently resourced to implement best practice as recommended by, for example, the National Institute for Clinical Excellence (NICE). NICE has issued guidelines on the use of stents, glycoprotein IIb/IIIa inhibitors, and implantable defibrillators<sup>1</sup> which have large financial implications without increased funding and resource. The same applies to the recent British and European<sup>2,3</sup> guidelines for the management of acute coronary syndromes which require a more interventional and therefore more expensive approach to this very common condition.

1.4 This is the fifth in a series of reports.<sup>4</sup> The fourth report was produced nine years ago and proved to be an important document providing a template for the design of cardiovascular services and predicting with a high degree of accuracy the developments likely to impact on the provision of cardiac patients' care.

1.5 This report hopes to emulate these achievements, but whereas cardiologists and cardiac surgeons wrote the previous report for their own consumption, this report has a multidisciplinary origin. It is written, in cooperation, by a wide range of health care professionals as well as patients and lay members. This is not a hollow gesture towards political correctness; it is a genuine recognition that complex cardiac care for adults and children requires a combined effort from all the members of the health care workforce and that this care needs to be patient centred.

1.6 Patients and their relatives, who are at the receiving end of cardiology care, are often in an important position from which to comment on what care is needed and suggest improvements in the way this care reaches them.

1.7 We believe it is important for the information contained within this report to be accessible to the public. Therefore it is accompanied by a comprehensive lay summary that will also be published separately. The relevant section of the lay summary also precedes each of the sections. The complete document and the lay summary are on the internet (website address to be printed later) for easy access, and the illustrations will be downloadable so that they can be used by others who wish to present the data.

1.8 This report is designed to present the main points as clearly as possible and, when appropriate, to guide the reader to sources in which they may find more detailed information. There is a comprehensive list of relevant web sites in appendix 4, and also in appendices 3 and 5.

1.9 All the authors of the report believe that there is a strong intention from the specialty in its broadest sense to improve the quantity and quality of care available to the cardiac patient and to reduce the burden of cardiac disease through primary and secondary prevention.

1.10 The provision of care for patients with heart disease in this country has been inadequate for many years. This was

recognised three years ago in the NSF for CHD<sup>5</sup> that outlines a programme of major improvements for the delivery of cardiac care which is now being implemented as fast as possible. The first results of this implementation are already proving excellent.

1.11 The intention of the Department of Health to fund the NSF has recently been re-affirmed by the Chief Executive of the NHS.<sup>6</sup> In the wake of the NSF for England, Wales and Scotland have been slowly developing individual policies similar, but potentially very different, to the NSF. These latter initiatives are in a less developed state and therefore have not been considered in detail in this report. This commitment by the Department of Health has been further demonstrated by the appointment of an experienced consultant cardiologist with wide ranging responsibilities (the National Director for Heart Disease) to develop cardiac services and oversee the implementation of the NSF.

1.12 Although the benchmark for measuring the activity of a tertiary cardiac centre is traditionally the number of coronary artery bypass grafting operations (CABGs) carried out, there is a very striking change in practice occurring and in many centres the number of revascularisation procedures done by percutaneous coronary intervention (PCI) has overtaken those done by surgery. Recent advances in the technology used for PCI is likely to increase the trend in its direction. The modern benchmark that is strongly recommended is the total revascularisation burden (CABG and PCI) and not the rate of CABG procedures.

1.13 This report is also being produced in the context of other recent major changes in the health care arena; these include the NHS Plan and the Human Rights Act.

1.14 It is clear that there are great regional inequalities in care within the UK that need to be addressed.<sup>7,8</sup> It is important to do away with any discrimination in the provision of cardiac care that may be based on region, race, age or sex.

1.15 A basic area of agreement between all authors of this report is that it is essential that the conditions develop as fast as possible such that the patient with suspected heart disease can be assessed by a cardiologist as a matter of course rather than good fortune.

1.16 The pattern of care and the need for resources outlined in this document are meant to be the minimum level which will give the population of the UK the standard of care that they need and deserve. Inevitably over the coming years the goals will change and there will be new advances which will influence the provision of care.

1.17 It will prove impossible to achieve these objectives unless innovative ways of improving the recruitment, training, and retention of the necessary workforce are found. This is perhaps the largest problem faced by the NHS and applies to all areas of endeavour.

1.18 The situation is particularly acute as far as nurses, perfusionists, and technicians (now known as cardiac clinical scientific officers (CCSOs)) are concerned. Extending and altering the boundaries of responsibility between different groups of workers is essential and this is exemplified by the extended role of the nurse (see chapter 12).

1.19 The number of technical staff is inadequate. This group of health care workers has been neglected and underpaid over the years despite the fact that they are essential if modern cardiovascular care is to be delivered. It is essential that workforce development confederations work with local cardiac networks to develop training programmes that will encourage recruitment to this type of work.

1.20 CCSOs lack a proper career structure and receive inadequate study leave. This must be urgently corrected.

**Table 1.1** Some essential elements of the service

- Multidisciplinary teamwork is essential and must be backed up by modern IT
- Listen to the patient's needs
- Re-evaluation of traditional roles to enable more flexible working and more satisfying jobs
- Improved recruitment and retention of staff
- Eliminate inequalities in service provision—both socioeconomic and regional
- Cardiac patients should be assessed by cardiologists as a matter of course
- High quality training and CPD are essential to produce and retain a motivated and skillful workforce. Time must be allowed for this
- The future must not be ignored—it is essential to invest in research

1.21 The expectations of patients for efficient, readily available, and high quality care can only be achieved if there are major investments in information technology (IT) at all levels. This is essential so that information regarding the patient is readily available in order that the health care professionals managing their care have protocols, guidelines, and advice immediately available.

1.22 Adequate provision of IT is also essential for:

- Audit
- Clinical governance
- Continuing professional development (CPD)
- Collection of reliable outcome data

These are key areas of modern medical practice.

1.23 This document aims to provide a template for service provision at all levels. It must not be forgotten that this cannot be delivered without a highly trained and motivated workforce. Such a workforce can only be achieved by excellent training and extensive, high quality CPD. This must link in with realistic mechanisms for revalidation of professional competence.

1.24 CPD and an increased level of clinical governance cannot be achieved by the main method in use at present—that is, stretching existing resources and personnel to breaking point and assuming that important developments can be “cost neutral”.

1.25 Planning for an improved provision of care for cardiac patients and calculating the necessary manpower must take into account the fact that there have been major changes in what is required of doctors and the rest of the health care team. These are dealt with in detail within the report but include some factors mentioned above, such as revalidation, increased amounts of CPD, as well as reduced involvement of junior staff in clinical care, more extensive training programmes for junior staff, and also an extended role of the clinician in management. All these factors mean that the very welcome, proposed, and projected increase in manpower and resources will only be a start and will not fully solve the problems that exist.

1.26 Research must also not be forgotten in the climate of pragmatism that is needed to move cardiac care forward rapidly. Without research at all levels within the specialty, progress will soon slow down and stop and the much needed development of services will be stunted.

1.27 Researchers in the UK have, in the past, made very important contributions to our understanding and treatment of heart disease—for example, much of the basis for the treatment for myocardial infarction with thrombolytic agents originated from the ISIS group in Oxford and there are many other examples.

1.28 Currently the UK contributes 10% of research publications, worldwide, in the area of heart disease. It is very important that this contribution continues and increases since it stimulates an important atmosphere of intellectual curiosity that is needed for progressive and effective development and delivery of health care.

1.29 It is crucial that all members of the multidisciplinary team are interested and involved in research. Day to day audit activities, which in themselves are essential to a high quality of care, are not a substitute for research.

1.30 The difficulties in which cardiac services have found themselves in recent years, with an exponentially expanding knowledge base and workload on the one hand and almost fixed resources on the other, has led to research becoming partially sidelined in the attempt to deliver essential care.

1.31 Although much has been done, much remains to be done. It must be remembered that large and important areas of cardiology were not included in the NSF, and the NSF itself is already out of date in the context of CHD. Some essential elements of the service are listed in table 1.1.

## CHAPTER 2: PATIENT PERSPECTIVE

### Synopsis

- Health care professionals need to show openness, honesty, and be accountable
- Personal health care issues must be fully explained to patients
- Patients have a right to a specialist cardiologist opinion whenever appropriate
- Health care professionals treating patients with heart disease should have training in the specialty
- Care must be as easily accessible as possible
- Waiting lists must be reduced to acceptable levels with no delay if the need is urgent
- Rehabilitation should be available to all who require it

### Lay summary: patient perspective

*The patient with heart disease has the right to receive a specialist opinion in an appropriate period of time. This should not be delayed at all if the matter is urgent. Once this opinion is obtained the doctor or other health care professional involved must deal with the patient's cardiac problem in an open and honest manner. Details must be explained to the patient fully so the patient understands the diagnosis, its effects on his or her future, and the treatment needed. There must be adequate time put aside to do this. It is important that face to face discussion is backed up with suitable literature and, when at all possible, this should be in language other than English if this is required. Furthermore, the patient should be able to have access to up to date results for their type of treatment from the institution in which they are being treated, and should be told how these results compare with what is available in other units.*

2.1 Patients require all health care professionals who treat them for their heart disease to show:

- openness
- honesty
- accountability
- understanding
- confidentiality

2.2 Patients with heart disease have the right to a specialist opinion when appropriate. This opinion should be from a cardiologist or other health care professional who has had specialist training in cardiology. It is not appropriate for doctors who do not have a specialist interest in cardiology to care for cardiology patients without the help of specialist input.

2.3 There is already a trend for more cardiologist patients to be seen by cardiologists. Indeed the Department of Health has announced that they do not expect any cardiologist to be working without a consultant colleague by 2004. It is essential that the number of cardiologists necessary to provide a full nationwide service is reached as soon as possible. At present there is a growth rate of over 10% per annum which should raise the number of consultant cardiologist to approximately 1000 by 2008. This will improve the present situation, but the figure will need to be revised upwards very significantly because of recent major changes in working practices (see 6.16 to 6.26).

2.4 Doctors and other health care professionals need to be trained in how to interact effectively and sympathetically with patients and their carers, and to give clear and comprehensible explanations to their patients of their disease and its treatment. This is already becoming a bigger part of undergraduate medical training, but training also needs to be available to those already in practice. There is a need for proper training of all health care professionals in the art of counselling. This is particularly important in the context of cardiac disease because the diagnosis is often both frightening and

threatening for the patient. Proper handling at an early stage will gain the patient's confidence as well as their cooperation with their future care. If this is not done from the outset then fears and resentment may become established and may not be modifiable at a later date.

2.5 Information needs to be given to patients in a format that is understandable. It is important that it is not imparted in scientific jargon but is translated into plain, everyday language without losing its accuracy. This can be difficult and the provision of written material whenever possible is often very helpful. Each cardiac unit needs to be able to provide a comprehensive set of written and visual materials for their patients and their relatives and carers. It follows that this service needs to be available as far as possible to all ethnic groups.

2.6 Every effort should be made to improve communication between health care personnel and patients. There is a very large potential role for nurses and trained counsellors to give advice to patients about the best way to understand and adapt to their disease. It is important that structures are put in place so that this type of comprehensive advice and counselling is available when required and is offered, particularly when important news is being imparted.

2.7 The issue of communication is also related intimately to the process of obtaining of proper consent. The British Cardiac Society has produced consent information leaflets and there have also been several important documents from the General Medical Council and Department of Health on this topic.<sup>9 10</sup> Consent forms for procedures need to be standardised and patients must have enough time to consider the implications of the procedure involved, ask questions about it, and be given written information to guide them further. The amount of time may by necessity be curtailed if the procedure is urgent. Done properly this is a time consuming process and resources are not currently available that are required to support a proper system.

2.8 Every attempt must be made to make specialist cardiologist care readily accessible. The use of rapid access clinics, and clinics run at times convenient to patients, will help to achieve this aim. Rapid access clinics for patients with chest pain are becoming generally available and this trend of "rapid access" is likely to expand to apply to patients who have cardiac symptoms other than chest pain.

2.9 Better communication between all health care professionals and agencies will improve patient care. It is essential that communication be facilitated between primary, secondary, and tertiary care. The electronic patient record needs to be implemented as soon as possible, as this will greatly speed this process.

2.10 Patients require that waiting lists should be much shorter than they are at present, and for treatment to be available without delay when their doctors assess them to be at risk if treatment is not undertaken urgently. The experience in continental Europe is that in countries with a similar economic situation to our own, there is virtually no waiting time for outpatient cardiology or revascularisation.

2.11 Patients must have access to rehabilitation when required—for example, after a heart attack, cardiac surgery, and intervention.

2.12 Where appropriate support groups exist patients should be provided with information that allows them to assess the potential usefulness of the group and make contact if they wish. Systems need to be put in place that will help the patient to see their cardiac problem in the context of their everyday life so that they can adapt to their problem and thus continue to live a satisfactory life.

2.13 These services to improve the patient's understanding of their disease are either non-existent or only partially available at present. The education and resources, including extra personnel, needed to set up services that are more responsive to patient's needs will require financing which is not at present usually identified or contained within budgets.

2.14 The patient interface is of such importance that it requires a combined initiative from bodies representing patients and health care professionals to devise methods of improving communication in both directions. This need has been recognised by the British Cardiac Society, which is

advancing plans to bring together health care workers of all types within cardiology and patient representatives to identify the problems and ways to solve them. This is seen as a first step in enhancing patients' rights and empowerment. It is a joint initiative with the British Heart Foundation.

2.15 This is an area of great importance, which is currently neglected and under resourced. It should be put on a much stronger basis nationwide and receive adequate funding. A time scale is needed and must be adhered to. It is proposed that by late 2003 nationally applicable systems will have been developed via the British Cardiac Society initiative.

## CHAPTER 3: AUDIT, CLINICAL GOVERNANCE, AND CONTINUING PROFESSIONAL DEVELOPMENT

### Synopsis

- Reliable data are needed and these data are dependent on proper information technology (IT)
- Harmonisation of data sets held by the various specialist societies is essential
- The Central Cardiac Audit Database (CCAD) has been shown to be feasible and now must be implemented widely
- There is a need to analyse local patterns of practice and audit these
- It is important to have local data on which to base service provision
- Data should be in the public domain but must be reliable and have been validated
- Continuing professional development (CPD) is essential to maintain high quality care

### Lay summary: audit, clinical governance, and continuing professional development

*It is essential that cardiovascular care is of high quality. The only way that this can be maintained is if all the health care professionals delivering the care have a high level of up-to-date medical education. This can only be achieved if everyone undergoes continuing education. This is known as continuing professional development (CPD). Furthermore, in the near future it is likely that doctors in the UK will have to undergo a process of "re-accreditation". This is to make sure that they have maintained their professional standards at a high enough level that they are able to continue in practice as doctors. Inevitably the same process will follow for other health care professionals. The overall quality of treatment can only be assessed by accurate collection of information regarding the results of treatment. These figures need to be analysed locally and compared against national figures. This checking of the quality of care is the major part of what is known as "clinical governance". "Clinical governance" is the term that covers the whole complex process of monitoring every aspect of patient care and assuring that it is of high quality. This is an important but very time consuming process. It needs secretarial and clerical input as well as extra time from already busy doctors. It must be properly funded if it is to succeed. In the future it is hoped that a central cardiac database will allow nationwide monitoring of the quality of treatment. At present a prototype is being developed. This is known as the Central Cardiac Audit Database (CCAD) and is at present collecting information on all children with heart disease. It is also undertaking an audit of all cases of heart attack (myocardial infarction) in England. This is known as the Myocardial Infarction National Audit Programme (MINAP).*

3.1 Audit, clinical governance, and CPD has been readily embraced by cardiology and cardiac surgery as the formalisation and advancement of the process of improving quality of care.

3.2 Some high profile issues, such as the Bristol enquiry, relating to professional standards, prompted a focus on quality issues relating to both process and outcome measures, outlined in *The new NHS. Modern and dependable* in December 1997, followed by *A first class service* in 1998.<sup>11 12</sup>

3.3 This resulted in the Health Service Act 1999, which imposed a statutory duty for clinical quality on chief executives and board members of trusts and health authorities. The Act highlighted the importance of processes to ensure quality of care rather than simply focusing on standards.

3.4 The structure and processes necessary for effective clinical governance need to be based on solid data. Within the cardiac surgical and cardiological arena considerable progress had already been made through the specialist associations who

had already been collecting "procedure specific outcome" data before the advent of clinical governance.

3.5 However, these data were not standardised for disease processes and risk, definitions were variable, and the existing registries were not validated. Furthermore, few registries had long term outcome data.

3.6 In 1995 the Department of Health invited the specialist associations (for example, the British Cardiac Society and the Society of Cardiothoracic Surgeons) to harmonise their data sets with a view to coordinated, centralised data collection on all patients undergoing a cardiac procedure. This initiative was spearheaded through the Central Cardiac Audit Database (CCAD) project.<sup>13</sup> This project subsequently demonstrated the feasibility of confidential data collection online using standardised encryption and transmission protocols. The system is being developed further under the umbrella of the NHS Information Authority.

3.7 The CCAD database will be linked to the Office of National Statistics, and its structure will allow tracking of patients from interventions until death and will therefore aid understanding of both disease processes and national practice. Perhaps most importantly these types of data will enable us to understand who will benefit most from which intervention.

3.8 A major initiative now underway, led by the Royal College of Physicians in conjunction with CCAD, is the nationwide (England and Wales) audit of myocardial infarction. This is the Myocardial Infarction National Audit Programme (MINAP). Almost all appropriate hospitals (201/216) contribute data, mostly online.

3.9 It is intended to extend CCAD to percutaneous coronary intervention (PCI) and cardiac surgery by 2002.

3.10 In any audit process patient confidentiality is an important issue which must be respected. The recent Health and Social Care Bill permits aggregation data on clinical outcomes so long as it is in the interest of the individual patients and the public. These provisions allow CCAD to carry out such an aggregation.

3.11 To be of real value clinical data obtained locally should be used to facilitate local clinical governance and planning.

3.12 The concept of quality in cardiology and cardiac surgery must encompass the whole clinical pathway from the time the patient seeks medical advice for the first time to the time of hospital discharge and beyond.

3.13 Individual procedural outcome measures represent only a small, albeit important, part of this process since there are many non-therapeutic influences on outcomes.

3.14 Such influences may include severity of illness, prevalence of comorbidities, the awareness and willingness of the patient to seek medical advice, and the threshold of referral from the general practitioner to the cardiologist and from the cardiologist to a surgeon when indicated. The threshold of acceptance by the interventionist or surgeon, standards of nursing, anaesthesia, surgery, and intensive care, adequacy of staffing levels, attitude to training, interpersonal relationships between staff, and even the physical design of the unit all play important parts.

3.15 Any one of these factors can influence the quality of patient care and its outcome. In the quest for measurable quality apparent variations in easily measurable outcomes should be perceived as barometers of success or failure of a complex pathway of care rather than of a single event—for example, the operation or intervention.

3.16 An important aspect of quality control is audit of cardiac departments. The British Cardiac Society is developing its own peer review system. This will provide regular external audit, and consequently significant variations in practice, poor organisation of clinical care, and poor results should be identified early and rectified. Although currently voluntary this process is likely to become a regular event for all units and will also be available to react to specific problems when they occur.

3.17 Out of respect for our patients any data released into the public domain must be validated, analysed appropriately, and presented in an easily understandable and digestible format. This is a complicated area, but the generic issues have been succinctly summarised in a Nuffield Trust publication *Dying to know: public release of information about quality of health care*.<sup>14</sup> This report concludes with some policy recommendations based on the review of US experience of public disclosure. They were presented to Mr Frank Dobson, the then Secretary of State for Health, in July 1999 and circulated to key policy-makers and health advisers in the UK. They are outlined in table 3.1.

3.18 It is now recognised that all health care professionals need to be kept well informed and up to date by participating in continuing professional development (CPD).

3.19 CPD has to be provided for the specialty by the specialty. Time must be allocated both for people to receive CPD and also for the teachers and mentors to administer CPD. This need must be factored into any service plans. Up until now the needs for those giving and receiving CPD have not been taken into account. It has just been one of a growing number of tasks that have been expected to be absorbed into an already full timetable (see 6.25 and table 6.3).

3.20 CPD must be available on a regular basis throughout the individual's career and should be regarded as part of the normal working day rather than something added on during free time.

3.21 Clearly, adequate and comprehensive CPD will be expensive since it takes people away from clinical work. This must be funded properly.

**Table 3.1** Public disclosure of potentially sensitive material relating to patients

- The intended purpose of public disclosure should be made clear to all stakeholders
- Public disclosure should be seen as an evolutionary process, becoming progressively more sophisticated and comprehensive over time
- Public disclosure should be seen as one component of clinical governance
- Provider organisations should be a key audience for information about performance
- The financial cost of implementing a national policy on public disclosure is likely to be significant and should be considered alongside the benefits
- Specific educational initiatives for target audiences should be implemented alongside public disclosure
- Health professionals and their representative bodies should be fully involved in the process of public disclosure
- Both process and outcome measures of quality should be published
- Outcome indicators must be risk adjusted
- Public disclosure should be accompanied by a strategy for monitoring the benefits and any unintended consequences
- Public disclosure should be accompanied by possible explanations for the variations reported
- A research and development programme focusing on the generation and evaluation of public performance data should be supported by the NHS R&D directorate

## CHAPTER 4: PRIMARY PREVENTION OF CORONARY HEART DISEASE

### Synopsis

- Specific objectives for primary prevention are laid out in the National Service Framework (NSF) for coronary heart disease (CHD) and the NHS Plan.
- There is a need to tackle modifiable risk factors for CHD in the community, primary care, workplace, and schools
- Public awareness of factors that increase cardiovascular risk should be increased
- Priorities in the community:
  - smoking cessation
  - increased intake of fruit and vegetables
  - increased physical activity
  - weight control through diet and physical activity
- Priorities in primary care are:
  - target patients with high lipids (cholesterol), high blood pressure, obesity, diabetes, smoking habit or a strong family history of premature CHD
  - reduce high lipids, obesity, and type II diabetes using dietary advice and medication as appropriate
  - smoking cessation advice/therapy and clinics

### Lay summary: primary prevention

*Prevention of coronary heart disease (CHD) is divided into **primary prevention**, which is the prevention of CHD in patients who do not have any evidence of the condition, and **secondary prevention**, which is the prevention of further problems with CHD in patients in whom there is already some clinical evidence of the disease—for example, angina or a heart attack (myocardial infarction).*

*The burden of CHD in the community will be reduced if public awareness of the factors related to peoples' behaviour and diet leading to coronary disease (risk factors) can be improved. Public awareness will hopefully lead to a healthier lifestyle. The main objectives are to encourage as many people as possible to give up smoking, since it is a major cause of CHD, to improve their diet, and in particular to reduce fat intake and increase the amount of fruit and vegetables eaten. An improved diet needs to be combined with increased daily activity, and this should lead to weight reduction. The most effective way of introducing these changes is in the community via the workplace, school, etc. Primary care doctors (general practitioners) and their team of nurses, pharmacists, etc, should back up the message in the community, and also identify those patients in their practice who are at high risk from coronary artery disease. Once these patients are identified they require more concentrated and targeted efforts to reduce their smoking and weight, and to improve their diet. Furthermore those with high cholesterol will need medication to reduce it if dieting alone does not work. Diabetes is a major risk factor of CHD; this needs to be identified and promptly treated.*

### Introduction

4.1 In this section, we focus on coronary heart disease (CHD)—the greatest single cause of premature death in the UK and the greatest burden on cardiovascular services.

### Prevention

4.2 The major factors known to be most influential in predisposing to CHD are shown in table 4.1.

4.3 Primary prevention aims to reduce the risk of CHD by tackling modifiable risk factors in individuals, groups, and whole populations. There are two main settings for this work:

**Table 4.1** Factors most influential in predisposing to CHD

- Increasing age
- Male sex
- Genetic tendency
- Cigarette smoking
- High blood cholesterol
- High blood pressure
- Lack of physical activity
- Diabetes
- Obesity
- Psychological factors ("stress")

- the community—for example, schools, workplaces, community groups, mass media
- primary care

Interventions, standards and milestones for both settings are outlined in the CHD National Service Framework (NSF) for England.<sup>5</sup> Similar strategies may be developed for other parts of the UK.

### Primary prevention in the community

4.4 The task of reducing heart disease in the community is encapsulated in the first two standards of the NSF for CHD:

**Standard 1:** The NHS and partner agencies should develop, implement, and monitor policies that reduce the prevalence of coronary risk factors in the population, and reduce inequalities in risks of developing heart disease.

**Standard 2:** The NHS and partner agencies should contribute to a reduction in the prevalence of smoking in the local population.

4.5 The NHS Plan,<sup>15</sup> through its national and local modernisation boards and task forces, has made heart disease a continuing priority and has endorsed the NSF. Heart health promotion and disease prevention are key themes. Equity of access to all services which impact on cardiovascular health, whether provided by the NHS, local authority or any other agency, is seen to be crucial.

4.6 The priority objectives of the NHS Plan include the following:

- increase access to smoking cessation services
- increase intake of fruit and vegetables
- increase everyday levels of physical activity
- improve access to effective weight management services

Short term targets have been set for smoking cessation among manual groups and pregnant women, and increased consumption of fruit and vegetables among low income groups.

4.7 **Smoking:** Measures that are aimed at reducing smoking are listed in table 4.2. The government's strategy is set out in its white paper, *Smoking kills*.<sup>16</sup> Substantial funding has been provided for this smoking cessation programme. Much more emphasis is required on banning smoking in public places and more resources are needed for national advertising regarding the health benefits of ceasing to smoke and of a healthy lifestyle

4.8 **Healthy eating:** Ten years ago the emphasis was on reducing saturated fats and hence controlling cholesterol. Although this remains a priority, the focus has switched to the cardiovascular benefits of antioxidants through eating more

**Table 4.2** Measures aimed at reducing smoking

- Reducing the temptation to start smoking, e.g.
  - education of children and young people
  - increase in tobacco duty
  - restrictions on advertising and promotion
  - prosecution of shopkeepers selling cigarettes illegally to minors
- Helping people who want to stop smoking, e.g.
  - advice and support
  - wider access to nicotine replacement therapy
  - prescribing bupropion (Zyban)

fruit and vegetables. The NHS Plan endorses the “five-a-day” message, and involves the development of a National School Fruit Scheme aimed at providing a daily free piece of fruit to every 4–6 year old child. Other initiatives include publicity campaigns extolling the virtues of fruit and vegetables and schemes to ensure that these foods are conveniently available to people living in deprived areas.

**4.9 Physical activity:** Regular moderate aerobic exercise can help to reduce CHD in various ways—by improving coronary blood flow, reducing the resting heart rate, moderating blood pressure, improving the blood lipid profile, controlling obesity, and other less well understood mechanisms. In the USA, 35% of premature CHD deaths have been attributed to inactivity.<sup>17</sup> The current public health message is to undertake at least 30 minutes of moderately intensive physical activity (which can be in bouts of 10–15 minutes) on at least five days a week.<sup>18, 19</sup> Effective interventions are listed in table 4.3.<sup>20</sup>

**4.10 Obesity:** A recent National Audit Office report<sup>21</sup> has drawn attention to the alarming increase in the prevalence of obesity in England. Currently about one in five adults is obese—a proportion which has trebled over the last 20 years. This trend shows no signs of abating, and the evidence suggests that it is caused by a steady decline in physical activity together with a shift to eating more calorie dense fast foods.<sup>22</sup>

**4.11** The NSF for CHD calls for the development of local action plans to tackle obesity. Recent guidelines from the Faculty of Public Health Medicine<sup>23</sup> outlining interventions are shown in table 4.4.

**4.12 Evaluation:** Interventions in the community do not lend themselves to easy evaluation. Randomised controlled trials are particularly difficult and costly to set up. Studies of effectiveness often have to rely on less rigorous methods and short term surrogate outcomes.

### Primary prevention in general practice

**4.13** The second broad setting for primary prevention is in primary care. This focuses on “high risk” individuals, and is subject to another standard in the NSF—standard 4:

**Table 4.3** Effective interventions for improving physical activity

- Promoting “active transport” (encouraging walking and cycling by providing safe routes and discouraging car use in inner cities)
- Increasing physical education and sports in schools
- Creating a greater awareness of the need for a more active lifestyle
- Referring patients deemed to be at “high risk” of CHD to leisure centre based, supervised exercise programmes

Source: Health Development Agency.<sup>20</sup>

**Table 4.4** Weight loss measures

- Physical activity initiatives
- Weight loss diet programmes
- Anti-obesity drugs in selected cases
- Counselling and support

**Standard 4:** GPs and primary care teams should identify all people at significant risk of cardiovascular disease but who have not yet developed symptoms and offer them appropriate advice and treatment to reduce their risks.

**4.14** The risk factors most amenable to modification in primary care include are:

- hyperlipidaemia
- smoking
- hypertension
- diabetes
- obesity/overweight

**4.15 Infrastructure:** Elements needed to achieve effective primary prevention (that is, risk reduction) are listed in table 4.5.

### Workforce and resource issues

**4.16 Cardiovascular services workforce issues:** All health care professionals involved in the care of patients with heart disease are likely to be in increased demand to give talks and demonstrations to groups in the community (for example, schools, workplaces, and to “high risk” ethnic minority groups such as south Asians), and to act as advocates for more resources for primary as well as secondary prevention.

**4.17 Resource issues:** Funding for primary prevention at the local level tends to come from monies allocated to support health improvement and modernisation programmes, health action zones, healthy living centres, education action zones, as well as a wide range of sources linked to regeneration initiatives through local authorities and local strategic partnerships. Much of this work is supported by local health promotion units and, at a national level, by the Health Development Agency in England and similar bodies in Scotland, Wales, and Northern Ireland.

**Table 4.5** Elements to achieve effective primary prevention

- An agreed approach to CHD risk assessment and management, using a validated tool such as the Joint British Societies assessment charts and guidelines<sup>13</sup>
- Well kept electronic patient records with risk factor levels and assessment scores clearly identified
- An easily retrievable database of cases designated as “high risk” (i.e. a high risk register)
- Suitable software to support the above
- Staff trained to input the data
- An adequate prescribing budget to cover preventive medication (e.g. statins, angiotensin converting enzyme (ACE) inhibitors, antihypertensives, nicotine replacement therapy, anti-obesity drugs, etc)
- Agreed referral criteria and specialist support for cases requiring more intensive treatment (e.g. lipid clinic, diabetic clinic, obesity clinic, smoking clinic, exercise referral schemes, etc)

4.18 While suitably trained primary care staff (particularly practice nurses) will carry out most of the primary prevention in general practice, outreach staff from the hospital may be needed to provide clinical support and training. Community pharmacists may also help with screening.

4.19 Outreach services from hospitals are increasingly likely to be based on clusters of practices. For example, dietetic support will be needed for effective control of hyperlipidaemia, diabetes, and obesity in primary care. As this case-finding and management becomes more sophisticated, there are likely to be knock-on effects with an increased demand for hospital based services to deal with the more intractable cases.

4.20 The greatest demand on resources will come from the increasing use of drugs to reduce cardiovascular risk.

4.21 Table 4.6 summarises the objectives and priorities of primary prevention.

**Table 4.6** Summary: primary prevention

- Primary prevention should reduce the impact of risk factors on individuals and populations with a view to preventing premature disease
- The most effective programmes in the community focus on discouraging smoking, promoting healthy eating, and increasing everyday physical activity
- The priorities in primary care are to detect and control cases of high cholesterol, high blood pressure, diabetes, obesity, and to help patients give up smoking
- Changing people's behaviour is not easy and primary care staff will need appropriate training and the support of community based specialists such as dieticians. The effectiveness of interventions in the community and primary care is often difficult to assess
- Specialist hospital staff may increasingly be called upon to support primary prevention in the community and general practice

## 5. PRIMARY CARE

### Synopsis

- Primary care organisations (PCOs) should spearhead the primary care effort
- Appropriate skill mix needed in the primary care team
- There is a need for continuing professional development (CPD) and lifelong learning in primary care for all workers
- The main patient database should be held in primary care
- Pathways of care should be developed in conjunction with secondary and tertiary care
- PCOs are pivotal in the delivery of cardiovascular services within the NHS and in particular in the care of heart failure and coronary heart disease (CHD)
- PCOs will commission secondary and tertiary services as well as providing primary care and community services
- By 2004 75% of the NHS budget will be directed through PCOs
- Coordination between primary, secondary, and tertiary care is essential to sustain and then improve service delivery
- Primary care has a major role in delivering many of the standards set out in the National Service Framework (NSF) for CHD
- PCOs will plan and support new models of care
- Developing information technology (IT) is a priority. Computerised disease registers, protocols, and audit packages are basic requirements for modern health care
- A uniform system of diagnostic codes (for example, Read codes) should be used across the NHS to aid communication
- There is a substantial shortfall in the numbers of general practitioners (GPs) at present and there will need to be a very large uplift to deliver the NSF and provide the “GPs with special interests” envisaged by the NHS Plan

### Lay summary: primary care

*Primary care and general practice are synonymous in the context of this document. Primary care has an important central role in the prevention of coronary artery disease and in implementing the National Service Framework (NSF) for coronary heart disease (CHD). The NSF is described in more detail in the lay summary of the Introduction. The standards in the NSF that primary care will address are twofold. Firstly, it will ensure that general practitioners (GPs) intervene to reduce risk factors in people who have not as yet had any symptoms of heart disease (this is called primary prevention). Secondly, it will ensure that interventions are made which help patients who have already had heart disease or are considered to be in a high risk category (this is called secondary prevention). High risk patients are those who are deemed to have more than a 3% risk per year of developing a cardiac event. A cardiac event is anything the patient experiences which is caused by CHD. This risk can be calculated from an equation that incorporates all the patients' known risk factors for CHD. The important risk factors are listed in detail within chapters 4 and 5 of this report. Briefly these risk factors are smoking, high cholesterol (hypercholesterolaemia and hyperlipidaemia), high blood pressure (hypertension), diabetes, and overweight (obesity). These same risk factors operate in patients who have already had CHD diagnosed. Once patients have definitely got CHD the need to improve their risk factors is more urgent, since these patients have a high risk of more problems that may be fatal. The main emphasis in secondary prevention is still on stopping smoking, improving the diet and lowering the cholesterol. Regular aspirin, at a low dose, is regarded as being routine treatment for patients with CHD unless there is a reason why they should not take this agent. This is because aspirin reduces clotting in the blood vessels and thus decreases heart attacks.*

*A recent important development in cardiac care is the coordination of the efforts of primary care with those of secondary and tertiary care*

*to produce what are now known as local networks of care. Primary care organisations (PCOs) made up of groups of GPs from the same area are being set up and will help create these networks. Delivery of care by the networks will be based on guidelines for treatment, which are agreed across the whole of the network. This will lead to an even standard of care.*

*The GP and other members of the primary care team need close and effective links with the hospital so that information from the GP gets to the hospital when the patient is admitted and information gathered during hospital episodes is transmitted back to the GP at discharge so they can then take appropriate action. Linking primary care with secondary and tertiary care requires a significant increase in information technology, and patient records must be computerised.*

*Currently a major problem in primary care is an enormous shortfall in the number of GPs. This is occurring at a time when there are plans to develop and increase the role of the GP, in particular to develop “specialist GPs” who have specialised training in cardiovascular disease.*

### Introduction

5.1 Much of the management of cardiovascular disease is already carried out in primary care. In the future it will become increasingly guided by carefully developed protocols. The new primary care organisations (PCOs), along with local networks for cardiac care, will develop these protocols.

5.2 The National Service Framework (NSF) for coronary heart disease (CHD)<sup>5</sup> is designed to improve cardiovascular health, reduce inequalities in care, and raise the quality of care. It also contributes to the strategy detailed in the NHS Plan.<sup>15</sup>

5.3 The NSF states that to achieve this objective care should be delivered in a more structured and systematic way. It establishes 12 standards for the prevention, diagnosis, and treatment of CHD. With each standard is information about clinical interventions required, systems that need to be in place, and suggestions relating to models of care that will be necessary to meet the standards.

5.4 Primary care has some role to play in all the standards and a pivotal role in many. The first priority is secondary prevention followed by “high risk” primary prevention. The management of heart failure and stable angina, and cardiac rehabilitation are other core activities.

### Prevention in primary care

5.5 **Primary prevention in primary care:** The NSF for CHD suggests that intervention in “high risk” primary prevention is targeted initially at those with an annual absolute CHD risk of 3% (or 30% over 10 years). Every attempt must be made to lower this target, which has been arrived at for pragmatic reasons alone because of the current limitations in the primary care workforce and funding. It does not have a scientific or humanitarian basis. Clearly the lower the level of risk targeted, the greater the cost. It must be remembered that the law of diminishing returns applies and at some point the risk becomes too low for it to be a reasonable target.

5.6 **Secondary prevention in primary care:** Standard 3 of the NSF states: “General practitioners and primary care teams should identify all people with established cardiovascular disease and offer them comprehensive advice and appropriate treatment to reduce their risks. Table 5.1 lists the targets for primary care effect.”<sup>24–33</sup>

### Development of the primary care team

5.7 The new PCOs will help plan and coordinate the primary care effort. They will need to develop detailed implementation plans in order to obtain an appropriate share of the essential financial resources.

**Table 5.1** Targets for primary care effect

- Advice and help to stop smoking including nicotine replacement therapy
- Information and advice about modifiable lifestyle risk factors
- Advice and treatment to maintain blood pressures below 140/85 mm Hg<sup>24 25</sup>
- Low dose aspirin<sup>26</sup>
- Statins and dietary advice to lower total serum cholesterol to below 5.0 mmol/l (LDL <3.0 mmol/l) or by 30%, whichever is the greater<sup>27 28</sup>
- ACE inhibitors for people who also have left ventricular dysfunction<sup>29</sup>
- $\beta$  Blockers for people who have also had a myocardial infarction<sup>30</sup>
- Warfarin when clinically appropriate for people over 60 years with atrial fibrillation<sup>31</sup>
- Meticulous control of blood pressure<sup>32</sup> and glucose in people who also have diabetes<sup>33</sup>

ACE, angiotensin converting enzyme; LDL, low density lipoprotein.

5.8 The primary care team needs to provide structured care. This will require the development of an appropriate multidisciplinary skill mix.

5.9 Continuing professional development (CPD) is essential for the primary care team and requires new approaches to education. Professional self regulation and revalidation will play a role in guaranteeing standards, and discussions are ongoing as to how this can be arranged. The primary care team should meet regularly to discuss clinical issues.

5.10 Clinical records need to be organised, summarised, and computerised. This will allow the construction of accurate disease registers enabling identification of the target population. The development of the electronic patient record will play a very important role in this endeavour.

5.11 To achieve these aims major information technology (IT) development is essential. The computer systems used by all health care professionals must be able to communicate with each other. Computer templates will be used to record therapeutic interventions. This will allow electronic audit, which will facilitate assessment of current performance and future progress.

### Nurses in primary care

5.12 The role of nurses in cardiovascular care is also dealt with in a separate section of this report (see chapter 12).

5.13 When delivering the chronic disease management and audit envisioned by the NSF for CHD, practice nurses are the key members of the primary health care team. They must have sufficient training to allow them to be competent in this role. They will work to protocols agreed by all members of the primary health team and this may involve the use of clinical decision support systems. Interventions will be recorded on standardised templates that will then be used to facilitate audit.

5.14 The clinical scope of practice nurses with special knowledge of cardiovascular management will be increased by the advent of nurse prescribing and by the development of nurse practitioners and nurse consultants.

5.15 Practice nurses require initial specialist training and this must be followed by regular updates and proper CPD.

### Development of models of care

5.16 Primary care must move from being largely reactive and adopt a more proactive approach. New ways of working will be needed to cope with the demands of the NSF and the NHS Plan.<sup>5 15</sup> These may, in predefined circumstances, involve referral to cardiovascular expertise within primary care rather than secondary or tertiary care. This may lead to some functions moving from secondary to primary care. Individual PCOs will

develop their own models of care and to achieve this there must be coordination between all interested parties.

5.17 “General practitioners with special interests”<sup>34</sup> who have specialist training in cardiology are likely to have an important role in delivery of cardiovascular care. They can provide immediate local access to high quality care and, by increased team working with consultants, will help to break down the barriers that can limit patient care at present (see 5.30).

5.18 It is essential that these general practitioners are subject to national minimum standards for training and accreditation and that they are active members of appropriate clinical governance mechanisms.

5.19 The primary/secondary/tertiary interfaces need to be developed and refined. This will involve detailed service planning, training, and education. The commissioning framework will provide a template for enabling the development of integrated health care solutions for the management of cardiovascular disease.

### Development of pathways and local clinical networks of care

5.20 The wide range of health care professionals inevitably involved in the care of the individual patient must coordinate their efforts when planning the provision of cardiological services. Local implementation teams, including PCOs, health authorities and trusts, and local networks of cardiac care must devise appropriate service models and provide protocols, which include both referral criteria and clinical guidance.

5.21 **Local clinical networks of care:** On the 31 March 2002 the most dramatic reform of the NHS for the last 10 years came about. This led to the abolition of the 95 district health authorities, curtailment of the activities and responsibilities of the regional health authorities, and formation of 28 new strategic health authorities.<sup>35</sup>

5.22 All the interested parties must work very closely. Cardiologists and cardiac surgeons in conjunction with primary care must help determine the extent of networks, and shape the service for the provision of care to the local communities. The clinical network will be responsible for commissioning, access, guidelines, protocols, practice, outcomes, and audit.

5.23 Following the emphasis on clinical networks in the NHS Plan,<sup>15</sup> it has become clear that the intention is to both simplify and standardise the provision of health care. The line of command and the funding stream will now pass through only three steps—the Department of Health, to the strategic health authority, then to the clinical networks. Clinical networks will include representatives from primary care trusts, district general hospitals, tertiary centres, as well as other important groups (for example, the ambulance service and social services).

5.24 IT links must be improved between all service providers and is central to the integrated care envisaged in pathways and networks of care. Secondary care should use a unified system of diagnostic codes on all discharge summaries, which can then be transmitted electronically. The system favoured at present is the use of “Read” codes. The main patient database will be based in primary care and shared with secondary and tertiary care and public health departments, as appropriate.

5.25 Various initiatives have been set up by the Department of Health in an effort to improve service delivery for patients. These include:

(a) **Primary care collaboratives:** This initiative is aimed at improving patient access to primary care and secondary care. To date 5.3 million patients have been enrolled and 318 000 patients with coronary artery disease have been identified. Proper access, particularly to secondary prevention, is expected to reduce mortality by 34%.

**(b) Coronary heart disease collaborative programme:**

This is a patient centred initiative, which is now being extended throughout England. Initially 10 groups of approximately 500 000 patients were followed from primary to secondary and possibly tertiary care to assess effects of altering ways in which patients are managed and to develop improvements in care. There are now 30 collaborators in England.

**(c) CHD information strategy:** This was published by the Department of Health in October 2001.<sup>36</sup> It has the following important components:

- developing and implementing the electronic patient record, and the electronic transfer of information between all levels of patient care
- development of local information strategies
- integration with hospital and other existing patient information systems such as PAS
- information for health care professionals via the web
- information for patients accessible via the web

**(d) Health informatics program for CHD:** This is being developed by the Department of Health. Its main purposes are to:

- develop a common approach to coding, since this is essential in any audit and is problematic at present
- allow staff to learn about best practice
- allow audit of the NSF

**Workforce planning**

5.26 An increase in funding for the NHS was needed urgently and the increased funding now available must be passed down to those directly involved in patient care.

5.27 The NHS Plan has significant and substantial implications for general practitioners and their staff. Much of the work needed to implement the NSF for CHD will be done by nurses. Substantial administrative and IT support will also be needed. Every effort must be made to obtain the optimal skill mix in primary care and to provide the support needed to rebuild morale.

5.28 None of this can be achieved without an adequate number of general practitioners (GPs). The position statement on the GP workforce, issued by the Royal College of General Practitioners in 2000,<sup>37</sup> states that to fulfil the government's objectives "smarter working, skill mix initiatives and contractual changes will not compensate for the substantial gap in the GP workforce". They estimate that an expansion of 30% in the GP workforce is required (10 330 GPs). Of this increase 1200 are needed to provide "specialised generalists" and 3000 to implement the NSFs. Community cardiovascular medicine

will account for many of these extra GPs. The needed expansion is not possible in the short to medium term because of the national shortage of appropriately trained personnel.

5.29 Since much of the implementation of the NSF will depend on nurses working in primary care there is an urgent need to increase their numbers

**5.30 Specialist GPs or "GPs with special interests" (GPSIs):** It is estimated that 4500 GPs have developed a knowledge base in a specialist area and have the necessary skills to apply it. Many of these will have significant training and experience in the management of cardiovascular disease. Although they do not have the full expertise of a consultant specialist they may be competent to give an opinion within a certain, pre-specified context. There are three main models of care that can accommodate the GPSI:

- The GPSI may be commissioned to provide a procedure based service such as echocardiography
- Provide an opinion or offer clinical services at the request of clinical colleagues
- Lead the development of appropriate clinical services

5.31 There must be a nationally agreed minimum set of standards for training and accreditation for GPSIs. The setting up of such a system must be supported through the involvement and commitment of secondary care. At present the Royal College of General Practitioners is working actively in this area to produce the necessary template, and this initiative has the support of the British Cardiac Society and the Royal College of Physicians. The British Cardiac Society must be closely involved in this development.

5.32 Considerable thought will be required to decide on the best use of the expertise of such GPs. They could be very useful in providing non-invasive investigations such as echocardiography and exercise testing for other GPs. The British Cardiac Society and its affiliated groups such as the British Society of Echocardiography and the British Pacing and Electrophysiology Group are committed to providing guidance for GPs with a special interest in cardiology so that standards are set and maintained from the outset.

5.33 The introduction of such services will need:

- close cooperation with local cardiologists
- initial intensive instructions and some form of certification
- continuing education to support (CPD)
- regular audit

5.34 Introduction of such services is to deal with the present shortfall in service provision and should not replace currently available services in secondary and tertiary care.

## CHAPTER 6: THE DISTRICT GENERAL HOSPITAL

### Synopsis

- There are inequalities in district general hospital (DGH) provision around the country
- In the near future many DGHs will have cardiac catheter labs which will:
  - perform routine coronary angiogram
  - perform electrophysiology and ablation as well as routine, low risk percutaneous coronary intervention (PCI) and implantable cardioverter-defibrillator (ICD) implantation when the necessary skills are available
- If primary PCI were to become the treatment of choice for acute myocardial infarction, DGH catheter laboratories would be required to provide this service
- Patients with heart disease need to be seen by staff who have specialist training in cardiology
- The expanded role of the nurse is very important in the DGH setting
- Careful liaison is required between DGHs and primary care in the provision of rehabilitation and coronary risk reduction
- Staffing must be improved to provide at least 1200 consultant cardiologists in the UK and the appropriate staff to support them as soon as possible. The present number is 630
- DGHs will need to have at least five cardiologists to be able to provide proper rotas
- There is a major shortage in the number of cardiac technicians (CCSOs) and the number needs to be increased substantially immediately
- Information technology (IT) must be improved in all areas of the DGH and this must be able to communicate with systems in primary and tertiary care

### Lay summary: district general hospital

The district general hospital (DGH) is the hospital that provides immediate care for a particular community. Some hospitals have only a DGH role while others—for example, teaching hospitals—provide very specialised care for some patients who are transferred to them from DGHs and also provide DGH care for the people living in their neighbourhood. In the past cardiovascular care was regarded as being complex and difficult to deliver and most cardiologists worked mainly in teaching hospitals (tertiary centres). This situation has changed and now the majority of cardiologists work in DGHs. The shift from specialist centre to DGH, by moving important services closer to where they are needed, has already produced major benefits for patients. Despite this, many patients with heart disease who are admitted to the DGH do not see a cardiologist. This is because of the large number of patients with heart disease and the relatively small number of cardiologists both in DGHs and specialist centres. This problem can only be solved by a large increase in the number of cardiologists throughout the country. There are encouraging signs that this problem has now been recognised centrally and is being addressed; there has been a rapid expansion in consultant numbers in the last few years. In the future most DGHs will have at least five cardiologists. Once this number is achieved it will be possible for specialised work, such as some forms of electrical testing of the heart (electrophysiology) and of angioplasty (PCI—opening blood vessels in the heart with balloons), which can already be carried out safely in DGHs, to be implemented more widely at the DGH level.

Although the number of cardiologists has been rising in recent years it is still inadequate. Until now the Royal College of Physicians and the British Cardiac Society have recommended that there should be one consultant cardiologist per 80 000 of the population. This requires the total number of cardiologists in the UK to rise to 820 (from 630 in

October 2001). However, it is now proposed that there should be more than one cardiologist per 50 000—that is, approximately 1200 cardiologists in the UK to meet the standards set by the National Service Framework (NSF) for coronary heart disease (CHD). Even more (1500 or more) consultant cardiologists will be needed to provide the inevitable increases in service demands and meet the provision of the European Working Directive.

As well as a shortage of cardiologists there is also a shortage of cardiac nurses in the DGH and all other types of hospitals. This is at a time when the role of the nurse is expanding and more nurses are required to provide a good service for patients. Many roles traditionally reserved for the doctor can and are being taken over by the nurse. In particular the specialist nurse can run specialised clinics—for example, for chest pain and cardiac failure—as well as running a large part of the programme for rehabilitation of patients with CHD and prevention of CHD.

Furthermore, when strategically placed in the hospital, specialist nurses can improve the quality of care enormously. One example is the introduction of nurses responsible for administering thrombolysis (“clot busting” agents) in the accident and emergency department to patients who are having a heart attack. This speeds up the administration of these life saving drugs and is very much to the benefit of the patient. There is also a severe shortage of cardiac technicians (CCSOs). The present number needs to be increased by one third. It is very important that ways are found to retain existing members of the workforce and to encourage others to become nurses and technicians. The DGH is now taking over the traditional role of the teaching hospital in the assessment and investigation of patients. Patients should undergo all investigations, unless extremely specialised, in the DGH and only be transferred to a specialist centre if they need a very specialised test or treatment not available in the DGH—for example, heart bypass surgery. The DGH, like all other areas, remains hindered by inadequate support staff and information technology, both of which are essential to communicate with patients and other doctors, keep up to date records, and collect information to allow the careful analysis of the quality of care and the results of treatment.

### Introduction

6.1 The crucial role of the cardiologist practising in the district general hospital (DGH) was emphasised in the Fourth Report,<sup>4</sup> but despite this, major inequalities of distribution of cardiologists from district to district persist. It should be remembered that all but a tiny number of tertiary centres also fulfil a DGH role for their local population (see 7.4).

6.2 Since the Fourth Report much of cardiology clinical practice formerly confined to the tertiary centre has been transferred to the DGH—for example, permanent pacing, cardiac catheterisation, nuclear cardiology, and transoesophageal echocardiography. In effect there has been a redefinition of what is regarded as tertiary care.

6.3 This transfer of services from tertiary to secondary care is occurring throughout the country with the full cooperation of all concerned and this trend will continue. A good example is percutaneous coronary intervention (PCI) where improved techniques have increased its safety and consequently it is now expanding in the DGH setting when there are appropriate facilities and expertise.

6.4 The evidence base for cardiovascular prevention has expanded impressively and is very clearly stated in the joint British recommendations on prevention of coronary disease,<sup>24</sup> which have been embraced by the National Service Framework (NSF) for coronary heart disease (CHD).<sup>5</sup>

**Table 6.1** National Service Framework standards 5–12 (inclusive). These impact directly on district general hospitals

<b>Standards 5, 6, and 7:</b> heart attack and other acute coronary syndromes	<p>People with symptoms of a possible heart attack should receive help from an individual equipped with and appropriately trained in the use of a defibrillator within 8 minutes of calling for help, to maximise the benefits of resuscitation should it be necessary</p> <p>People thought to be suffering from a heart attack should be assessed professionally and, if indicated, receive aspirin. Thrombolysis should be given within 60 minutes of called for professional help</p> <p>NHS trusts should put in place protocols/systems of care so that people admitted to hospital with proven heart attack are appropriately assessed and offered treatments of proven clinical and cost effectiveness to reduce their risk of disability and death</p>
<b>Standard 8:</b> stable angina	<p>People with symptoms of angina or suspected angina should receive appropriate investigation and treatment to relieve their pain and reduce their risk of coronary events</p>
<b>Standards 9 and 10:</b> revascularisation	<p>People with angina that is increasing in frequency or severity should be referred to a cardiologist urgently or, for those at greatest risk, as an emergency</p> <p>NHS trusts should put in place hospital wide systems of care so that patients with suspected or conformed coronary heart disease receive timely and appropriate investigation and treatment to relieve their symptoms and reduce their risk of subsequent coronary events</p>
<b>Standard 11:</b> heart failure	<p>Doctors should arrange for people with suspected heart failure to be offered appropriate investigations (for example, electrocardiography, echocardiography) that will confirm or refute the diagnosis. For those in whom heart failure is confirmed, its cause should be identified—treatments most likely to both relieve their symptoms and reduce their risk of death should be offered</p>
<b>Standard 12:</b> cardiac rehabilitation	<p>NHS trusts should put in place agreed protocols/systems of care so that, before leaving hospital, people admitted to hospital suffering from coronary heart disease have been invited to participate in a multidisciplinary programme of secondary prevention and cardiac rehabilitation. The aim of the programme will be to reduce their risk of subsequent cardiac problems and to promote their return to a full and normal life</p>

6.5 District cardiologists should be experts in rehabilitation and preventive cardiology as stated in the British Cardiac Society interface report,<sup>38</sup> and become team leaders of their multidisciplinary cardiac care workforce in coordinating strategies to reduce cardiovascular risk.

6.6 The workload of the district cardiologist is also expanding rapidly both numerically and in scope and complexity. This change in the practice of the district cardiologist severely restricts the time available for general internal medicine commitments.

6.7 The additional impetus provided by the NSF (table 6.1) for cardiologists to assume responsibility for all patients with acute coronary syndrome means that responsibilities for other “acute take” patients without cardiac disease must be reduced commensurately. We should now aim for a “next working day” cardiological service for cardiac patients, and work as quickly as possible towards staffing levels which would allow a 24 hours a day, seven days a week, consultant led cardiology service for acute coronary syndrome and other cardiac conditions. It must be the long term aim of the specialty that there will be appropriate cardiological input into the care of all patients with significant heart disease.

6.8 These aspirations for a comprehensive cardiological service will only be met in the context of a major increase in a number of consultants in cardiology. This needs to be mirrored by a

parallel increase in the number of consultants and other medical specialties involved in the acute medical take.

6.9 Between 30–40% of unselected general medical admissions have a significant cardiovascular component. The size of this problem means that there needs to be a very significant increase in the number of cardiologists working in DGHs.

6.10 The facilities for treatment of myocardial infarction in the UK have recently been audited by the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians. This shows that the standard across England is patchy and much could be done to improve it.

6.11 Local networks of cardiac care are evolving (see 5.21) and will form the basis for delivery of care to cardiac patients in the near future, coordinating care pathways across district networks within a tertiary catchment area and incorporating all relevant professionals including the ambulance service. Pre-hospital thrombolysis may prove to be as effective as direct PCI in acute myocardial infarction, and this will need considerable cooperation to implement if proved to be a desirable and cost effective option.

6.12 Patients rightly expect that they will receive a uniform high standard of cardiological care along their entire pathway from the community to the DGH, tertiary centres, and back into the community.

**Table 6.2** Main areas other than straightforward CHD

- Heart failure
  - ischaemic
  - cardiomyopathy
- Cardiac arrhythmias
  - atrial fibrillation
  - ventricular tachyarrhythmia and sudden arrhythmic death
  - complex electrophysiology
  - ablation
  - pacing
  - implantable cardioverter-defibrillators (ICDs)
- Valve disease
  - infection (endocarditis)
  - diagnosis
  - surgery/balloon valvuloplasty
  - infection (endocarditis)
  - complications of prosthetic valves

6.13 DGHs have an important role in coordinating both acute and long term care of cardiac patients in conjunction with primary care, health authorities (or their successors), and other agencies.

#### Conditions not emphasised by the NSF

6.14 The NSF, as the first centrally coordinated initiative intended to make a major impact on the management of heart disease, concentrates quite properly on CHD.

6.15 There are several important facets of cardiology care that are not mentioned in the NSF. The most important of these, which are complex and expensive, are summarised in table 6.2.

#### Number of cardiologists

6.16 Up until recently the target for the number of cardiologists in the UK was set at 1 per 80 000 of the population (that is, 830 consultant cardiologists in the UK). This level has not as yet been achieved although soon single handed consultant cardiologists in DGHs should be a thing of the past. The Department of Health accepts that the number of cardiologists must increase and this is consistent with the recent Royal College of Physicians and British Cardiac Society recommendations. Simply to cover a full time rota each DGH or group of DGHs will require at least five consultant cardiologists. This will be difficult to attain but must be achieved eventually.

6.17 The Royal College of Physicians and British Cardiac Society now recommend a staffing level for cardiologists of one whole-time consultant per 50 000 population<sup>39</sup>—that is, 1194 consultants for the 59.7 million population of the UK. This compares with the present number of consultant cardiologists in the UK of 630, which is about half the required number. The Royal College of Physicians job plans have defined appropriate sessions for the district specialist cardiologist.

6.18 However these numbers may well be inadequate, although a major improvement over the present situation (see 6.23).

6.19 With the advent of the new European working time directives, the average DGH will require at least five cardiologists to allow legal cardiology on-call rotas.

6.20 All the areas listed in table 6.2 are complex and need the same type of multidisciplinary team to deal with them. Many treatments in these areas have an evidence base that makes clear their effectiveness.

6.21 Because of their time consuming and often intricate nature these areas together probably make up at least a third of the time and resources needed to treat the totality of heart disease.

6.22 Heart failure is a very major consumer of health care resources, and new techniques for its management such as revascularisation and multi-site pacing have increased the amount of time needed. Furthermore, care of this condition is a prime example of where the patient derives enormous benefit from a multidisciplinary approval involving all levels of care and centred in the community.

6.23 The proposed number of 1194 cardiologists for the UK (see 6.17) as a whole will need to be substantially revised upwards. This is because many of the factors which have led to overload of the system and the people working in it have not been properly allowed for in calculating this figure, and current working practices are likely to change. It will soon be essential to have at least five cardiologists per DGH to cover rotas and allow a proper system of consultant cover at all times. Tertiary centres will need at least twice as many. The authors of this report believe that an overall figure of 1500 consultant cardiologists in the UK by 2010 is not excessive.

6.24 The increasing complexity of cardiological practice means that nearly all consultants in tertiary centres and many in DGHs will develop a subspecialty interest (for example, PCI, electrophysiology (EP), echocardiography, nuclear medicine, grown-up congenital heart disease (GUCH), etc).

6.25 The most important new aspects of a modern cardiology service that require more consultant time than in the past are summarised in table 6.3.

6.26 Serious overload has developed as cardiologists and other members of the team are asked to do more and more while the patient load and patient expectations have been rising. This overload is bad for morale, and is one of the factors leading to clinical mistakes, and possibly to a major loss to the profession in the form of early retirement.

#### Role of nurses

6.27 The expanding role of the nurse in all areas of cardiac care has been described elsewhere in this report (see chapters 5 and 12), with the issues surrounding future staffing.

6.28 In the DGH setting, key areas requiring additional senior cardiac nurses undertaking an expanded role are nurse led thrombolysis, chest pain clinics/medical assessment units, liaison with primary care, and heart failure services. This is in addition to the established roles in the cardiac care unit (CCU), progressive cardiac care unit (PCCU), cardiology catheter laboratory, and rehabilitation/prevention network.

#### Technicians, clinical physiologists (CCSOs) (see also 7.40–7.42)

6.29 Cardiac technicians will in the future be known as cardiac clinical scientific officers (CCSOs). They are currently seeking state registered status. CCSOs will in future be represented by the Registration Council for Clinical Physiology (RCCP).

6.30 Cardiac technicians have seen no recommended numbers published since the 1994 report<sup>40</sup> which did not alter those of 1987, despite the massive changes that have occurred in cardiac services, and consequently in the need for CCSOs.

6.31 It is however clear, even in the absence of survey data and work force assessment, that there is a gross shortfall of technical support. CCSOs are essential in nearly all areas of cardiological endeavour from the outpatient clinic to the operating theatre.

6.32 A reasonable estimate nationwide is that there are 3000 whole time equivalent CCSOs of MTO2 grade.

6.33 With the increasing technical complexity of cardiovascular services it is probable that an increase of one third is needed—that is, to a workforce of 4000 whole time equivalents.

**Table 6.3** Major changes in consultant practice and workload

- Reorientation of services to allow expert cardiological input into the care of all patients with heart disease. At present a great deal of the care of patients with heart disease is delivered by non-cardiologists (for example, general physicians and physicians from other subspecialties who admit patients on take). This is particularly true of acutely ill patients who are in most need of expert management
- Involvement of cardiologists in time consuming but important activities, which have been recently introduced, are essential but do not help deal with the enormous volume of cardiac patients:
  - audit
  - clinical governance
  - risk management
- Responsibilities for teaching/training and mentoring of medical students, specialist registrars and other health care professions
- Revalidation—both personal, and involvement with assessment of others
- Peer review of other units as part of the British Cardiac Society scheme
- General management issues for NHS trusts
- Involvement across the healthcare district in leading the development of networks of care
- Introduction of increased requirements for personal continuing professional development (CPD)

6.34 Even if the number of posts required is funded there will be a significant delay while recruits are trained, always supposing that people can be encouraged to enter the profession.

6.35 CCSOs will inevitably specialise further as units grow in size and the complexity of cardiology increases. Echocardiography, EP, catheter laboratory skills, and pacing are examples of these specialisms.

6.36 Echocardiography is leading the way with proper training programmes for CCSOs. The British Society of Echocardiography has developed these programmes. The British Society of Echocardiography is affiliated to the British Cardiac Society and is now regarded internationally as promoting one of the most advanced and comprehensive training programmes in the world.

6.37 It is estimated that there should be one dedicated CCSO per 1000 echocardiographic procedures carried out, and that an average DGH would have two such CCSOs, one of whom would be MTO5 grade.

6.38 The shortage of CCSOs was acute before the NSF and now with the increase in work, which is being generated by the NSF, has become one of the most serious problem areas in the provision of cardiological care in both the secondary and tertiary setting.

6.39 Unless the post of CCSO is made more attractive in terms of status and financial reward, the shortage of people wanting to follow this career path will be a major obstacle in providing cardiovascular care.

6.40 **Staff training and retention (see 7.39c):** Retention and training of CCSOs, critical care nurses, etc, are being addressed via the workforce development confederations, which are being developed by the Department of Health.

#### Bed and other space requirements in the DGH

6.41 The cardiac care unit (CCU) requires four beds per 100 000 population<sup>40</sup> and a contiguous progressive care area with at least 1.5–2 times the number of CCU beds, depending upon whether an additional cardiology team ward is available for continued care. There should be telemetry for monitoring of high risk pre- and postoperative patients, the number of telemetry channels necessary being similar to, but additional to, the CCU bed number for the population.

6.42 The ever increasing need for cardiological care of acute coronary syndrome patients requires reassessment of CCU bed numbers or a defined appropriately staffed area within the emergency medical assessment unit.

6.43 The cardiology department in the DGH has a large investigative role and there must be adequate dedicated space for:

- ECG recording
- exercise testing
- echocardiography
- Holter monitoring
- tilt testing
- pacemaker (and in the future, implantable defibrillator) follow up

6.44 There must be adequate space to accommodate technicians, medical staff, and secretarial/administrative staff.

6.45 There must be provision of modern computing facilities to generate reports and store information. Computerisation of the cardiology department is a requirement of General Medical Council revalidation<sup>9</sup> and will aid participation in regional and national audit.

6.46 Most large DGHs will have a cardiac catheter laboratory and a pacing theatre. Nuclear cardiology should be sited either within an independent nuclear medicine facility or in a radiology department liaising closely with cardiology for provision of the service and reporting.<sup>41</sup>

6.47 It is likely that there will be major advances in cardiac imaging with new and improved forms of fast computed tomography (CT) and magnetic resonance imaging (MRI). Although these techniques have not established their place as yet it is probable that they may be particularly valuable in the DGH setting. Development of these techniques requires good links with the x ray and other imaging departments within the hospital.

6.48 The NSF demands improvement of local cardiological services for traditional low access patient groups—the elderly, ethnic minorities, and women. Local quality and practice development teams should address these issues and audit them.

6.49 Elective invasive investigational work (mainly coronary angiography) will be undertaken in many DGHs in the future. This invasive work will be mainly coronary angiography. However, at least some (DGH) units will also undertake electrophysiology and radiofrequency ablation to treat arrhythmias and insert implantable cardioverter-defibrillators (ICDs).<sup>41</sup>

6.50 The numbers of diagnostic cardiac catheterisation and angiography procedures in the UK is relatively small when compared with other European countries. The NSF for CHD has proposed targets for revascularisation procedures of at

**Table 6.4** Immediate priorities of the National Service Framework to be achieved by April 2002 in district general hospitals

- Development of rapid access chest pain clinics providing assessment of recent onset angina within 2 weeks of referral
- 75% of eligible patients receiving thrombolysis within 30 minutes of hospital arrival
- 80–90% post-myocardial infarction patients discharged on aspirin,  $\beta$ -blockers, and statins and offered rehabilitation

least 750 percutaneous interventions, and at least 750 coronary artery bypass graft operations, per million population per year. In order to achieve this, the numbers of invasive diagnostic procedures can be estimated to be at least 3300 cardiac catheterisation and angiography procedures per million population per year. Greater numbers would be required where the local burden of coronary disease is high.<sup>41</sup>

6.51 The British Pacing and Electrophysiology Group has advised that 450 new pacemaker systems and an additional 100 replacement pacemaker systems—a total of 550 pacemaker implants—should be planned per million of the population per year. The National Institute for Clinical Excellence has estimated the total need for new and replacement ICDs at 50 per million population per year.<sup>1</sup>

6.52 Elective invasive diagnostic procedures, and pacemaker implantations, are increasingly being performed and are appropriate to be done in secondary care in DGHs.<sup>41</sup> In calculating the total laboratory time required for a population, it is necessary to consider the case mix of procedures, the laboratory time involved for each procedure, the number of cases which can be performed within the constraints of staff availability for each session of laboratory time, and training requirements, and should allow for peaks and troughs of demand. It can be estimated that one diagnostic cardiac catheterisation and angiography laboratory would be required per 450 000–600 000 population; and one pacemaker and defibrillator implantation laboratory per 1.4–1.6 million population; or one combined laboratory per 350 000–400 000 population if pacing and cardiac defibrillators are implanted in the same facility as cardiac catheterisations and angiography procedures.

6.53 This requirement should be adjusted relative to the local burden of disease, with the expected reduction in local incidence of coronary morbidity in the future, for training requirements, and for the independent provision and use of local cardiology services. This issue is of central importance when planning the provision of care for the future.<sup>41</sup>

6.54 Secondary prevention regimens are best organised in a specialist nurse clinic at secondary care level, with maintenance provided in primary care in a CHD register clinic.

6.55 There should be reassessment of rehabilitation and prevention pathways to achieve an integrated service within every district, with nurses fulfilling a key interface role in primary care. Rehabilitation is dealt with more fully in sections 12.16–12.25.

6.56 Training of district cardiologists needs to be broad, but as consultant numbers increase in the DGH some degree of specialisation is bound to develop, at least in large DGHs.

### Thrombolysis: in and out of hospital

6.57 The NSF for CHD recommends that patients experiencing myocardial infarction should be assessed by a professional and receive thrombolysis within 60 minutes of calling for

**Table 6.5** Key summary points: district general hospitals (DGHs)

- Comprehensive cardiological service should be provided in the DGH
- All patients with acute coronary syndromes (including myocardial infarction) and other important cardiac disease should be assessed by a cardiologist by the next working day (see 6.7)
- More consultants are urgently required in DGHs, as are cardiac nurses and CCSOs
- A commensurate reduction in commitment to general internal medicine is required for the district cardiologist to go some way to accommodating the presently unmet need for cardiology expertise
- DGHs have a very important role in coordinating both acute and longer term cardiac care, both in their hospital and outside their health district
- Uniform high standards of care should be available across all DGHs and the regional (tertiary) centre of any cardiac care network. This requires close liaison with both primary and tertiary care
- Computerisation of departments is essential to maintain standards and provide accurate data
- PCI can now be a safe procedure in the DGH with careful case selection if relevant quality issues are satisfied
- District cardiologists should be experts in rehabilitation and preventive cardiology and also in modern non-invasive investigations.

CCSO, cardiac clinical scientific officer

assistance (table 6.4). The British Heart Foundation recommends a call to needle time of 90 minutes or less.

6.58 It has been demonstrated thrombolysis administered by paramedics or general practitioners achieves faster thrombolysis than waiting for hospital admission.<sup>42</sup> Selective thrombolysis by paramedics or general practitioners is recommended.

6.59 A review of the pooled mortality data from the randomised and controlled studies of pre-hospital thrombolysis shows that there is an odds ratio of 0.83 (95% confidence interval 0.70 to 0.98) in favour of pre-hospital thrombolysis.<sup>43</sup> No trial reported a significant increase in adverse event rate which influenced outcome. Furthermore the European Society of Cardiology recommends that if indications are present for thrombolysis (and in the absence of contraindications or arrangements for primary angioplasty) it should be initiated in the pre-hospital phase, especially if journey time may be more than 30 minutes or the call to needle time for in-hospital thrombolysis may exceed 60 minutes.<sup>44</sup>

6.60 All patients with an indication for thrombolysis, and where there is no contraindication, should receive this treatment from the first available qualified person able to provide coronary care, whether this is a primary care physician, paramedic or hospital based clinician.

6.61 Thus it is important that in rural areas the whole issue of where thrombolysis is given is carefully reviewed in collaboration with the ambulance service.

### Angioplasty in the DGH

6.62 Angioplasty (PCI) is developing in some DGHs. This is driven by long interhospital transfer times to tertiary centres and convenience for patients who may largely present at secondary care level. This has become a realistic option because of the improvements in technology, including stenting and glycoprotein IIb/IIIa inhibitors, which have increased safety and significantly reduced the need for emergency coronary bypass surgery, which is now required in less than 0.5% of procedures.

6.63 At present only very few DGH units can undertake primary PCI—that is, angioplasty in patients who are actually having heart attacks. This treatment may be superior to

hospital based thrombolysis for acute heart attack. However, there are no data that compare pre-hospital thrombolysis with PCI.

6.64 If a nationwide primary angioplasty service is to be provided there will have to be very extensive re-thinking of the way care for acute heart attacks is delivered. Such an initiative will need a great deal of money and staff. Should PCI prove superior, plans to deliver such a service must be explored as a matter of urgency.

6.65 PCI services should only be developed in the DGH if they can satisfy the recent guidelines produced by the British Cardiac Society and British Cardiovascular Intervention Society.<sup>45</sup> This requires a high level of facilities, a fully trained team, adequate numbers of operators, and appropriate arrangements for surgical cover. Angioplasty provided in this type of setting is already the norm rather than the exception in much of mainland Europe.

6.66 It is probable that a significant number of large DGH cardiology units will have PCI facilities in the future, and that the operators working in the DGH will also maintain their expertise by performing PCI at their local tertiary centre.

#### **Achieving NSF targets**

6.67 The expanded multidisciplinary workforce working flexibly together with a well led local cardiac network has the best opportunity to achieve all the NSF goals. Networks are being developed rapidly and will improve the amount and quality of patient care that can be provided and thus help approach the NSF goals. The big uncertainty is the size of the problem in terms of the presently undiagnosed and untreated CHD which will be unearthed by application of the NSF to the population. In parts of the country—for example, the north west of England—the seam of undiagnosed CHD runs very deep.

6.68 Table 6.5 lists the key points of the DGH section.

## CHAPTER 7: TERTIARY CARDIAC SERVICES

### Synopsis

- Multidisciplinary teamwork is essential
- Services which complement those in the district general hospital (DGH) (secondary care) should be provided
- Cardiac surgery is usually only available in tertiary centres
- Some very specialised services—for example, complex and expensive procedures and imaging facilities—are also restricted to tertiary centres
- The disposition of some specialised services—for example, adult congenital heart disease—between secondary and tertiary care depends on local circumstances
- The tertiary centre also has a DGH role for its surrounding population
- Tertiary cardiac services should take a leading role in research, coordinate teaching, and liaise with medical schools
- Percutaneous coronary intervention (PCI) has already outstripped surgery in terms of numbers nationwide
- The National Service Framework (NSF) for coronary heart disease (CHD) will lead to more patients with heart disease being discovered and this will increase demand on service
- Revascularisation will not be reduced by improved prevention at present since the present under provision is so great
- The aging population contains a large number of otherwise fit patients with CHD who need active investigation and treatment

### Lay summary: tertiary cardiac services

*A tertiary cardiac centre is a highly specialised unit which provides expert specialty back up for the district general hospital (DGH) and which undertakes open heart surgery. Services are restricted to the tertiary centre if they are either very specialised, involve only a small number of patients in a single DGH, or if the variety of expertise needed is very wide and can only be brought together in a tertiary centre. The most important single activity that is largely restricted to the tertiary centre and not usually performed in the DGH is cardiac surgery. Cardiac surgery is extremely labour intensive and needs to be carried out in sufficient numbers for the unit and the individual surgeon to maintain their expertise. The National Service Framework (NSF) for coronary heart disease (CHD) makes it clear that the amount of revascularisation—that is, restoring blood flow to the heart by either angioplasty (PCI—opening vessels with balloons) or coronary artery bypass grafting surgery (CABG)—needs to increase. Encouragingly this is now occurring; there have been some 9000 extra procedures as a result of the implementation of the NSF. CABG, which is the main operation for treating CHD, is now one of the most common major operations carried out in the developed world. Because of increasing improvements in anaesthetic and surgical skills, patients can be safely operated on at increasingly greater ages. Since coronary disease is a disease which is common in the elderly this means that a large number of people who would not in the past have been considered for surgery are now routinely given this choice. These elderly people have high expectations and coronary surgery gives them major benefits. The situation is complicated by many patients requiring further procedures, having previously undergone either angioplasty or CABG. Repeat procedures are always more complicated and time consuming than the first procedures.*

*As elsewhere in the health care system, one of the biggest needs within the tertiary centre is for adequate numbers of properly trained staff. At present there is a shortage of cardiologists, cardiac surgeons, cardiac anaesthetists, and nurses. Cardiac technicians (CCSOs) and clerical staff are also in short supply. These longstanding staff shortages mean that many people are doing more work than they should do. They are doing this at a time when they are also asked to undertake many other tasks that they have not had to do in the past—for example, auditing their own performance and that of others. This is an essential activity but one which has only evolved recently, and usually there is*

*inadequate time and staff allocated to it. The consequence of this increased load at all levels is that people are under more and more pressure and often feel forced to work close to or in some cases beyond margins of safety. Inevitably medical mistakes become more likely as a result of overload at all levels of the system. This serious problem can only be solved by improving staffing levels, changing work patterns, providing adequate information technology (computerisation), and examining systems of working very closely.*

### Introduction

7.1 The infrastructure, staffing requirements, and workload of tertiary centres depend on the services they provide and the demand for them; there is variation from centre to centre. Tertiary centres are optimally situated within a large multispecialty district general hospital (DGH) and should not be stand alone monodisciplinary institutes.

### Special services provided by the tertiary centre

7.2 The tertiary centre provides services requiring multidisciplinary expertise where issues of cost efficiency or the rarity of the medical condition dictate concentration of resources in hospitals serving larger populations than a DGH.

7.3 These services currently may include:

**(i) Cardiac surgery:** This is performed almost exclusively in tertiary centres. Most centres will also undertake thoracic surgery but this is outside the specific remit of this report and therefore its impact on staffing and resource allocation has not been considered in this report. However, it must be taken into account when the overall need for resources and staffing is planned

**(ii) Interventional cardiological techniques (PCI):** For example, coronary angioplasty and stent implantation, percutaneous balloon valvuloplasty, atrial septal defect closure, brachytherapy, embolisation techniques, etc

**(iii) Complex electrophysiology:** Ablation, mapping, and multi-site pacing, and implantable cardioverter-defibrillator (ICD)—for example, insertion

**(iv) Specialised investigative techniques:** For example, cardiac magnetic resonance imaging (MRI), nuclear or positron emission tomography (PET) scanning, which are not usually available in the DGH at present because of cost. All echocardiographic modalities need to be provided at a high level of expertise so that complex cases can be investigated

**(v) Highly specialised services:** These are often undertaken on a supra-regional basis, such as transplantation, the treatment of paediatric and adult patients with congenital heart disease, and the management of severe pulmonary hypertension

**(vi) Paediatric services:** Specialised inpatient, outpatient, and outreach paediatric cardiological services and paediatric cardiac surgery

7.4 Secondary care (DGH) services to the tertiary centre's own local population of the type provided by an average DGH; these include:

- acute cardiac care
- diagnostic catheterisation
- pacing
- echocardiography
- other non-invasive investigations
- outpatient services (table 7.1)

These local demands on the tertiary centre have often been overlooked in the past when infrastructure and staffing levels are identified for a tertiary centre.

**Table 7.1** Outpatient services to be provided by the tertiary centre

- Transthoracic and transoesophageal echocardiography
- Stress echocardiography
- Exercise testing
- Nuclear cardiology
- Magnetic resonance imaging
- Ambulatory ECG and blood pressure recording/analysis
- Cardiography (ECG) services
- Tilt testing
- Open access echocardiography service

**Clinics**

- General adult ± paediatric cardiology clinics
- Cardiac surgical clinics
- Specialised cardiology clinics (electrophysiology, ICD, heart failure, adult congenital heart disease, primary and secondary prevention)
- Pacing clinics
- Rapid access chest pain clinics
- Rehabilitation services

Where a tertiary centre also provides regional paediatric and/or local secondary services there should be an increase in facilities accordingly.

7.5 The limited tertiary facilities that are available have, for geographical reasons, often tended to be used preferentially by the population living close to the centre, at the expense of others further away in their regional catchment areas.

7.6 The teaching and training of undergraduate and post-graduate medical staff, nurses, technicians, perfusionists, and radiographers.

7.7 Research, collaborative work with university staff, and the support of academic cardiology programmes.

**Revascularisation: general**

7.8 There are two principal methods of revascularisation: coronary artery bypass grafting surgery (CABG) and percutaneous coronary intervention (PCI). This section deals with both but there are further detailed sections on CABG in the surgery chapter (chapter 9) and on PCI in this section (see 7.18).

7.9 Coronary heart disease (CHD) is responsible for the majority of the demand placed on regional services and clear targets for revascularisation procedures have been set in the National Service Framework (NSF).<sup>5</sup> This states that at least 750 CABG operations and at least 750 PCIs should be undertaken per million of the population by the year 2010. This target still falls short of activity *currently* provided in many western European countries.<sup>45</sup> However, it represents approximately a doubling of the present rate in the UK. Trends elsewhere in Europe, in the USA, and in Australia make it clear that:

(a) These estimates fall short of the probable need of the population

(b) The number of PCIs will significantly outstrip the number of bypass operations as more sophisticated techniques and better adjunctive therapies, such as drug eluting stents and more powerful antiplatelet agents, become available

(c) A ratio of at least 1.3 PCIs to 1 CABG will be achieved in the near future. The number of PCIs in the UK exceeded those of CABG in 1998, and in the year 2000 there was approximately 34 000 PCIs compared to 25 000 CABGs (fig 7.1). Recently the number of CABGs has increased by approximately 1000 per annum due to improved funding for surgery

(d) Health services in the UK and other countries in Europe and elsewhere strongly suggest that the ratio of 1.3:1 will soon be exceeded and the universal figure of in excess of 2:1 is quite possible. This has implications for commissioning, training, and the development of facilities

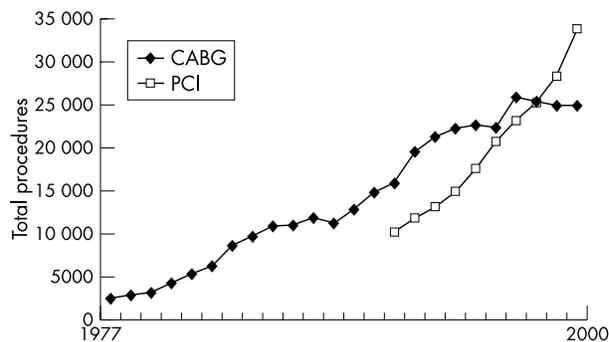


Figure 7.1 Relative number of coronary artery bypass graft (CABG) operations (isolated) and percutaneous coronary interventions (PCI) performed in the UK from 1977 to 2000. Sources: Society of Cardiothoracic Surgeons of Great Britain and the British Cardiovascular Intervention Society.

(e) The increase in PCI will only partly replace CABG. Many of the additional PCI cases will probably be patients who currently receive medical treatment.

7.10 The initial introduction of the NSF in March 2000 has led to an extra 5500 CABG operations in the subsequent 18 months against an initial target of 3000. This represents an increase in the national rate of surgical revascularisation of 25 per million population. The introduction of the “Patient Choice” initiative should lead to further improvements.

7.11 The NSF’s targets<sup>5</sup> regarding the identification and investigation of patients with heart failure will generate further demand for revascularisation procedures, since CHD is its most common aetiology.

7.12 The need for revascularisation is not likely to be reduced in the next decade by better primary and secondary prevention, since these measures are likely to postpone rather than prevent disease and because there is a large immediate unmet need in elderly patients.

7.13 The impact and interaction of primary and secondary prevention with intervention rates is complex. The best estimation is that for a long time into the future increased resources will be needed because:

- there is a shortfall in provision for known cases
- there is still much undetected, severe CHD in the population
- CHD is a disease of the elderly and so will be seen frequently in the new group of “fit, elderly” in the population. These people have high expectations and are also strong enough to undergo whatever intervention is appropriate

7.14 Targets for service delivery can usually be calculated from a combination of local data:

- the size of the population served
- the age structure and ethnic make up of the population served
- levels of past activity (historical demand)
- current waiting times (an indicator of the identified but unmet need)

7.15 This has to be combined with:

- estimates of the need derived from projection regarding the consequences of future developments in cardiological care
- consequences of improved diagnosis in revealing the unmet need
- the effect of increased demand, particularly from older patients

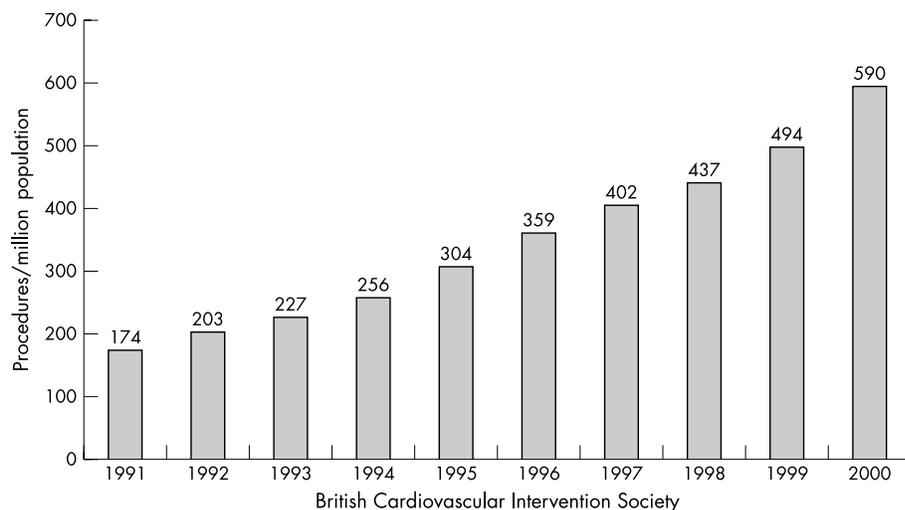


Figure 7.2 Percutaneous coronary interventions in the UK, 1991 to 2000.

7.16 For a catchment area of 1.5–2.5 million, each tertiary centre should currently be performing 1200–2500 open heart operations and a greater number of PCI procedures.

7.17 Further work is being undertaken to determine the optimum infrastructure for the delivery of the NSF targets for revascularisation. It is anticipated that there will be a major expansion in existing services in the geographic areas where the need is greatest and this will be combined with the building of new cardiac surgical centres.

#### Revascularisation: PCI

7.18 The emphasis on PCI is increasing (fig 7.1) and the advent of drug eluting stents, which will become available for clinical use in 2002, will further shift the balance away from CABG. These stents have been shown to reduce drastically the occurrence of restenosis of the coronary artery at the angioplasty site. Up until now restenosis has been one of the major drawbacks of PCI and therefore this breakthrough will increase the range of patients likely to benefit from PCI.

7.19 The relative ease with which PCI numbers can be increased (*vis-à-vis* CABG) should fit with the need to provide an overall increase in patients undergoing revascularisation. Although the NSF indicated a 1:1 PCI:CABG ratio, the Department of Health has accepted a PCI:CABG ratio of 1.2:1. In some European countries and the USA, the ratio of PCI:CABG is already 2 or 3:1.

7.20 All hospital trusts have recently been circulated with the document *Development of coronary angioplasty services: report of an ad hoc advisory group of the CHD taskforce*. Within the document is further emphasis on networks of cardiac care (see chapter 5) which will determine the rollout of PCI to additional sites, particularly to a limited number of DGHs that can fulfil the British Cardiovascular Intervention Society (BCIS) institutional and operator requirements (see sections 6.62–6.66).

7.21 New DGH PCI sites will require BCIS/British Cardiac Society (BCS) peer review before starting such a service. The BCIS and BCS peer reviews have been integrated (since 2001) through the BCS Professional Standards and Peer Review Committee.

7.22 The audit data of the BCIS for the year 2000 audit data show that a total of 33 652 PCI procedures were performed in the UK, representing a figure of 590 per million population (fig 7.2). This was an unprecedented 20% increase on 1999.

#### Electrophysiology services (EP)

7.23 In the last few years it has become clear that EP has changed from a niche subspeciality to an important component of everyday cardiology. There have been major advances in the

diagnostic and therapeutic aspects of EP. In particular ablation techniques, applied in a wide range of situations, are now very effective. Insertion of implantable cardioverter-defibrillators (ICDs) has proved life saving for certain patient groups and this has been accepted by the recent recommendations of the National Institute for Clinical Evidence.<sup>1</sup> This recommends 50 ICDs per million of the population, representing a major increase in implants which needs a commensurate increase in the number of cardiologists trained in EP. New indications for ICD therapy will require a rapid increase to 200–300 ICDs per million of the population. Lack of resource has limited ICD implantation despite current recommendations.

7.24 More recently multi-site pacing for patients with heart failure has begun to show great promise. This is a time consuming procedure and it is important that the needs for this new technology are assessed and funded to an appropriate level.

7.25 The success of modern EP to deal with serious and common cardiological problems means that this area of cardiology is now grossly underfunded and understaffed. There is an increasing requirement for EP services and along with this for more trainees in EP. The need for the proper funding of EP services is acute. This area of cardiology has not received the emphasis given to CHD because it was not included in the NSF. Nonetheless the need for these services is just as urgent as it was for CHD, and the evidence base for their effectiveness is strong.

#### Delivering the NSF

7.26 The cardiological community has welcomed the NSF and wishes to implement it fully. However, since it will identify presently unmet needs and also require additional work on the patients already identified, it will inevitably require major increases in the number of health care professionals of all types to deliver it.

7.27 Future planning to deliver the important standards of care demanded by the NSF will also need to take account of the changes in working practice that have arisen because of:

- reduction in service commitment by doctors in training
- increase in time allocated to training of junior doctors
- increased commitments of senior staff to management, audit, clinical governance, and appraisal; these are often the result of important initiatives introduced by the Department of Health without any increase in staffing
- changes in employment law that have reduced maximum working hours and will do so further over the next few years
- changes in working practices due to examination of competency/skill mix issues etc

**Table 7.2** Summary of major facilities needed for an average sized tertiary centre. Outpatient facilities are summarised in table 7.1

3–4	General cardiac catheter laboratories (5 if a paediatric cardiology service is also provided). Sufficient daycare beds to provide for the caseload of the catheterisation laboratory. This number must be sufficient to allow for over 90% of catheter lab procedures being done as day cases.
1	Dedicated electrophysiological catheter laboratory
10	Dedicated cardiac ITU beds per 1000 cardiopulmonary bypass operations per year. Additional and separate services needed if there is paediatric surgery
10	High care surgical beds per 1000 adult cardiopulmonary bypass cases
6–8	High care cardiology beds other than ITU and CCU beds
8	Cardiology ward (overnight) beds per 1000 cardiac catheterisations (over and above day care beds)
15	Cardiology ward beds for patients not undergoing investigation and intervention (e.g. infective endocarditis, heart failure, type B dissection, etc)
Additional beds	
<ul style="list-style-type: none"> <li>• Patients awaiting urgent surgery and who cannot be discharged in the meantime</li> <li>• Adult congenital heart disease services</li> <li>• To fulfil the tertiary centre's role as DGH for its local population (see section 6)</li> </ul>	

Such changes will have a considerable impact on the number of trained staff that is needed to deliver a proper level of service and a safe emergency rota, and as a consequence the cost of such care will inevitably rise (see also 6.25 and table 6.3).

7.28 With the opening of three additional tertiary centres with cardiac surgery since the Fourth Report<sup>4</sup> (Middlesborough, Plymouth, Brighton), the catchment populations of existing centres will have fallen slightly. However, all centres have to provide for increasingly aged populations with greater co-morbidity, and more repeat procedures. This is combined with higher public expectation and demand of the services available, and the uncovering of unmet need particularly as a result of the NSF for CHD.

7.29 Despite welcome progress since the introduction of the NSF, including an extra 5000 coronary bypass operations and the identification by the Department of Health of coronary disease as one of the most important health problems, the level of resourcing of cardiac services still remains too low.

7.30 Tertiary centres require adequate buildings, space, equipment, and facilities in order to provide a safe and efficient service. Arrangements for the provision of these will vary depending on local circumstances. Taking into account the considerable increase in demand for surgical, invasive, interventional, and EP techniques since the Fourth Report,<sup>4</sup> and assuming a regional catchment population of 1.5–2.5 million for a tertiary centre's facilities, the minimum requirements are shown in table 7.2.

7.31 Most tertiary centres currently function routinely at near 100% bed occupancy and have significant waiting lists of patients with acute problems waiting for inter-hospital transfer from DGHs (see below) and for admission from home. Unless average bed occupancy can be reduced to around 85% it will remain impossible to deal expeditiously with the clinical load that presents to the tertiary centre both acutely and chronically.

### Emergency facilities

7.32 By its very nature heart disease often presents acutely and facilities must be sufficiently well provided so that these emergency and urgent demands can be accommodated. In practice this means that some staffed but unoccupied wards, cardiac care units, and intensive care beds must be kept avail-

able at all times. At present this is not the case and this inevitably compromises care in many cases.

7.33 At present the lack of availability of such beds is a serious limiting factor in providing the type of acute service that is demanded by modern cardiology. At any one time there are a very large number of patients throughout the country who are awaiting transfer to a tertiary centre to have urgent investigation of an acute coronary syndrome. This deficiency in the service has become particularly important with the recent emergence of data showing the advantages for the patient with acute coronary syndrome that accrue from early investigation and intervention. This problem can only be dealt with by increased beds and staffing to rectify longstanding deficiencies in tertiary care.

### Staffing levels

7.34 Tertiary centres cannot function without an adequate number of trained staff, to provide both the elective and emergency services. All major staff groups currently experience chronic shortages of trained personnel. This is at a time when the pressure of public and professional expectations and the demand for expansion of cardiac services have never been higher. Low morale, staff sickness, and difficulties recruiting and training staff have resulted and this has a major effect particularly on nurse and technician recruitment. Until the shortages of trained staff are rectified or ameliorated by the creation of additional support groups (such as operating assistants to assist surgeons) cardiac services will continue to fall far short of public need.

7.35 The underprovision of staff leads to inadequate care as health care professionals struggle to treat more patients than is ideal. In turn this leads to overload of the system, poor care, and clinical mistakes. The many reasons why this overload is occurring has been addressed elsewhere in this report (6.26 and table 6.3).

7.36 Adequate staffing levels will not be achieved in any part of the cardiac care service unless there is careful planning and also creative thinking in retaining staff. There have to be adequate numbers of trainees coming through on time to provide the number of fully trained health care professionals required. These people have to be retained in their posts with attractive conditions and remuneration. Furthermore, loss of staff—by emigration, moving outside the NHS to work in the

private sector and industry, and earlier retirement—all need to be reduced, if at all possible. Ultimately this will not be achieved unless the service provides the right environment, experience, and reward for the people working within it. These problems need to be addressed for every group of health care professionals.

### Cardiologists

7.37 In many centres staffing levels remain well below those recommended in the Fourth report in 1992.

(a) There should be an immediate increase in the number of consultant cardiologists in secondary cardiac services to 1 per 80 000 of the population and to at least 1 per 50 000 within the next five years.

(b) This degree of uplift in staffing will lead to over 1000 cardiologists in the UK as compared to the present number of approximately 630. This increase must be achieved as soon as possible. Extending the duration of training at a time when specialist numbers cannot be achieved because of a lack of trained personnel will not help the specialty or the Department of Health achieve this goal.

(c) Tertiary centres must recognise that cardiologists within their centre will usually have responsibility for the local (district) population, in addition to their regional, more specialised roles. The total workload, both secondary and tertiary, must be calculated in determining overall consultant staffing levels.

(d) To fulfil its tertiary responsibilities each centre should have at least 5–6 consultant interventional cardiologists, 2–3 electrophysiologists, and 1–2 consultants with responsibility for non-invasive services—that is, between 8–12 cardiologists per centre depending upon the size of the unit. Many units have only half the number of cardiologists they need to provide a proper service.

(e) The number of cardiologists in training is being increased to accommodate these expansions. To this end 25 extra training numbers in cardiology are being created in 2001–2002, and this will go some way to help the services shortfall in trained cardiologists.

(f) The combination of increased tasks expected of the cardiologist, increasing size and complexity of the workload, and the need for rotas to be acceptable means that in reality significantly more than the officially projected numbers are needed. A target of at least 1500 cardiologists at the earliest possible time needs to be adopted and strived for.

### Cardiac surgeons (see chapter 9)

7.38 Cardiac surgeons:

(a) In order to achieve the increase in revascularisation procedures demanded by the NSF additional consultant cardiac surgeons must be appointed, with further increases for any additional expansion in future surgical activity. This was hindered by the shortage of surgeons available to be appointed, but is being addressed by the Department of Health by the creation of additional training numbers (25 in 2000 and 25 in 2001).

(b) Each tertiary centre should have 6–8 consultant cardiac surgeons, each performing some 200 cardiac operations per year. Where individual surgeons have thoracic as well as cardiac surgical commitments the total number of consultants required will necessarily be larger and the number of cardiac operations each individual performs will be lower.

(c) It is essential that each centre has at least the minimum number of surgeons needed to provide a safe emergency on-call service and also to perform routine operations, allowing for annual leave, etc. Thus every centre will need at least six surgeons (see 9.17).

(d) The increase in consultant surgical posts will need to be matched by a corresponding increase in cardiac anaesthetists, sufficient to cover the additional work in operating theatres and cardiac intensive care units.

### Cardiac nurses (see also chapters 5, 6, and 12)

7.39 Cardiac nurses:

(a) The number of trained cardiac nurses needs to be increased considerably so that ward, intensive, and high care beds are safely staffed, training of junior nurses is ensured, and shortages in specific specialised areas, such as cardiac catheter laboratories, cardiac theatres, and intensive care are redressed.

(b) With changes to the working practices and hours of junior doctors, allowance should be made for the increase in need for appropriately trained nurses with an expanded role.

(c) Recruitment and retention of cardiac nurses is a major problem, which is worst in critical care areas. Without these key workers it will prove impossible to achieve the required expansion of cardiac services. This problem is very difficult to solve, particularly in urban areas. This has been recognised by the Department of Health that has set up the workforce development confederations. These confederations provide training and mentoring and the retention of critical care nurses.

### Cardiac technicians (clinical physiologists in cardiology or CCSOs) (see also section 6.29–6.40)

7.40 Cardiac technicians:

(a) The importance of this staff group in the provision of services, that have become considerably more dependent on complex technology, has long been under recognised.

(b) There is a national shortage of trained staff because of difficulties in recruitment and retention. It is essential that this group of staff are regulated by government legislation as soon as possible. There has been progress towards state registration but this has not yet been achieved.

(c) There should be an average of 25 trained technicians for the average sized tertiary unit (serving 1.5 million people), which also has a local secondary catchment area of 250 000.

(d) As cardiology and cardiac surgery become more technical, this number should rise to 39 by 2010.

(e) Technicians acting as trainers are required at a ratio of 1 trainer to 10 ordinary technicians posts.

(f) All technicians must be at MTO2 grade or above. An increasing number of MTO4 and MTO5 posts will be required as the complexity increases.

(g) MTO1 grades are not appropriate for cardiac work.

7.41 It is extremely difficult to recruit and train the technicians (CCSOs) needed to run cardiac catheterisation laboratories. One possible solution is multiskilling areas that are perceived at present to be the individual preserves of CCSOs, nurses, and radiographers. A pilot project to explore the possibility of the “common catheter lab worker” is being funded by the CHD collaborative.

7.42 The complexity of the work of CCSOs is increasing in all areas. This is most pronounced in all types of echocardiography and in providing the back up for EP, pacing, and cardiac catheter laboratory services.

### Cardiac perfusionists

7.43 Each tertiary centre should have at least 6 qualified and 3–4 trainee perfusionists. There is currently a national shortage of perfusionists, without whom operations requiring cardiopulmonary bypass cannot be undertaken. However, more perfusionists will be needed if further major increases in surgical revascularisation is to be achieved. Despite this shortage many additional procedures have recently been achieved without employing additional staff.

### Cardiac radiologists and radiographers

#### 7.44 Cardiac radiologists and radiographers:

- (a) Cardiac imaging (computed tomography (CT) and magnetic resonance image (MRI) scanning) has advanced greatly over the last decade and have become the investigations of choice for many cardiothoracic abnormalities.
- (b) Close working relationships must exist between cardiac and radiology departments.
- (c) Most catheter laboratories employ cardiac radiographers and there is a national shortage of trained staff with advertised posts often attracting no applicants. Increasingly stringent radiation protection regulations originating from the EU have recently been introduced (IRMER) and are likely to increase the need for radiographers in the future.

### Administrative and clerical staff

#### 7.45 Administrative and clerical staff:

- (a) In common with all other areas of the NHS the tertiary centres rely heavily on these staff for the delivery of a quality service. Correspondence needs to be efficiently handled and most administrative and clerical staff take a highly responsible role involving frequent direct contact with patients. Their importance in the delivery of services has also been poorly recognised, they are low paid, and recruitment and retention is poor.
- (b) When new clinical posts are created the administrative and clerical support needed for them must be recognised and provided. This is frequently not the case and this lack of provision is unacceptable and unsafe.

### Additional support services and IT support

7.46 Support from a number of other medical disciplines is required for high quality tertiary cardiac services to be provided. These include vascular surgery, neurology, renal medicine, general medicine, blood transfusion services, haematology, histopathology, microbiology, clinical chemistry, pharmacy, etc. Full allowance needs to be made for these requirements when planning future developments. The wide range of support needed from other specialties means that tertiary centres are best sited in conjunction with a general hospital.

7.47 The whole unit must be backed up by modern information technology (IT). This is essential for safe practice since it underpins:

- safe clinical care with reliable and easily available patient record results
- effective audit
- assessment of quality of care

7.48 This area has been sadly neglected and in many centres it has proved impossible to obtain the necessary funding for what is essential infrastructure.

### Future developments

7.49 Since the Fourth Report<sup>4</sup> there has been further devolvement of some services (diagnostic cardiac catheterisation, permanent pacing) to DGHs.<sup>41</sup> As new therapeutic and investigative techniques become available they will usually be assessed and developed first in tertiary centres. Some will subsequently prove not to be widely applicable, but those that are will inevitably tend to devolve to district hospitals with time. This model is encouraged since it leads to the more comprehensive, more available, and more local services.

7.50 **Angioplasty in DGHs (see sections 6.62–6.66):** Over the next 10 years it is almost certain that coronary angioplasty undertaken outside surgical centres will increase, particularly since there will probably be a major increase in demand for coronary angioplasty in the emergency treatment of acute myocardial infarction. Tertiary centres will continue to provide a full range of PCI but will undertake the more complex or difficult cases referred from district hospitals and will be more involved in training.

7.51 Similarly, some EP procedures and ICD implantations are likely to be undertaken in the DGH. This change is likely to be accelerated considerably by the recent National Institute for Clinical Excellence guidelines that recommend a significant increase in the number of ICDs implanted.

### Comment

7.52 The Fourth Report<sup>4</sup> made particular reference to the dangers of providing “conveyor belt medicine”. Many who work in tertiary and secondary cardiac centres would argue that this is precisely what has developed since that report. The overload that has developed in the service for a wide variety of reasons has reduced the time available to individualise therapy for the individual patient.

7.53 Increasing demand and advances in the treatment and investigation of heart disease have far exceeded any increase in facilities over the last 10 years, and there remains a worrying underprovision of hospital beds (particularly in intensive care units), operating theatres, and trained staff in all groups.

7.54 Staff are under ever increasing pressure to deliver more and meet higher public expectations, but do not have resources to do so. This has led to low morale and a failure to recruit and retain trained staff in many important areas of the workforce. Furthermore, it encourages mistakes in patient care despite the best intentions of the workforce.

7.55 Despite these problems there remains an enormous amount of goodwill in the service. It is clear that there is a major commitment from the Department of Health to address many of the issues highlighted in this section and throughout this report, and to give the treatment of cardiovascular disease a high priority.

## CHAPTER 8: OUTPATIENT CARDIOLOGY

### Synopsis

- The way outpatients services are delivered needs a major overhaul
- Open access for investigations is sometimes helpful
- Rapid access chest pain clinics are increasing and proving successful
- The maximum wait for these clinics should be two weeks
- There should be a maximum wait in other cardiology clinics of four weeks
- Improved information technology resources are essential to improve the service
- More staff are needed for outpatients departments; this includes nurses with an extended role as well as staff grade, associate specialist, and clinical assistant doctors
- Patients must not be seen by a senior house officer unless closely supervised by a more senior doctor
- An increase in the discharge rate of patients with chronic problems is essential so new patients can be seen expeditiously

### Lay summary: outpatient cardiology

*Until recently, hospital outpatient services had been provided in the same way for decades. Only recently has there been a major rethinking of the way that such care is delivered. It is extremely important that care delivered through the outpatient department is available without delay, and is of high standard. Speed of access to specialist care is important for patients with recent onset of chest pain. This has been transformed by setting up rapid access chest pain clinics. These should be available in every district general hospital by 2003. These clinics provide a "walk-in" service for patients sent by their general practitioner and so there is immediate or almost immediate access to care (less than two weeks). In the meantime specialists clinics for other important conditions such as heart failure are being built up. The current aim is that all patients attending an outpatient clinic for the first time are seen within four weeks. A major deficiency in the past has been that many patients coming to the outpatient department have been seen by doctors who are at an early stage in their training. Although this was almost always done under the supervision of a more senior doctor, this supervision has often not been sufficiently close. The way the clinics are run needs to be changed so that patients are seen by a senior member of the staff. This will not always be a consultant and this is an area in which doctors with specialist training and permanent posts in cardiology at a grade lower than consultant level can help provide and maintain a high quality outpatient service. These doctors are usually in grades known as "associate specialists", "staff grade", "trust cardiologists" or "clinical assistants". Furthermore general practitioners with a special interest in cardiology can make a major contribution to running clinics. It is also very important that patients who have chronic disease, and who do not need to continue to come to the clinic, can be looked after by their general practitioner and sent back to the general practitioner. This is the only way that space can be cleared within the clinic so that there is time to see new patients quickly.*

### Introduction

8.1 The delivery of outpatient cardiology services has undergone radical change since the Fourth Report<sup>4</sup> and it now merits its own section in this report.

8.2 A major driver of this change has been an increasing demand and need for outpatient assessment coupled with an expectation among patients and general practitioners of easier access to investigations and reduced waiting times.

### Rapid and open access service

8.3 The parallel development of open access investigations in a whole range of areas has led to an evaluation of such serv-

ices in patients with suspected cardiac disease. Initially reservations were expressed as it was thought that tests might be ordered and acted upon inappropriately without direct consultant input. There remains doubt about the advantages and disadvantages of this approach and further well designed research is needed to resolve this issue.

8.4 Nonetheless there is evidence, in particular for echocardiography, that open access investigations can be used appropriately and to the benefit of the patient with the aid of clear, well designed proformas and guidelines for the general practitioner who requested the service.<sup>46-47</sup> Frequent audit of such services will lead to an improvement in patient selection.

8.5 Open access echocardiography and heart failure services need strong links.<sup>48</sup>

8.6 Heart failure is a specialist area which needs provision of both hospital and community services. Heart failure clinics are needed with close links to primary care re "heart failure" nurses and also, when necessary, links to palliative care.

8.7 Other investigations such as 24 hour ECG monitoring and 24 hour blood pressure monitoring can also be used in a similar manner. There are other situations where these investigations are better undertaken in conjunction with expert clinical assessment. In these situations appropriate arrangements for open access investigations should be established through local networks of care.

8.8 Open access services must be high quality and led by staff with proper training in the subspecialty involved.

8.9 In the assessment of patients with suspected stable angina it is generally agreed that exercise testing should be linked to the initial outpatient clinic evaluation.<sup>49-50</sup> From this concept rapid access chest pain clinics emerged and have been shown to function effectively, with a reduction in the time to coronary angiography and for intervention where appropriate.

8.10 A considerable number of such clinics are already in operation. The National Service Framework (NSF) for coronary heart disease has stated that all district general hospitals in England will have rapid access chest pain services by the year 2003 with 50 such clinics being in operation by the end of the year 2000.<sup>5</sup> In fact this number was far exceeded and by mid 2002 180 such clinics had been established mainly as a result of the Department of Health initiative linked to the NSF.

8.11 An essential component in the setting up of these rapid access clinics is a maximum waiting time goal of two weeks, although in many places considerably shorter waits are the rule.

### Other clinics

8.12 There is also a need for guarantees to be in place for waiting times of patients with other cardiac disorders, some of which may be as urgent as patients presenting with chest pain. Ideally the same standards as are applied to chest pain—that is, a maximum wait of two weeks—should apply. However, at present this cannot be achieved, but four weeks is an appropriate target at present.

8.13 The efficiency of outpatient clinics can be improved considerably if tests such as routine blood tests such as fasting lipids are arranged by the general practitioner and sent to the clinic with the patient. Careful screening of clinic letters will also allow hospital based tests such as 24 hour monitoring, echocardiography, etc, to be done before the clinic if it is clear from the referral letter they will be needed.

8.14 Referral letters should all be carefully screened by an experienced cardiologist so that an appropriate degree of priority is given to the patients.

8.15 There should also be facilities in place for same day investigations (“one stop shop”) with a review later the same day to discuss the results with the patient.

8.16 Clinics in specialist areas of cardiology are becoming established—for example, arrhythmias, pacing, and cardiovascular risk factor clinics. The latter are often linked with cardiac rehabilitation programmes.

8.17 Some centres are developing special expertise in handling rare conditions. These services often involve special outpatient clinics and occasional admission to hospital. Examples are clinics for patients with Marfan syndrome, hypertrophic cardiomyopathy, and pulmonary hypertension. In some cases—for example, pulmonary hypertension—these services will be funded centrally via national specialist commissioning (NSCAG). Other rare conditions have no such arrangements and funding remains poorly defined or non-existent. This problem must be addressed.

8.18 There is a need to plan for provision of all such services and a review of the way such services are planned is overdue.

8.19 Improvement in the way in which outpatient services are delivered will only be achieved by radical changes in the way in which clinics are organised. Firstly, there needs to be a commitment to an increase in appropriately trained personnel. The case for an increase in the consultant establishment has already been made in this document and the major developments in the way outpatient cardiology is delivered will also require a significant increase in consultant time available to the outpatient department.

#### Staffing of clinics

8.20 Associate specialists, staff grade cardiologists, and other non-consultant grades have a clear role in this area, but suitably trained individuals to fill these posts are often hard to come by. Utilising well trained general practitioners in outpatient clinics should be developed further, as should the use of specialist nurses with appropriate training.

8.21 The dependency of some clinics on senior house officers (SHOs), who are at an early stage of their training, is not desirable and will become unacceptable both from an educational and from a clinical governance point of view in the near future. Alternative medical staff will have to be made available in these clinics if a proper outpatient service is to be maintained.

#### Patient discharge

8.22 Follow up clinic attendances are currently at an unprecedented level and are preventing expansion of many clinics to accommodate new patients. A significant number of follow up patients continue to attend unnecessarily partly because of

the practice of them being seen by junior doctors who are unwilling to discharge them. Such patients fill spaces, which could be used to see new patients more quickly than at present.

8.23 Clear guidelines to define which patients require continued outpatient review and close cooperation with primary care should allow a major reduction in patients under hospital follow up.

#### Resources

8.24 The advent of open access services and rapid access clinics has not led to a reduction in the size of clinics; indeed the converse appears to be the case due to the increased profile of cardiac departments that open access services bring with them. Again this underscores the need for increased resources at all levels in the provision of outpatient services, and better cooperation with primary care.

8.25 The optimal delivery of modern outpatient services is intimately linked to improvements in information technology. Electronic reception and handling of referrals, generation of appointments, and return of reports to the general practitioner must be developed and indeed such services are already being piloted in a number of centres.

8.26 These innovations will reduce the pressure on secretarial and administrative staff while delivering key information to the general practitioner promptly with its attendant benefit to the patient. The resource implications of these developments must be recognised. The key points of the outservices section are listed in table 8.1.

**Table 8.1** Outpatient services: key points

- Rapid access services are now an integral part of outpatient cardiology services
- Rapid access chest pain clinics are currently being developed throughout the country for the management of patients with suspected stable angina with a guaranteed waiting of no more than 2 weeks
- All other cardiology referrals should be seen with a waiting time of no more than 4 weeks
- Priority should be decided by careful screening of referral letter
- Optimal communication with general practitioners is fundamental to the success of cardiology outpatient services
- This must include clear guidelines on the indications for open access investigations, tailored referral and report forms, information on all clinics, and regular educational feedback meetings
- The future way in which clinics must be run requires major reorganisation and provision of adequate medical, nursing, and administrative personnel.
- Adequate IT facilities must be available to underpin an efficient and safe outpatient service.

## CHAPTER 9: CARDIAC SURGERY

### Synopsis

- Cardiac surgeons' performance in England is monitored regularly by the Society of Cardiothoracic Surgeons ([www.scts.co.uk](http://www.scts.co.uk))
- The number of cardiac operations has risen steeply in the last few years
- Straightforward cases are being treated by cardiologists using percutaneous coronary intervention (PCI), so that the overall complexity of surgery is increasing
- There has been an increase in the number of re-do operations and this increase will continue
- More arterial revascularisation will be done in future
- Increase in "off-pump" surgery is likely
- Surgery is becoming more demanding because of an aging population, and the increasing number of diabetics and Asian patients who often have particularly severe disease
- Complex cases need longer stays in the intensive therapy unit (for example, elderly patients, reoperations, etc)
- Surgeon assistants may be a great help in the future
- A unit should perform 1200–2500 open heart operations per year and there are some advantages in not having units doing less than 1500
- Each unit needs a minimum of six surgeons

### Lay summary

Cardiac surgery is performed only in tertiary centres, or hospitals with a close link with a tertiary centre. The main reason for this is to allow a sufficiently large number of operations to be done so that the skill of the unit and the individual surgeons is maintained. Cardiac surgery requires the close cooperation of a wide variety of health care professionals. As time goes by the patients taken on by cardiac surgeons are presenting increasingly complex technical problems. A major reason for this is that cases, which are surgically straightforward and used to undergo surgery, are now often suitable for angioplasty (balloon treatment). Furthermore, as the population ages and surgery and anaesthesia become safer, so more of the patients operated upon are elderly. These patients do well but take up more resources than younger patients since they tend to stay in the intensive care unit and in hospital longer. Surgical treatment is also becoming more complex because of the large number of patients who have to undergo a repeat procedure following a previous angioplasty or operation. The average cardiac surgical unit needs at least six cardiac surgeons so as to allow surgeons

**Table 9.1** Cardiac surgical results in the UK for year ending March 2000

	Number	Died	Mortality (%)
CABG only	24728	547	2.2
Valve surgery only	5393	295	5.5
CABG and valve surgery	2641	207	7.8
Other operations for IHD	462	79	17.1
Congenital	3876	162	4.2
Miscellaneous	1479	220	14.9
<b>Total</b>	<b>38579</b>	<b>1510</b>	<b>3.9</b>

CABG, coronary artery bypass grafting; IHD, ischaemic heart disease

enough time off duty and to provide an on-call emergency service 24 hours per day, 365 days a year. Present calculations suggest a cardiac surgical unit should perform between 1200 and 2500 open heart cases per annum. The results of all surgeons in the UK have been monitored regularly by the Society of Cardiothoracic Surgeons. This allows problems to be identified early and dealt with. It is important that all centres keep precise records of their mortality for particular operations. This allows the patient to be properly informed about risk before consenting to any surgical procedure.

### Introduction

9.1 The number of cardiac surgical operations performed in the NHS in the UK has steadily increased during the last 20 years (fig 9.1).

(a) Most of this upsurge has been caused by the dramatic increase in surgery for coronary artery disease. Valve surgery has also risen, with an increasing number of elderly patients undergoing aortic valve replacement and a greater proportion of patients receiving concomitant coronary bypass surgery.

(b) Congenital heart disease has remained relatively constant, but demand for congenital heart surgery, particularly in adults and adolescents, is rapidly increasing and in general this surgery is becoming increasingly complex and demanding on resources.

9.2 The breakdown of cardiac surgical results in the UK for the year ending March 2000 is shown in table 9.1.

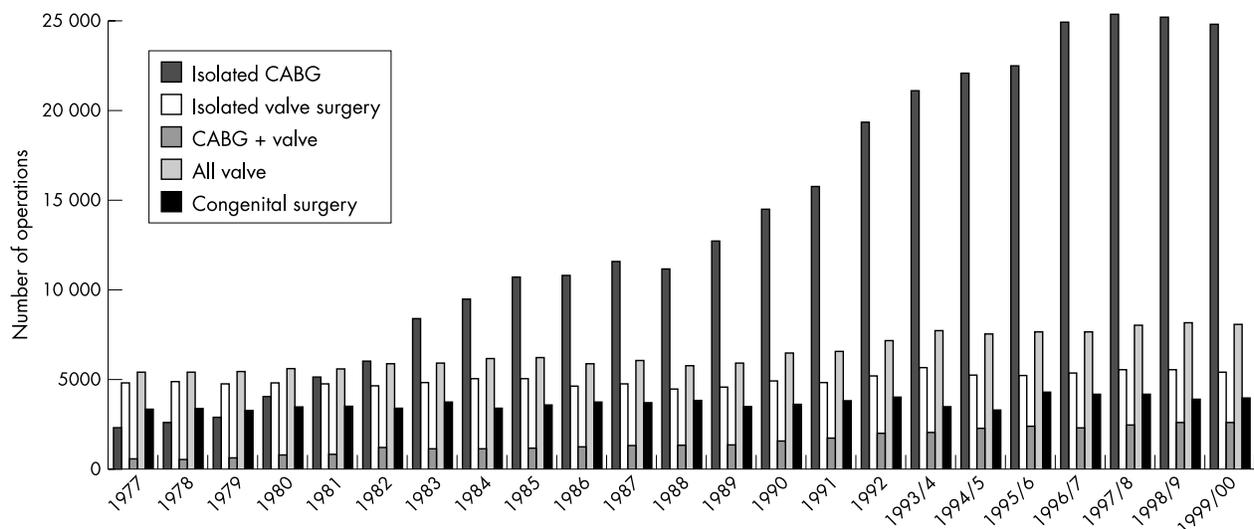


Figure 9.1 Trends in cardiac surgery in the UK. CABG, coronary artery bypass graft.

9.3 Despite a 40% increase in surgical revascularisation since the Fourth Report in 1992,<sup>4</sup> the requirement for more cardiac surgery has been relentless and waiting lists had risen, with many patients waiting more than a year for routine coronary artery bypass grafting surgery (CABG). Although the waiting lists remain unacceptably long, there are no longer any patients who have waited for 12 months or more for coronary artery surgery.

9.4 The increasing demands for cardiac services, particularly in the area of coronary disease, led to the National Service Framework (NSF) for coronary heart disease.<sup>5</sup> The average number of CABGs per million population in the UK in 1999 was 460 (including combined CABG and valve operations). The NSF has set a minimum target of 750 CABGs per million by 2010 and aims to eliminate inequalities of access between different geographical areas. This requires a 63% increase which can be achieved by a combination of maximising the throughput of existing units and the creation of new units.

9.5 Revascularisation will be provided by either CABG or percutaneous coronary intervention (PCI), with a possible future ratio of 1 CABG to 1.5–3.0 PCI (see sections 7.18–7.22). There are, however, many variables that will ultimately determine this ratio, including the medium and long term results both in medical and economic terms of new PCI technology, including the new generation of drug eluting stents.

### Future trends

#### 9.6 Changing patient population:

- (a) The average age at surgery will increase as life expectancy increases and older patients have increasing expectations and are generally more robust, and anaesthesia improves.
- (b) There will be more patients with significant comorbidity and more surgery for patients with adult (grown-up) congenital heart disease (ACHD or GUCH).
- (c) There will also be a change in ethnic distribution with increasing requirements for the Asian population, since this ethnic group has an exceptionally high incidence of coronary artery disease.
- (d) The number of diabetics in the population is increasing. Diabetics have severe coronary disease and many other complex medical problems.

#### 9.7 Changing revascularisation strategies:

- (a) There will be a reduction in simple coronary cases because of improved angioplasty for multiple discrete lesions.
- (b) There will also be an increasing amount of surgery for heart failure (70% of all heart failure is caused by ischaemic heart disease). This will be driven by the NSF.
- (c) Increasing numbers of patients will undergo extensive arterial revascularisation strategies.
- (d) There will be a major increase in off-pump surgery and subspecialisation in transplantation and aortic surgery.

### Changing clinical environment

9.8 It is inevitable that there will be difficulties in recruiting enough nurses. Greater professional flexibility is essential.<sup>3</sup> The use of surgeon assistants has been widespread in the USA for 20 years but has been slow to catch on in this country. However, adequately trained surgeon assistants could make a major contribution to cardiac surgery in general and to coronary surgery in particular.

9.9 Longer operations will consume greater theatre resource and lead to longer intensive therapy unit (ITU) and ward stays. To some extent this may be offset by evolving anaesthetic strategies.

**Table 9.2** Requirements for a unit doing 2000 open heart operations per year

- 8 or more surgeons
- 10 cardiac anaesthetists
- 10 perfusionists (6 trained, 4 trainee)
- 8 cardiac surgical SpRs
- 8 SHOs
- 2 surgeon assistants
- 3–4 theatres
- 20 ITU beds—flexible use
- 10 or more HDU beds—flexible use
- Adequate number of nurses
- Adequate number of technicians (CCSOs). One per operating theatre and holiday cover and others to provide necessary ECG services.

CCSOs, cardiac clinical scientific officers; HDU, high dependency unit; ITU, intensive therapy unit; SHOs, senior house officers; SpRs, specialist registrars.

9.10 There will be an increasing commitment to audit, teaching, and clinical governance, which will require dedicated time.

### Size and composition of a cardiac/surgical unit

9.11 The minimum size of a cardiac surgical unit is determined by considerations relating to acceptable and reasonable individual surgical workloads coupled with on-call guidelines. A one-in-four on call rota for cardiac surgeons is the minimum acceptable. This requires a minimum of six surgeons in a unit so as to cover for holidays, sickness, etc.

9.12 The Society of Cardiothoracic Surgeons has recommended that a cardiac surgeon should be allocated between 4–6 operating sessions per week. Although it is difficult to generalise, a cardiac surgeon should therefore perform or supervise around 200 cardiac operations a year.

9.13 Surgeons who do thoracic work will perform proportionally less cardiac operations, depending on the extent of their thoracic practice.

9.14 The total number of open heart cases performed annually within a unit should, in the future, ideally be more than 1200 cases per annum. This requires adequate anaesthetic, perfusion, and nursing staff, as well as adequate provision of operating theatres. The step-up in facilities and personnel needed to increase workload to over 2500 cases per annum risks becoming administratively cumbersome.

9.15 The number of operating theatres will vary depending on how many operations per day are conducted in one theatre. Scheduled long operating days of 12 hours for one surgeon are no longer sustainable and should be discouraged.

9.16 A guide to the resources needed by a unit undertaking 2000 open heart procedures per year is shown in table 9.2.

9.17 For smaller units—for example, doing 1000 open heart cases per year—a proportionally small number of staff will be needed. However, there is a minimum number of staff needed to ensure adequate rotas—for example, six surgeons. Thus it is probably most cost effective for individual units to undertake in the region of 1500 cases per year.

9.18 Recently increasing numbers of CABGs are being performed “off-pump” and some surgeons are now performing as many as 60% of their cases in this way. The impact of this is uncertain. If this practice increases there may be a reduced requirement for perfusionists for scheduled surgery, but any reduction in perfusionists for this reason will be balanced against the requirement for provision of adequate on call rotas.

9.19 The Society of Cardiothoracic Surgeons has recently published outcome data for all participating surgical units in the UK.

#### **Paediatric cardiac surgery**

9.20 Paediatric cardiac surgery is currently performed in 13 units in the UK. Four units are paediatric only and the rest have mixed adult and paediatric cardiac surgery. Only one unit has a single surgeon, two units have more than two surgeons, and the rest have two surgeons to perform the paediatric surgery.

9.21 An on call commitment of more frequently than one in three is not appropriate and it has been agreed among the paediatric cardiac surgeons that there should be at least three paediatric cardiac surgeons in each unit. The number of units in the country may have to be reduced to accommodate this, but there are many factors that have to be considered and

there is currently a committee looking at the future of paediatric cardiac services.

9.22 The results of surgery for congenital heart disease have improved steadily over the last two decades, particularly for infants. The operative mortality for infants undergoing open heart surgery in the last four years was 8.0%, whereas it was 32.5% in the first four years, recorded by the Cardiac Surgical Register (1977–1980).

9.23 The Society of Cardiothoracic Surgeons has been monitoring the performance of individual surgeons for the last three years. In addition to monitoring the early mortality for each surgeon's total paediatric operations, seven specific operations have been assessed. The results have been collected and analysed to ensure adequate outcomes and will be published in 2002.

## CHAPTER 10: CONGENITAL HEART DISEASE IN ADOLESCENTS AND ADULTS

### Synopsis

- Numbers are increasing as more patients operated on in childhood survive into adult life
- There are now approximately 130 000 adult patients in the UK with congenital heart disease
- Wide variations exist in the level of service provision throughout the country
- The majority of these patients should be looked after in specialised units
- Units dealing with this patient group are best situated in centres that have both paediatric and adult surgery
- There is a need for more consultants trained in the care of such patients
- Close liaison between district general hospital tertiary centres is needed to promote good care
- A very wide range of services are needed for these complex patients to deal with all types of problems they may encounter
- Units must provide advice re pregnancy, contraception, genetics, general surgery, and dentistry

### Lay summary

*The population of patients born with heart defects (congenital heart disease) who are surviving into adult life is already large and growing steadily as more patients survive heart surgery in childhood. These patients have complex problems and need to be looked after by health care professionals with specialist training in this area of cardiology who work in a unit dedicated to the care of such patients. The Department of Health should support an adequate network of units to care for this special and very demanding group of patients. More dedicated units with at least two suitably trained cardiologists, and access to surgery preferably in very close proximity, are urgently needed. A comprehensive report regarding the setting up of these units has been produced by the British Cardiac Society.*

### Introduction

10.1 There is an ever increasing number of patients with congenital heart disease who are surviving into adult life. They require provision of specialist care and attention.<sup>51 52</sup> It has been estimated that there are now 132 000 such patients in the UK at present and by 2010 this number is expected to reach 165 000.

10.2 There is significant divergence of views about the desirable name for this subspecialty. In general paediatricians prefer the term adult congenital heart disease (ACHD) while other practitioners within the area prefer grown-up congenital heart disease (GUCH). The term GUCH has been accepted by the European Society of Cardiology. In this section the two terms and abbreviations are used interchangeably.

10.3 Services for GUCH must be run by cardiologists who have special training in this complex area of cardiology. Both adult or paediatric cardiologists can train in this subspecialty. Perhaps the best pattern is close cooperation between representatives of both specialities.

10.4 It is not appropriate that relatively common conditions involving the heart valves which may have a congenital origin—for example, aortic stenosis caused by a bicuspid aortic valve—are regarded as part of ACHD.

### Pattern of care

10.5 The ever increasing success rate of paediatric cardiac surgery in the last three decades means that the number of patients requiring follow up for congenital heart disease

corrected by surgery is increasing at a rate of about 2500–3000 per year. This is already imposing a considerable strain on the paediatric services, and the interface between the paediatric and adult cardiologists is often blurred.

10.6 Although much progress has been made in looking after these patients since the Fourth Report,<sup>4</sup> the care provided for them still varies widely in different parts of the country and is often patchy at best. There are still too few well set up units with cardiologists specifically trained to look after these patients and with appropriate clinics and facilities.

10.7 **Patients who have not had surgery:** These patients comprise a large proportion of the population under consideration. Some have less severe conditions, but require monitoring to guard against the development of pulmonary vascular disease and other complications. Others may be inoperable and require sympathetic management of conditions such as Eisenmenger's which ultimately will be fatal or lead to transplantations. Another small group is made up of patients who present well into adulthood with conditions such as coarctation or atrial septal defect, which require correction.

10.8 **Patients who have had previous cardiac surgery:** Most of these patients need to be followed up for life. Certain patients—for example, those who have had correction of a persistent ductus arteriosus, atrial septal defect, and perhaps ventricular septal defect (VSD)—may not need continued follow up if they have been seen in outpatients for follow up on several occasions following surgery and the defects shown to be closed.

10.9 The need for a further operation maybe **unplanned** (for example, residual VSD), **planned** (for example, correction following previous palliation), or **inevitable** (for example, replacement of the conduit in the right ventricular outflow tract in truncus arteriosus or pulmonary atresia).

### Staffing and resources

10.10 Units undertaking both paediatric and adult cardiac surgery will find follow up and subsequent surgery easier than units with geographically separated services for adults and children. Expertise in pacing, electrophysiology, and adult valve treatment techniques are also necessary.

10.11 The appointment of cardiologists specialising in ACHD and appropriate ward and outpatient space is needed urgently. Although some cardiologists with a special interest in ACHD exist, their numbers are few, and whether they started out as paediatric or adult cardiologists, they will need an adequate training in both specialities.

10.12 Tables 10.1 and 10.2 show a list of requirements for the setting up of a unit for the care of ACHD. It is now estimated that, with the increasing number of adults with congenital heart disease, by 2010 there will be as many operations for congenital heart disease carried out on patients over 16 years of age as below that age.

**Table 10.1** Facilities required for setting up a unit for adults with congenital heart disease

- Outpatient facilities
- Ward facilities for young adults/adolescents
- Echocardiography
- Stress test, ambulatory monitoring
- Facilities for electrophysiology and pacing
- Catheter laboratory
- Operating theatres
- ITU and HDU beds

**Table 10.2** Medical staffing requirement for GUCH (ACHD)

- The following specialists with an interest in GUCH (ACHD):
- 2 cardiologists with necessary investigational and interventional skills
  - cardiac surgeon(s) with a special interest
  - radiologists (particularly MRI and CT)
  - specialist interventionists
  - specialist nurses
  - specialist psychologists

ACHD, adult congenital heart disease; CT, computed tomography; GUCH, grown-up congenital heart disease; MRI, magnetic resonance imaging.

10.13 Provision of GUCH care will be mainly an activity provided by tertiary centres. There has been a national review carried out by the British Cardiac Society. This has recently been published and will be available on the *Heart*, British Cardiac Society, and British Paediatric Cardiac Association websites.<sup>53</sup>

10.14 Centres need to have close liaison with neighbouring district general hospitals and, depending upon the distance involved, the needs of the patients involved may best be served by establishing outreach clinics.

10.15 A unit which provides services for ACHD needs all types of health care professionals trained in every aspect of cardiology and cardiac surgery as it applies to patients with ACHD (tables 10.1 and 10.2).

### Other issues

10.16 All activities should be audited and results submitted to the Central Cardiac Audit Database (CCAD) to be part of the central national audit process (see section 3). There should be regular meetings between all health care professionals involved in the care of such patients.

10.17 It is very important that provision is made to allow the smooth transition of the patient from the paediatric to the ACHD clinic.

10.18 Management of other problems in ACHD:

- (a) Pregnancy\* and delivery\*
- (b) Prenatal diagnosis/fetal cardiology
- (c) Genetics and counselling
- (d) Contraception
- (e) Dental surgery\*
- (f) General surgical procedures\*

\*All these also require appropriately trained anaesthetic staff

10.19 Patients with GUCH frequently have major psychological needs and these need thorough but also sensitive handling so that patients and their carers can come to terms with their particular condition.<sup>54</sup>

10.20 Specialist registrar training programmes for cardiology, cardiac surgery, cardiothoracic anaesthesia, and radiology should include the possibility of adequate training for those intending to specialise in GUCH.

## CHAPTER 11: PAEDIATRIC CARDIOLOGY

### Synopsis

- Workload is increasing despite the static birth rate
- There is a shortfall in consultant paediatric cardiologists
- There is an increase in subspecialisation. This leads to problems because it is impossible to have enough subspecialists in a unit to provide 24 hour subspecialty cover
- Increasing therapeutic catheterisations are being performed
- There is a shortage of cardiac technicians (CCSOs) with specialist knowledge in paediatrics
- Liaison nurses and clinical psychologists are in short supply
- There is a need to make it easier for cardiologists whose basic training is in adult cardiology to move into the specialty
- More anaesthetists are required for catheter intervention, cardiac catheterisation, and transoesophageal echocardiography as well as cardiac surgery

### Lay summary: paediatric cardiology

*Although the incidence of congenital cardiac defects can be predicted from the birth rate, and the birth rate is static, for unknown reasons the workload in paediatric cardiology is increasing. Because of this increase in workload there is a shortfall in paediatric cardiologists, paediatric cardiac surgeons, and all other health care professionals involved in treating children with heart disease. Complex procedures in which problems persisting after previous operations are solved by blowing up balloons within the heart and implanting devices that close holes or open up tubes can be very demanding in levels of skill, time, and resources. This type of work is increasing steeply. At the other end of the scale there is a growing need for paediatric cardiologists to see patients in order to exclude heart disease, since non-cardiologists are no longer prepared to take the responsibility of deciding whether a patient is normal in the way that they were in the past. There is also a need for more specialist anaesthetists since many procedures which can be carried out on adults under local anaesthesia have to be performed under general anaesthesia in children.*

### Introduction

11.1 Almost every aspect of congenital heart disease medicine has changed in the eight years since the last report on provision of services.<sup>4</sup> Supraregional funding for infant cardiac surgery has been abolished and there has been too little planning for the financial impact of a larger, more comprehensive, more successful, and more sophisticated service.

11.2 The workload continues to increase despite a fairly static national birth rate. Non-specialists are increasingly reluctant to take responsibility for diagnosing normality, the demand for screening of families deemed at increased risk of cardiac anomalies is rising, and there is a growing view that any child requiring cardiac assessment should be seen by a cardiologist.

11.3 There has been a huge expansion in outreach clinics, improving links with general paediatrics, but often requiring long journeys for consultants and necessitating their absence from the specialist centre.

11.4 Referrals for detailed fetal echocardiography are increasing as obstetric departments' routine anomaly scans become more searching.<sup>55</sup> Antenatal diagnosis of cardiac anomalies is now recognised as an opportunity to reduce morbidity by optimising early neonatal treatment.<sup>56</sup> However, fewer parents are opting for termination of pregnancy and a large reduction in numbers of children born with major congenital heart disease is unlikely.<sup>57</sup>

11.5 Infant surgical mortality has fallen, leading to many more patients with complex heart disease requiring long term follow up into adult life.<sup>58</sup>

### Staffing

11.6 The recommendation of the last report made in 1992—for a target of one consultant paediatric cardiologist per million of population—has still not been achieved even though the numbers have increased from 48 consultants in 1992 to 59 in 2000.

11.7 The increasing clinical workload as well as the demands of much more formalised and time consuming junior staff training, continuing professional development, and audit cannot possibly be maintained without further expansion in consultant posts; a target of one paediatric cardiologist per 500 000 of the population is now appropriate—that is, a target of approximately 120 consultants for the UK.

11.8 If an average paediatric unit serves a population of 5–5.5 million, its centre will require at least 10 paediatric cardiologists.

11.9 This expansion may necessitate a further increase in the number of specialist registrars in training posts if a repetition of the shortage of appropriately trained applicants for consultant posts that occurred in the early 1990s is to be avoided.

11.10 Subspecialisation of consultants within the area of congenital heart disease has evolved over the last decade. The British Paediatric Cardiac Association (BPCA), which is a British Cardiac Society affiliated group, recommends concentration of expertise, recognising that it is now not appropriate for all cardiologists to be performing all procedures.<sup>59</sup>

11.11 The role of therapeutic cardiac catheterisation has expanded and improvements in radiofrequency ablation treatment for arrhythmias have resulted in many patients now being treated in childhood rather than as adults.

11.12 Similarly, there is demand for consultants with special expertise in areas such as fetal cardiology, clinical genetics, adult congenital heart disease, and postoperative paediatric intensive care.

11.13 This subspecialisation is likely to be of benefit to the patient but raises practical difficulties in service provision. It is unsatisfactory for any particular aspect of care in a cardiac centre to be dependent on one individual. Many existing centres are not large enough on their own to provide a workload to allow two subspecialists in a particular area to maintain expertise. Reconfiguration of the natural provision of congenital heart disease services, taking into account these difficulties, is likely to be required.

11.14 These evolutionary changes in the way in which consultants work, as well as the obvious benefits of offering adult and paediatric cardiac facilities on the same hospital site as obstetrics, neonatology, paediatrics, and adult medicine, are likely to play an important role in future organisation of tertiary congenital heart disease services. A Congenital Heart Disease Services Review Committee has been commissioned by the Department of Health to report to government on current and future provision of care for all aspects of congenital heart disease. The committee is due to complete its report in 2002.

11.15 The technical complexity of modern treatment demands more specialised technical staff with particular expertise in electrophysiology, pacemaker implantation and follow up, and ultrasound. The need to recruit and retain technical staff with such skills is hampered by shortage of training programmes as well as the lure of greater financial rewards available in the commercial sector of health care.

11.16 The estimates of need for technicians put forward by the Society for Cardiological Science and Technology, which is the technicians' professional body affiliated to the British Cardiac Society, estimates that there is a need for eight technicians

dedicated to paediatric cardiology per centre in 2001 rising to 10 per centre in 2010.

11.17 Specialist support staff such as liaison nurses and clinical psychologists now play an essential role in tertiary centres, particularly in addressing the problems related to an underestimated need for general health information<sup>60</sup> and psychological difficulties which arise in adolescent patients.

### Training

11.18 Higher specialist training in paediatric cardiology now takes five years, a substantial reduction in the duration of training for most individuals. Both training programmes and the assessment of trainees' progress are now more formal than in the past and the element of service provision expected of trainees has been reduced, adding further to the workload of consultants.

11.19 The complexity of new technologies is likely to necessitate an additional, specifically tailored, year of training for some trainees wishing to subspecialise as consultants.

11.20 In the past entry into higher medical training in paediatric cardiology has been from both adult and paediatric general professional training. It is unfortunate (particularly considering the increasing demand for adult congenital heart disease specialists) that entry has become more difficult for candidates with an adult medicine background, even though the curriculum for paediatric cardiology still permits it.

11.21 Changes in recommendations for higher medical training in congenital heart disease are being considered by the Royal College's Specialist Advisory Committee in the hope of encouraging physicians as well as paediatricians to enter the specialty. This will be particularly beneficial in the area of adult congenital heart disease.

### Research

11.22 A sound introduction to research is essential for future consultants. This gives the consultant ability to assess objectively the evidence base for new treatments and is particularly important in a specialty which is rapidly changing.

11.23 The year of research recommended in the curriculum is unlikely to be sufficient to develop independent academic skills or to obtain a higher degree, and it is likely that "out of training" research posts will resume their importance of 10 years ago.

### Intensive care

11.24 The particular nursing and medical expertise required for patients with congenital heart disease has led to the development of dedicated paediatric cardiac intensive care units, avoiding the need to nurse critically ill cardiac patients in the immediate vicinity of general intensive care patients with potentially communicable infections.

11.25 The national shortage of general paediatric intensive care beds, particularly in winter months, poses a threat to bed occupancy in specialised cardiac care units. These specialised units must be protected if the quality of care for patients with congenital heart disease is to be maintained.

11.26 These units should have a ratio of one nurse per patient.

11.27 Efficient use of cardiac intensive care facilities has improved with the development of cardiac high dependency units (HDUs), which work on the basis of one nurse to two patients (as opposed to the 1:1 ratio for intensive care). It is now possible to care for some patients by direct transfer from the operating theatre to the HDU, or by a "fast track" approach, transferring the patient to the HDU after only a few hours of intensive care.

11.28 There is an increasing need to cope with the particular problems of adolescents and adults with major congenital

heart disease; providing these in a paediatric cardiac intensive care setting can allow optimum use of staff expertise.

11.29 The major developments in the specialty have increased the demand for nurses with experience in congenital cardiac intensive care at a time when recruitment of nurses is difficult.

11.30 Because of the complexity of modern postoperative management most centres in the UK now employ intensivists. Specific training programmes combining the disciplines of anaesthetics, cardiology, paediatrics, and neonatology will need to be developed with collaboration between the Royal Colleges' committees on higher medical training or the NHS Training Authority.

### Anaesthetic services

11.31 Paediatric cardiac departments rely heavily on the support of anaesthetists and operating department assistants. Cardiac catheterisation in children under local anaesthetic is now rare, even for diagnostic procedures. It is often safer to investigate a child under carefully monitored general anaesthesia rather than with heavy sedation being administered by the operating cardiologist.

11.32 Therapeutic catheterisation usually demands that the patient remains still if complications are to be minimised, and it is now accepted practice in the UK that all except simple procedures (such as balloon atrial septostomy) are safer and more easily performed using general anaesthesia.

11.33 Transoesophageal echocardiography has proved to be a valuable adjunct to the investigation and treatment of congenital heart disease, but it is poorly tolerated under sedation alone in the young or if long periods of imaging (for example, during transcatheter closure of septal defects) are required in adults.

### Retrieval services

11.34 Until recently transfer of a child to a tertiary centre was carried out by the referring hospital, but there is now great demand for tertiary centres to provide a retrieval service. A dedicated team of paediatrician or intensivist and an intensive care nurse, with a paramedic ambulance and crew, travel from the tertiary centre to the referring hospital, stabilising the patient before transfer.

11.35 Such an arrangement works well for general paediatric intensive care patients but there is debate over the benefits of such a system for neonates with cardiac disease. Most babies with congenital heart disease will improve with conventional medical treatment and often there may be no great urgency to transfer.

11.36 For others (for example, simple transposition) time is of the essence; immediate balloon septostomy may be the only effective treatment. On occasions delay caused by waiting for a team to arrive from another centre could increase the risk of serious morbidity such as hypoxic cerebral damage.

11.37 Careful liaison between those developing retrieval services, cardiologists, and referring paediatricians will be essential to avoid paradoxical harm being caused to the small minority of patients to whom a "scoop and run" policy may be lifesaving.

### Audit

11.38 The paediatric part of the UK Central Cardiac Audit Database (CCAD) pilot project was completed in the summer of 2000 (see section 10) and has now been approved (and funded centrally) by the Department of Health for use across the whole of the UK.<sup>13</sup> It is the first project of its kind, which includes independent data validation. In its initial phase it will allow accurate collection of national and institutional statistics for paediatric cardiac surgery and therapeutic catheterisation.

11.39 On-line analysis of mortality and freedom from re-intervention will be possible using the internet. Individual institutional and operator results will be available to each centre in comparison with anonymised data from the rest of the UK.

11.40 This will represent a major step forward in national audit, but further development will be required to establish risk stratification to allow analysis of results taking case mix into account. Collection of morbidity data, particularly

perioperative cerebral damage (a much more complex task), will be a future challenge.

11.41 Taking part in such national audit is likely to become a prerequisite for any consultant being approved as a trainer as well as an integral part of formal peer review and of fitness to practise. These developments should be welcomed by the profession as an aid to maintenance and improvement of quality of treatment for patients with heart disease.

## CHAPTER 12: CARDIAC NURSING

### Synopsis

- The role of the nurse in cardiology has been evolving since the 1960s
- Initially specialist cardiac nurses were found only in the acute cardiac care unit settings. They are now required at all points where cardiac care is delivered
- A strong nursing workforce is essential for successful cardiac services
- Retention of staff is a high priority
- The nurse consultant is a new grade and is likely to be very beneficial to cardiac services
- Cardiac nurses have a major role in the link with primary care, rehabilitation, etc, and in rapid access chest pain clinics, clerking patients, and carrying out supervised procedures

### Lay summary

*The need for nurses with special training in cardiology has been emphasised in nearly every other part of this report. This chapter dedicated to cardiac nursing pulls all these roles together and deals specifically with nurses. As well as carrying out their traditional role nurses are becoming more and more involved in the areas that were previously regarded as the domain of the doctor. Doctors are encouraging nurses to take on this extended role which they are performing extremely well and indeed in some areas nurses can deliver and supervise care more effectively than doctors. The new roles for nurses extend into the running of specialist clinics and link with primary care and rehabilitation. The new grade of nurse consultant should allow for the very important and changing role of the nurse to be fully exploited with beneficial effects for the patient.*

### Introduction

12.1 This sections is at the end of the report because the role of nurses is so wide it covers all aspects of cardiac care and has been mentioned in the preceding sections. This section represents an attempt to summarise these roles.

12.2 The role of the nurse in cardiac care has evolved considerably during the last decade. Nurses were pivotal to the success of coronary care units at their inception, expanding their role to meet the challenges of technical innovations during the 1970s and 1980s. In 1967 Killip and Kimball<sup>61</sup> stated: "In our opinion, optimal treatment . . . cannot be attained unless stated certain prerogatives hitherto reserved for the physician are delegated to the nurse". From the 1990s to the present, cardiac nurses have developed a much broader remit that includes working with cardiac patients in a variety of settings and with a range of knowledge and skills that encompass not only acute but also chronic disease management. The fundamental skill of defibrillation, which played a major part in the early concept of coronary care, remains a mandatory requirement in the hospital setting, and arguably in the wider health setting.

12.3 The term "cardiac nurse", once applied solely to those who were highly trained and technically skilled in the management of acute cardiac conditions in the cardiac care unit or in the postoperative intensive care setting, has been redefined to encompass nurses working in a wider variety of settings in primary and secondary care including the provision of rehabilitation, and support for people with heart failure.

12.4 Ongoing developments in cardiac care necessarily require a strong, highly educated nursing workforce. The role of the nurse is evolving rapidly to the considerable benefit of cardiology patients and the efficient and effective delivery of care.

12.5 Areas where cardiac nurses may be involved in the care of cardiac patients are listed in table 12.1.

**Table 12.1** Examples of areas in which cardiac nurses play an important role

- Operating theatres
- Invasive cardiology and intervention—catheter laboratories
- Acute care (A&E, CCU, PCCU, critical care, resuscitation, and the ambulance service)
- General medical, cardiology, and cardiac surgery wards
- Cardiology clinics including "rapid access" facilities
- Rehabilitation and cardiovascular prevention services
- Heart failure
- Community and primary care
- Genetic counselling
- Research and development
- Clinical audit

These all apply to adult and paediatric cardiology.

### Nursing workforce

12.6 Nurse recruitment and retention is essential to the provision of high quality cardiac care irrespective of setting. Organisations offering cardiac care must have an active policy in place for ensuring an adequately staffed service. Government policies on recruitment and retention of nurses are ambitious, and their success is pivotal to the future delivery of improved cardiac services.

12.7 In hospital, the nurse to patient ratio will vary according to the dependency levels of patients.<sup>62</sup> Estimated staffing ratios for different acute settings are given below, and apply to whole time equivalents throughout a 24 hour period:

- critical care/ITU 1 nurse: 1 patient
- CCU/HDU 1 nurse: 2 patients
- cardiac ward 1 nurse: 5 patients

NB: These staffing ratios are based on the Department of Health's Critical Care Review and apply to critical care settings. The recommendations focus on levels of patient dependency rather than number of beds, as a more appropriate means of estimating safe staffing levels. Extrapolation to the staffing requirements of wider cardiac care settings may be difficult in the absence of appropriate methodologies for estimating staffing requirements.

12.8 Accurate data on the number of nurses working in cardiac care are lacking, suggesting a need to carry out a detailed census to identify local and national variations in staffing policies. It is acknowledged, however, that staff movements and turnover rates, particularly in the junior grades, make more than a simple "snapshot" of staffing numbers difficult to achieve.

### Advanced and "extended" nursing roles

12.9 Throughout modern health care old hierarchical ways of working are giving way to more flexible team working. NHS employers are now required to empower appropriately qualified staff to undertake a wider range of clinical tasks, including the right to make and receive referrals, admit and discharge patients, order tests, run clinics, provide defibrillation, and prescribe drugs: the Chief Nursing Officer's "10 key roles for nurses".

12.10 The cardiac nursing role has already evolved in many instances to take into account advances in medical treatments and other aspects of care, such as those listed in table 12.2.<sup>63-66</sup>

### Nurse consultants

12.11 Nurse consultant posts are being established in the NHS to help improve quality and services, to provide new career opportunities, and to strengthen professional leadership. Nurse consultants will have responsibilities in four main areas:

**Table 12.2** Advances in cardiac nursing roles

- Primary care and nursing in the community, including work on prevention and chronic disease management
- The management of acute coronary syndromes and acute myocardial infarction, including speeding up the provision of thrombolysis and other therapies in a variety of settings<sup>63 64</sup>
- The provision of rapid defibrillation and advanced life support
- Rapid access chest pain clinics and preoperative assessment and support<sup>65</sup>
- Critical care, especially in the perioperative setting
- The cardiac catheter laboratory
- Secondary prevention and rehabilitation
- Elective cardioversion<sup>65</sup>
- Supporting patients with heart failure<sup>66</sup>

- expert practice
- professional leadership and consultancy
- education and development
- service development linked to research and evaluation

12.12 A growing number of nurse consultants is being appointed to take a lead in developing services for patients with cardiac conditions. This welcome development provides a range of opportunities to enhance further the nursing contribution to cardiac care.

#### Education for nurses

12.13 Changes in health care practices and nursing roles have impacted upon the education and training needs of nurses. Post-registration cardiac nurse education must develop to address the expanded role of the nurse. It now needs to cover issues such as the clinical assessment and triage of patients, patient education about their medication and self management, and may shortly need to include limited nurse prescribing. As shifts in the traditional professional boundaries occur, post-registration cardiac nurse education will also need to include skills such as exercise testing, clinics dedicated to conditions such as chest pain, management of heart failure, etc.

12.14 Delivery of education and training is best performed by nurses currently involved in day to day nursing practice. Nursing shortages make this difficult and innovative approaches should be considered, such as more joint appointments between the NHS trusts and the local university under whose auspices nurse education is being provided. It is yet to be seen how cardiac nurse education will develop once the four national boards have been dissolved later this year.

12.15 Education and continuing professional development (CPD) for nurses is central to supplying the nurses needed to provide cardiovascular care in all areas of cardiovascular disease. This is not just confined to the narrow area included in the National Service Framework (NSF) for coronary heart disease (CHD), although they will be crucial in delivering the very important objectives encompassed by the NSF.

#### Cardiac rehabilitation

12.16 The NHS Executive funded a survey of cardiac rehabilitation programmes in England and Wales in the mid 1990s that included aspects of structure, content, organisation, coordination, staffing, and funding. Wide variations in cardiac

rehabilitation services were demonstrated, supporting the findings of an earlier report from a working group of the British Cardiac Society.<sup>67-71</sup>

12.17 These findings led to a multiprofessional consensus workshop resulting in the first national guidelines and audit standards for cardiac rehabilitation in the UK.<sup>71</sup> Cardiac rehabilitation as a discipline has acquired further recognition through its inclusion in the standards for the management of CHD in the NSF.<sup>5</sup>

12.18 Cardiac rehabilitation and secondary prevention are essential parts of cardiac care. They need to be overseen by the local implementation groups and be part of the local area network of care. Every cardiac unit must have access to an adequate level of rehabilitation and every general practice should also be able to access these facilities. Cardiac nurses require the necessary training<sup>72</sup> for this role.

12.19 Cardiac rehabilitation facilities need to be made available to all cardiac patients requiring it. The potential range is very wide but at present concentrates on patients who have experienced an acute episode such as a myocardial infarction, coronary intervention or cardiac surgery. Every effort should be made to ensure that there is appropriate and equal access to all patients regardless of age, sex, ethnicity, socioeconomic status, and mental illness.

12.20 In the UK cardiac rehabilitation is generally run by specialist nurses in conjunction with a multidisciplinary team, which includes doctors, physiotherapists, exercise physiologists, dieticians, and occupational therapists with input from pharmacists and psychologists. The availability and type of cardiac rehabilitation throughout the UK is very variable. The vast majority of programmes are hospital based (68%) and only 9% are based solely in the community.<sup>73</sup> The majority of programmes are organised by specialist nurses (77%), and a much smaller number are run by physiotherapists (14%) or doctors (3%) in collaboration with a multidisciplinary team. This preponderance of nurse led clinics is likely to remain the most common model.

12.21 Rehabilitation and secondary prevention clinics<sup>74</sup> should be run in conjunction and once the patient's needs are established, coordination with continuing management in primary care must be facilitated.

12.22 Delivery of rehabilitation and secondary prevention must be regularly audited and there must be a structure for lifelong learning and CPD for staff involved in running rehabilitation services.

12.23 There must also be an identifiable budget for cardiac rehabilitation and secondary prevention services. This should include funding for the multidisciplinary aspects of the service so as to avoid services becoming dependent on goodwill and thus vulnerable to fluctuation. The government's commitment in its NHS Plan to expand cardiac rehabilitation services is long overdue and welcomed.

12.24 The resources required to provide cardiac rehabilitation services vary according to the model used, which may be hospital based, community based or self help at home. The choice of model will depend on the demographics of the population and the incidence of CHD.

12.25 Many such services are under resourced; services may be interrupted because of sickness and leave, especially where there is only one coordinator in post. Access to psychosocial services are generally poor, with long waiting lists for individual referral to psychologists.

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## APPENDIX 1: HUMAN RIGHTS (HR)

### Synopsis

- Denying the chance of effective treatment because of delays is not acceptable
- Blaming lack of resources will no longer be a defence for inadequate care
- Treatment should not be degrading to the patient because of lack of resources

### Lay summary

*The recent introduction of the Human Rights Act is likely to have a large impact in the area of health care. In the past a lack of resources has been often put forward as a reason for not being able to provide the most effective care for patients in a timely fashion. This will no longer be acceptable. This will have a major impact in a situation where the provision of cardiac care is less than adequate because of a shortfall in resources. It is important that treatment should be provided in conditions which are of sufficient quality to maintain the patient's dignity and privacy.*

HR 1: The Human Rights Act came into force in the UK on 2 October 2000 and it is likely to have an impact in all areas of life including medicine. The Act enshrines most of the rights conferred by the European Convention on Human Rights. The articles most likely to be relevant to medicine and to the care of patients with heart disease are articles 2, 3, 8, and 14.

HR 2: Patients are likely to look to law if they feel that their human rights are being undermined. Expectations are rising; patients want and expect more from their physicians and surgeons, and from the NHS in general. Denial of treatment because of expense, long waiting lists, treatment by non-specialists, etc, may all come under scrutiny under the Act. It should be borne in mind, however, that our domestic laws already make provision for dealing with suboptimal treatment. However, arguments in law that resources were not available, which are at present accepted as being valid, may well be considered contrary to article 2; gross neglect of vulnerable patients resulting in pain and suffering may be considered inhuman and degrading treatment, and therefore a breach of article 3; while treating a patient in a manner different to that of other patients, just because that patient engages in an activity which may undermine the treatment (for example, smoking), may be a breach of article 14 which prohibits discrimination.

HR 3: **Article 2** of the Act concerns the right to life and provides:

- "Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a Court following his conviction of a crime for which this penalty is provided by law."

This is an absolute right unlike other rights within the European Convention that are subject to reservation or qualification. The patient who has had his/her operation cancelled on several occasions may be able to successfully bring a claim under article 2 if the late operation would not have been as successful as any earlier operation. The state may find that it can no longer rely on any lack of resources argument, as it has done up until now.

HR 4: **Article 3** enshrines the provisions against inhuman and degrading treatment. Again this is an absolute right, so it is no defence to argue that the patient has been subjected to degrading treatment because resources were not available to provide treatment of an acceptable standard.

HR 5: **Article 8** is the Right to Respect for Private and Family Life and provides:

- Everyone has the right to respect for his private and family life, his home and his correspondence.
- There shall be no interference by a public authority with the exercise of this right except as in accordance with the law and as necessary in a democratic society in the interests of national security, public safety or the economic well being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.
- Article 8 is a qualified and not absolute right [the qualification is set out in the paragraph above]. A claim may be brought under article 8 if a particular treatment has damaged a person to the extent that it has interfered with the way they would normally have conducted themselves in family life.

HR 6: **Article 14**, Prohibition of Discrimination, provides:

- "The enjoyment of the rights and freedoms set forth in this convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion or other opinion, national or social origin, association with a national minority, property, birth or other status."

### Conclusions

HR 7: This report, which is aimed at highlighting how care can and should be improved, is being written against a legal background, which is likely to change greatly. This should give further impetus to the urgently needed improvements in resources and services for heart disease patients.

## APPENDIX 2: INFORMATION TECHNOLOGY (IT)

### Lay summary

*The gathering and use of information is a major factor in modern medicine. Information technology (IT) relates both to the information itself and to the technology required to acquire and analyse it. Information about heart disease is of interest to the general public, who particularly want to know how to avoid it, and what lifestyle changes are important. Patients who are unfortunate enough to develop heart disease have different needs including information about their specific condition, how they should be investigated and treated, but also information such as waiting times for appointments, and what standard of care they should expect from their local hospitals. Doctors, nurses, and other health care workers have additional needs. They must communicate information about the patients they treat and the procedures they are carrying out. They need accurate and easily accessible records so they can analyse and record the outcome in all the patients they treat; this allows them to measure their standard of patient care against accepted good standards and against other workers carrying out the same type of procedures. They also require educational information about new procedures and treatments. It is clear that information and the technology to support it is an important part of modern health care, yet the resources for this have been very limited both in terms of money for equipment and for the personnel to support the computers and information systems, as well as workers to check that all the information is gathered, entered, and analysed so that it is available in a useful and understandable format for patients, health care workers, and the general public where appropriate. IT is critical but it is also expensive and requires rigorous controls to protect the security of patient related information and to ensure that the right information gets to the right person at the right time. As patients records and all other associated information needed by patients, doctors, and other health care workers become increasingly computer based, substantial investment is required to ensure that this is developed in a coordinated and structured manner taking into account the needs of the patient, the doctor, and other health care workers as well as the general public at large. The development of adequate databases, search methods, access opportunity, analysis techniques, data collection methodologies, etc, is an essential foundation on which to base modern cardiac services.*

### Introduction

IT1: The increasing reliance on information technology (IT) is a recurrent theme throughout this report and highlights the need for major investment in both information strategy and the technology required to support it. Investment in IT within the health care budget has been poor and to achieve the necessary requirements for clinical information, integration, audit, governance, research and development, and continuing education, it is likely that up to 10% of the total health care budget may be required.

IT2: Information needs are wide ranging and include:

- patients, carers, and the public
- health professionals and their requirements to deliver effective clinical care
- clinical governance, performance management, service planning, and public health

IT3: Other general requirements for information are:

- integration of IT systems and strategies across the NHS
- effective communication and sharing of information between health care professionals and across cardiac networks

IT4: Publication of the National Service Framework (NSF) for coronary heart disease (CHD) and the CHD Information Strategy (<http://www.doh.gov.uk/nhsexipu/strategy/nsf/chdisdoc.pdf>) will form the template of the Department of Health information strategy for CHD. The priorities for IT development within this document are largely focused on NSF standards.

IT5: Many other areas of cardiac care have major deficiencies in information technology. Those not covered within the NSF document may suffer from lack of investment as priority is targeted at CHD. Steps should be taken to ensure that an integrated approach to IT development does not ignore this issue. This is a priority of the British Cardiac Society.

### Patients, carers, and general public

IT6: There are a number of national sources of information relating to heart disease available to the general public (see appendices 3, 4, and 5), most notably the British Heart Foundation (<http://www.bhf.org.uk>) with web based access to information. Information technology will play an increasingly important role in disseminating information of this kind to the general public. The cause, symptoms, and treatment of common cardiac problems, how to recognise the symptoms of a heart attack, how to call for help, etc, as well as information regarding prevention of heart disease, risk factor modification, and lifestyle adjustment are all examples of basic information relevant to the general public.

IT7: Patients will require information on the nature of their illness, the treatment options and outcomes, and the standard of care they can expect, and the nature of the patient journey throughout the management of their illness. Such information needs to be simple to understand as well as sufficiently detailed to be informative. The British Heart Foundation (<http://www.bhf.org.uk>) provides much background information on cardiac related illness, and the British Cardiac Society (<http://www.bcs.com>) has developed information about common cardiac procedures such as coronary angiography and permanent pacemaker insertion which can be used as an adjunct to informed consent.

IT8: Patients and carers will also require local information about waiting lists, procedures, and institutional and individual outcome data. This requires a substantial investment in IT infrastructure and strategic direction. Nationally agreed datasets are crucial to allow any accurate comparison, and proper funding and support, both for infrastructure and personnel, are required for local and national databases to provide meaningful clinical and administrative information.

### Clinical information

IT9: Communication between health care professionals and the sharing of clinical information are essential for improved patient care. Traditional information barriers between primary, secondary, and tertiary care must be broken down. This can only be achieved with major investment in IT at all levels, and an integrated approach to patient information. The key component of this strategy is the development of the electronic patient record as detailed in the Department of Health *Information for health* document (<http://www.doh.gov.uk>) with implementation scheduled to occur by 2005.

IT10: The electronic patient record should be an integrated part of a clinical information system that incorporates guidelines for management and from which audit, governance, and administrative information is acquired as a byproduct. It must satisfy the needs of a multidisciplinary team.

IT11: Integration of clinical information between primary and secondary care requires the development of shared health care records, primary care access appointment booking systems, and generation of coded discharge summaries (Read code).

IT12: In primary care, IT systems, software, and support are required for CHD registries, identification of high risk patients, and for integrated systems that have the facility to provide guidance on referral, investigation, and management of patients with cardiac disease.

IT13: In secondary care, the emphasis for the national IT strategy will reflect implementation of the standards in the NSF for CHD. However, much of the IT infrastructure required for this has broader implications for handling of clinical information, data security, audit, performance review, etc. Integration of this strategy should be focused through the local implementation strategy coordinated through developing clinical cardiac networks. Specific information requirements for acute myocardial infarction, stable angina, revascularisation, and rapid access chest pain clinics are evolving as part of the CHD Information Strategy (<http://www.doh.gov.uk/nhsexipu/strategy/nsf/chdisdoc.pdf>).

IT14: Chronic underfunding of IT development has meant that many primary and secondary care trusts do not yet have basic, essential IT facilities and support. Development and implementation of clinical information systems will require a major increase in resources to achieve the aims the Department of Health *Information for health* and the development of the electronic patient record.

### Audit and governance

IT15: The poor development of clinical information systems has meant that capturing audit, governance, and performance data, as a byproduct of the clinical information, has not been possible on a wide scale. Despite this, there is a wide spectrum of successful local and national audit projects that have acquired robust and useful data, often over many years. The Bristol enquiry has highlighted the need to provide such information in a structured and transparent manner to ensure the highest quality of patient care.

IT16: The Society of Thoracic and Cardiovascular Surgeons (STCS), the British Cardiac Society (BCS) and its affiliated groups have strongly supported the evolution of clinical outcome, audit, and governance information projects. The British Cardiac Society is taking a strong lead in the involvement of patients in the design and provision of cardiac care.

IT17: In order to provide meaningful information on clinical management, cardiac procedures, and their outcome it is essential that similar, complete, and accurate data are collected in different centres to ensure valid comparison. The Central Cardiac Audit Database project (CCAD)<sup>13</sup> was developed through the enthusiasm of health care workers, and sponsored by the Department of Health and the specialist cardiac societies, to pilot a national project of data collection on cardiac procedures and their outcome in an attempt to acquire robust and accurate national data, and allow comparison of “apples with apples” rather than “apples with oranges”.

IT18: The specialist societies such as STCS, British Cardiovascular Intervention Society (BCIS), British Pacing and Electrophysiology Group (BPEG), and the Association of Cardiothoracic Anaesthetists (ACTA) have been instrumental in developing nationally agreed datasets for cardiac intervention procedures, cardiac pacing, and revascularisation.

IT19: The pilot project of CCAD highlighted the value of comparative national data, seamless transfer of data, and long term outcome analysis via central mortality tracking, and provided sophisticated, robust methods of data encryption at both a local and national level. However, it also highlighted the enormous deficiencies in IT infrastructure within institutions and the underprovision of IT and audit support staff required to ensure accurate and complete data collection. The pilot sites enthusiastically supported the project, but the Department of Health has not clarified the funding for further development or to roll out the project more widely. The CCAD projects have the full support of the professional bodies and subspecialty groups, and renewed funding for national rollout is seen as critical to the development of respected and meaningful clinical audit on a national level.

IT20: Development of a national dataset for acute myocardial infarction in conjunction with the Royal College of Physicians (MINAP project), and paediatric cardiology/cardiac surgery in conjunction with the British Paediatric Cardiac Association (BPCA), has been funded by the Department of Health, allowing CCAD to continue acquiring national audit data in these areas. However, even here the level of funding provided is generally insufficient for the task required, and the lack of resources for IT infrastructure places yet more pressure on already overstretched health care workers.

### Workforce and facilities planning

IT21: Ensuring adequate workforce and facilities planning for cardiac care on a local, regional, and national level requires accurate and contemporary information to be acquired and collated. This relates not only to doctors but to all groups of health care workers, both trained and training. The British Cardiac Society has taken on a responsibility to acquire national information on existing cardiac facilities and staff in secondary and tertiary care centres as much of this information remains unknown or out of date.

### Research

IT22: The introduction of guidelines for research activity, research governance, and its funding within the NHS has led to the requirement for a more comprehensive database of research activities in individual trusts. This too has major implications for IT and needs to be adequately resourced. Integration with universities, research funding bodies, and NHS research and development directorates is required to ensure a structured approach and a lack of duplication.

### IT requirements

IT23: An enormous investment in IT is required at all levels to provide a comprehensive, robust, and secure platform for integration of patient related information, clinical information, audit, governance, research and development, and continuing professional development and education.

IT24: Each health care worker should have, or at least have immediate access to, an appropriate PC or computer terminal.

IT25: Network development and integration is required to provide high speed transfer of all forms of clinical information. Delays in access to information through high levels of network traffic via slow networks or underpowered PCs will lead to inefficiency and incomplete data generation.

IT26: Development of websites for patient related information should progress at a local level to provide patient/carer information, which is relevant to the local population. Such information requires regular updating, and the impact of this on health care personnel time as well as technological support needs to be addressed.

IT27: Individual cardiac units and/or trusts should develop intranets to disseminate information to multidisciplinary health care professionals.

IT28: As reliance on IT to provide clinical information increases, primary care units and individual cardiac departments should have dedicated IT support personnel in addition to the higher level of support required at a primary and secondary care trust level. This support should be immediately available. Data entry clerks, audit assistants, and information officers are required for each unit to ensure comprehensive and accurate data entry for audit/governance.

IT29: Workforce planning for health care professionals should take into account the need for IT related training and education. In addition, the updating of web based patient information, guidelines for primary care, etc, and the

generation and management of clinical information require a significant time commitment from multidisciplinary health care workers and should be an integrated part of their job plan.

IT30: Healthcare communities, possibly defined through cardiac networks, should have an integrated IT strategy, project board, and sufficient financial and personnel support

to implement and support clinical information systems and the necessary related audit/governance and administrative information.

IT31: Primary and secondary care trusts and clinical networks should have a commitment to support national audit projects such as MINAP and CCAD, with sufficient resources identified centrally for IT infrastructure and data management.

## APPENDIX 3: PATIENT SUPPORT GROUPS

**British Cardiac Patients Association:** Unit 5D, Station Road, Swavesey, Cambridgeshire, CB4 5QJ. Tel: 01954 202022; email: admin@bcpa.co.uk; website: www.bcpa.co.uk *A patient support group giving help and advice to patients and relatives.*

**\*British Cardiac Society:** 9 Fitzroy Square, London W1T 5HW. Tel: 020 7383 3883; fax: 020 7388 0903; website: www.bcs.com  
*General information for the specialty. Has some patient information on specific subjects mainly related to procedures.*

**British Heart Foundation:** 14 Fitzhardinge Street, London W1H 6DH. Tel: 020 7935 0185; website: www.bhf.org.uk  
*Can supply a wide range of information on heart disease.*

**Cardiomyopathy Association:** 40 the Metro Centre, Tolpits Lane, Watford, Hertfordshire, WD18 9SB. Tel: 01923 249977; fax: 01923 249987; email: cmaassoc@aol.com; website: www.cardiomyopathy.org  
*An organisation supporting affected families, medical professionals and research into heart muscle disease.*

**Cardiac Risk in the Young (CRY):** Tel: 01737 363222; website: www.cry.dircon.co.uk  
*Self funding charity that is committed to fundraising for ECG testing programmes working with local communities—highlighting awareness of cardiac abnormalities that can endanger lives—and supporting those families who require more information or have suffered a tragedy from sudden cardiac death.*

**Child Death Helpline:** Bereavement Services Department, GOS Hospital for Children NHS Trust, London WC1N 3JH. Helpline: 0800 282 986; tel: 020 7813 8550/1; website: www.childdeathhelpline.org  
*Operated from Great Ormond Street and the Alder Hey Children's Hospital. A confidential helpline staffed almost entirely by bereaved parents, offering befriending and support to anyone affected by the death of a child.*

**Children's Heart Federation:** 52 Kennington Oval, London SE11 5SW. Helpline: 0808 808 5000; email: chf@dircon.co.uk; website: www.childrens-heart-fed.org.uk  
*Supports families through the helpline (9.30 am to 9.30 pm Monday to Friday), provides grants to families with immediate needs, holiday, INR machines. Campaigns for improved services for families.*

**Compassionate Friends:** 53 North Street, Bristol BS3 1EN. Helpline: 0117 953 9639; email: info@tcf.org.uk; website: www.tcf.org.uk  
*An organisation of bereaved parents who offer support and understanding to families whose child of any age has died.*

**Grown up Congenital Heart Patients Association:** 12 Rectory Road Stanford-le-Hope, Essex SS17 0DL. Helpline: 0800 854759; fax: 01375 676900; email: info@guch.demon.co.uk; website: www.guch.demon.co.uk  
*Provides information and support for adolescents and adults with congenital heart disease and their families. Confidential freephone helpline provides emotional support and practical advice on living with a congenital heart defect.*

**Heartline Association:** Rossmore House, 26 Park Street, Camberley, Surrey U15 3PL. Tel: 01276 675 655  
*A support group for children with heart conditions and their families.*

**Patient support:** Website: www.heartline.org.uk  
*Independent group offering support for patients, family, and carers. Useful information on surgery, procedures, etc; easy to use.*

**Sudden Death Support Association:** Dolphin House, Part Lane, Swallowfield, Reading, Berkshire RE7 1TB. Tel: 0118 889797; fax: 0118 869797  
*Provides support for those bereaved by sudden death; 24 hour answerphone.*

\*There is a very large number of small patient associations and support groups. The British Cardiac Society has formed an overarching group known as the Heart Health Partnership UK (HHPUK) that will seek to enrol and assist all patient support groups.

## APPENDIX 4: USEFUL WEBSITES

Websites have been divided into general useful sites and those of particular value to patients/general public.

Each of the sites has been assessed for:

- content (C)
- ease of use (E)
- connectivity to other sites (CS)

Grading has been carried out using the following scoring system:

- 0 (poor)
- 1 (adequate)
- 2 (good)
- 3 (excellent)

### General useful sites

**Alliance of over 40 national organisations for reduction of CHD including BHF, BMA, BDA:** Role of organisation is to provide a forum for exchange of information and ideas on CHD prevention (for example, role of exercise, diet, tobacco control measures, etc). The site has limited content but provides good links.

[www.heartforum.org.uk](http://www.heartforum.org.uk)

C1 E1 CS3

**American College of Cardiology (ACC):** Excellent site for health care professionals providing access to ACC/AHA guidelines, continuing education, data registry, fellows in training, and ACC journals. Limited content for general public—AHA website better in this respect. Excellent links.

[www.acc.org](http://www.acc.org)

C3 E3 CS3

**American College of Physicians/American Society of Internal Medicine:** Good site providing access to journals, CME, guidelines, and evidence based medicine.

<http://www.acponline.org/journals/ebm/ebmmenu.htm>

C2 E2 CS2

**British Cardiac Society:** Excellent anchor site for cardiac health care professionals. Comprehensive links with other medical professional sites and with British Cardiac Society affiliated groups

<http://www.bcs.com>

C2 E3 CS2

**British Heart Foundation (BHF):** Charitable organisation involved in funding of research on heart disease, providing support and information to patients and families, educating the public and health professionals about heart disease, and providing training in emergency life support skills for the public and health professionals. The site provides access to educational materials, publications, and ongoing research, and has reasonable links to mother sites. Particularly good for patients and relatives: information on heart disease, fund raising, life support training, etc.

[www.bhf.org.uk](http://www.bhf.org.uk)

C3 E2 CS2

**British Hypertension Society:** Provides hypertension guidelines, publications, and information on courses and meetings. Does have a limited information service for patients (for example, validated blood pressure monitoring devices). Site easy to use.

[www.hyp.ac.uk/bhs](http://www.hyp.ac.uk/bhs)

C2 E2 CS1

**British Medical Association (BMA):** Good site for health care professionals with easy access to Medline, library, BMA publications (for example, BMJ), publications on ethics,

policy, science and international links. Has good links to other sites. Limited content for general public.

[www.bma.org.uk](http://www.bma.org.uk)

C2 E2 CS2

**Cardiology search engine:** Information on books, conferences and guidelines. Also some patient information.

<http://www.cardiofind.org/>

C1 E1 CS1

**Central Cardiac Audit Database (CCAD):** national system for centralised confidential data collection, rapid online comparative reporting, data quality reporting, mortality tracking. At present covers myocardial infarction patients (MINAP), adult cardiac surgery and intervention, paediatric cardiac surgery and intervention, heart valve surgery, pacemakers. Has many useful links—for example, to NSF for CHD.

[www.ccad.org.uk](http://www.ccad.org.uk)

C2 E1 CS1

**CCTA Government Information Service:** Entry portal to UK government information and service online—for example, list of central government departments, local councils, etc.

<http://www.ukonline.gov.uk/online/ukonline/welcome>

C1 E1 CS1

**Cochrane Library:** Provides high quality evidence to inform people providing and receiving care. Site provides access to abstracts of reviews. Need to subscribe to library to gain access to full reports.

<http://www.cochranelibrary.com/enter/>

C2 E1 CS1

**Consumer Association:** Health pages provide access to a limited number of reports. Need to be a member to use site (30 days free membership).

<http://www.which.net/health/contents.html/>

C1 E1 CS1

**Commission for Health Improvement:** Aim is to improve quality of patient care in NHS. Responsible for assessing every NHS organisation and making findings public, investigating where serious failures have occurred, advising NHS on best practice, and checking NHS is following national guidelines. Site provides access to clinical governance reviews, commission meeting dates, reports.

<http://www.chi.nhs.uk/>

C2 E2 CS1

**Data Protection Agency:** Responsible for keeping register of data controllers. Site also has access to freedom of information act, education, and training issues.

<http://www.dataprotection.gov.uk/>

C1 E1 CS1

**Department of Health:** Good site providing access to latest news (for example, NHS Plan) and information on the department. This includes access to previous Department of Health publications, in particular the National Service Frameworks. Links limited.

[www.doh.gov.uk](http://www.doh.gov.uk)

C3 E2 CS1

**Department of Health, Social Services, Public Health:** Responsible for policy and legislation for hospitals, family practitioners, community health, social services, public health, and public safety—for example, review of cardiology services in Northern Ireland. Useful for health care professionals but very limited for general public.

[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

C2 E1 CS1

**Department of Health National Service Framework (NSF) for coronary heart disease (CHD):** Guidelines, seven chapters on prevention, patients, myocardial infarction, angina, revascularisation, rehabilitation. Most important government document on cardiovascular disease management in recent years

[www.doh.gov.uk/nsf/coronary.htm](http://www.doh.gov.uk/nsf/coronary.htm)

C3 E2 CS1

**European Society of Cardiology (ESC):** Good site for medical professionals, with information on journals, education, ESC guidelines, committees, working groups, and meetings. Also has a virtual press office. Excellent link to other societies. Has limited content for general public, mainly in the form of press releases.

[www.escardio.org/](http://www.escardio.org/)

C2 E2 CS3

**General Medical Council (GMC):** Body charged with promoting high standards of good medical practice. Site contents include register of qualified doctors, information on revalidation, standards of practice, complaints procedures etc.

[www.gmc-uk.org/](http://www.gmc-uk.org/)

C2 E1 CS1

**Health Development Agency:** Aims to reduce health inequalities and improve general health of people. Gathers evidence and advises on standards. Provides health promotion and public health advice. Site has limited cardiovascular content.

[www.hda-online.org.uk](http://www.hda-online.org.uk)

C1 E1 CS1

**Medical Devices Agency:** Aim is to safeguard interests of patients by ensuring medical devices and equipment meet appropriate standards of safety, quality, and performance. Contents include UK implant registers (for example, stents), reports on wheelchairs, reducing needlestick and sharps injuries, etc.

<http://www.medical-devices.gov.uk/mda/>

C1 E1 CS1

**Medical Research Council:** Aims to improve health by promoting research into all areas of medical and related science, through its research establishments, grants to individual scientist and support for postgraduate students. Site includes ethics guides, press releases, and also has a schools resource section.

[www.mrc.ac.uk](http://www.mrc.ac.uk)

C1 E1 CS1

**North American Society of Pacing and Electrophysiology (NASPE):** Comprehensive site with North American perspective on cardiac rhythm problems. There is an excellent patient information section and up to date information for health care professionals.

[www.naspe.org](http://www.naspe.org)

C3 E3 CS2

**NHS Workforce:** Developing the NHS Workforce report.

<http://www.doh.gov.uk/wfprconsult/>

**National Electronic Library for Health:** Digital library for NHS staff, patients, and public. Site has good links to NHS Direct, nhs.uk, Department of Health, Medline, Cochrane Library, British National Formulary, and information on NSF for CHD, care pathways, databases, guidelines (including NICE guidelines). Also has access to an electronic library for social care. Includes a frequently asked questions section and headline news. Easy to use site and helpful for general public.

<http://www.nelh.nhs.uk/>

C3 E3 CS3

**NICE (National Institute for Clinical Excellence):** Role is to provide patients, health professionals, and public with authoritative, robust, and reliable guidance on current best practice. Site has various appraisals available (for example, glycoprotein IIb/IIIa antagonists, stents, defibrillators).

<http://www.nice.org.uk/>

C2 E2 CS1

**NHS Research & Development:** Reports available on ongoing funded research and covers opportunities for bidding for research monies.

<http://www.doh.gov.uk/research/>

C1 E2 CS1

**Office of Fair Trading:** Promotes and protects public health by helping safe and effective products reach market and monitoring products for continued safety after they are in use. Site provides access to press releases, meetings, "hot" topics (for example, BSE ("mad cow disease"), bioterrorism), safety alerts, comments on drugs, medical devices, food etc.

<http://www.oft.gov.uk/>

C2 E1 CS1

**Primary Care Cardiovascular Society:** Aims to improve care and outcome of patients with cardiovascular disease through exchange of knowledge and promotion among clinical practitioners of research, education, and development relating to cardiovascular disease in general and community cardiovascular disease in particular. Society's journal is *British Journal of Cardiology*. Site is limited, has details on meetings, members, etc.

<http://www.pccs.org.uk/>

C1 E1 CS1

**Pub Med Entrez:** Free online search engine of worldwide medical publications. Run by the National Library of Medicine in the USA.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>

C3 E3 CS1

**Resuscitation Council UK:** Provides education and reference material to health care professionals and general public in most effective methods of resuscitation including guidelines. Site includes publications, guidelines, legal ramifications, etc.

<http://www.resus.org.uk/SiteIndx.htm>

C2 E2 CS1

**Royal College of Physicians (London):** Good site covering conferences at RCP, education issues, audit issues, committee reports and minutes, library services, membership examination, senior house officer and specialist registrar training, publications.

<http://www.rcplondon.ac.uk/>

C2 E2 CS1

**Scotland—Health Education Board:** General site with limited cardiology data. Of limited use for the general public.

[www.hebs.scot.nhs.uk](http://www.hebs.scot.nhs.uk)

C1 E1 CS2

**Scottish Executive:** General website with very limited health information/content.

[www.scotland.gov.uk](http://www.scotland.gov.uk)

C0 E0 CS0

**Scottish Intercollegiate Guidelines Network:** Set up to improve quality of health care in Scotland by reducing variation in practice and outcome, through development and dissemination of national clinical guidelines for effective practice (for example, secondary prevention following myocardial infarction, etc). Over 60 evidence based guidelines

available on this site. SIGN council includes patient representatives.

<http://www.show.scot.nhs.uk/sign/index.html>

C2 E2 CS1

**Society of Cardiothoracic Surgeons of Great Britain and Ireland:** Responsible for setting, monitoring and raising standards in cardiac and thoracic surgery and improving standard of education and training for cardiothoracic surgeons. Site includes guidelines, committees, surgical audit and outcomes, and link to journal. There is a patient information glossary, with information on a number of surgical procedures.

<http://www.scts.org/>

C2 E2 CS1

**Society of Pharmaceutical Medicine:** Multidisciplinary agency which aims to promote acquisition and dissemination of knowledge concerning action and development of medicinal agents. Limited site covering meetings and archive reports.

<http://www.socpharmed.org/>

C1 E1 CS1

**US National Heart, Lung, and Blood Institute:** Part of National Institutes of Health (NIH). Provides leadership for a national programme in diseases of the heart, blood vessels, lung and blood, blood resource, and sleep disorders. Institute plans, conducts, and coordinates programme of basic research, clinical and observational trials, and educational projects. Site provides access to publications, studies seeking patients, committees, forthcoming meetings, research funding, events, etc. Useful information available for patients on heart and vascular disorders as well as blood and lung diseases.

[www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)

C2 E2 CS1

**US National Institutes of Health:** Responsible for conducting research in own laboratories and supporting research in non-federal laboratories and training of investigators. Site provides access to resources such as human embryo stem cell registry. Site also has news and events, grants, health information, and a Healthwise newsletter for patients.

<http://www.nih.gov/>

C2 E2 CS1

**Welsh National Assembly:** General website. Inadequate health information/content.

[www.wales.gov.uk](http://www.wales.gov.uk)

C0 E0 CS0

**World Health Organization:** Site includes international statistical classification of diseases, disease surveillance, library of public health, publications, directory of medical schools. Site has limited coverage for general public.

<http://www.who.int/home-page/>

C2 E1 CS1

**World Heart Federation:** Aim is to provide international strategies and programmes for prevention of cardiovascular disease, with numerous countries represented. However, site is limited (covers meetings and organisation publications only).

<http://www.worldheart.org>

C1 E1 CS1

#### Sites particularly useful for patients/general public

**Coronary Heart Disease:** Useful site providing information on coronary heart disease including treatment, prevention approaches and people who can help. Some links to other useful sites.

<http://www.bbc.co.uk/health/heart/index.shtml>

C2 E2 CS1

**Cardiomyopathy:** Cardiomyopathy Association. Charitable organisation set up to provide support for families with cardiomyopathy as well as to increase knowledge and awareness of these conditions to health professionals. Site has details of members, information on different cardiomyopathies, dates of meetings.

<http://www.cardiomyopathy.org/homepage.htm>

C1 E1 CS1

#### General patient advice and information

**American Heart Association (AHA):** Good site with extensive access to AHA journals, AHA/ACC guidelines, conferences, publications, healthy lifestyles, cardiopulmonary resuscitation, national programmes. Has good section for general public including cookbooks, patient education notes (My Heartwatch programme). Not as easy to access contents as ACC website.

[www.americanheart.org](http://www.americanheart.org)

C3 E2 CS2

**British Heart Foundation:** Charitable organisation involved in funding of research on heart disease, providing support and information to patients and families, educating the public and health professionals about heart disease, and providing training in emergency life support skills for the public and health professionals. The site provides access to educational materials, publications, ongoing research, and has reasonable links to other sites. Particularly good for patients and relatives: information on heart disease, fund raising, life support training, etc.

[www.bhf.org.uk](http://www.bhf.org.uk)

C2 E2 CS1

**Consumer Association:** Health pages provide access to a limited number of reports. Need to be a member to use site (30 days free membership).

<http://www.which.net/health/contents.html/>

C1 E1 CS1

**Hertnet (Hertfordshire Primary Care Research Network):** Covers heart attacks, angina, heart failure, and prevention of heart disease. There is also a glossary of cardiological terms. Also has useful links to other sites.

<http://www.heartsforlife.com/>

C2 E2 CS2

**National Electronic Library for Health:** Digital library for NHS staff, patients, and public. Site has good links to NHS Direct, nhs.uk, Department of Health, Medline, Cochrane Library, BNF, and information on NSF for CHD, care pathways, databases, guidelines (including NICE guidelines). Also has access to an electronic library for social care. Includes a frequently asked questions section and headline news. Easy to use site and helpful for general public.

<http://www.nelh.nhs.uk/>

C3 E3 CS3

**NHS Direct online:** Good site which includes the NHS Direct Healthcare Guide: this covers many common conditions, including common symptoms of conditions and who to call for help. Also has links to other sites—for example, “hot topics” provided by Health Board for Scotland.

<http://www.nhsdirect.nhs.uk/>

C2 E2 CS2

**Prevention of Coronary Heart Disease:** Coronary Prevention Group site. Good site which is easy to use and has extensive fact sheets on diet, exercise, smoking, and stress.

<http://www.healthnet.org.uk/>  
C2 E2 CS2

**Surgery Door:** Site provides access to information on common conditions, health news, and simple advice on emergencies and immunisation etc.

<http://www.surgerydoor.co.uk/>  
C2 E2 CS1

**Smoking:** Action on Smoking and Health (ASH) is a national campaigning charity working to tackle problems of smoking and smoking related disease. Useful information on quitting or cutting down.

<http://www.ash.org.uk/>  
C2 E1 CS1

**Virtual hospital website:** Site provides description of many common conditions, including cardiological, for both patients and medical professionals.

<http://www.vh.org/>  
C2 E1 CS1

## APPENDIX 5: IMPORTANT ORGANISATIONS IN CARDIOVASCULAR CARE IN THE UK

There is close interaction between many of these bodies and in many cases cross representation on important committees and governing bodies. There are other important bodies and only the largest are listed below with their web addresses (if available).

**BCS—British Cardiac Society:** The BCS is the professional (specialist) society that represents cardiology in the UK. It is a registered charity and almost all cardiologists in the UK belong to it. An elected President and Council run it. Its main interests are in maintaining professional standards, education of professionals, the interface between cardiologists and patients, and advancing the way in which cardiology is delivered to the population. Although the majority of members are cardiologists, a significant proportion of cardiac surgeons are also members. There is also affiliation for general practitioners, cardiac technicians (CCSOs), and nurses. There are affiliated groups that deal with specific areas of cardiology under the umbrella of the BCS. These are an extremely important aspect of the BCS and expertise can now be brought to bear on each of these special areas. They are as follows:

- Cardiovascular research (BSCR)
- Echocardiography (BSE)
- Heart failure (BSHF)
- Intervention (BCIS)
- Nuclear (BNCS)
- Nursing (BANCC)
- Pacing/EP (BPEG)
- Primary care (PCCS)
- Rehabilitation (BACR)
- Technology (SCST)
- Training (BJCA)

The BCS provides some patient information particularly related to procedures.  
[www.bcs.com](http://www.bcs.com)

**BCIS—British Cardiac Intervention Society:** The BCIS oversees and sets standards for the practice of interventional cardiology in the UK and is affiliated to the BCS.  
[www.bcis.org.uk](http://www.bcis.org.uk)

**BHF—British Heart Foundation:** The BHF is a major charity that is devoted to providing funding for research into cardiovascular disease both at a basic science and at a clinical level. It also provides information to the public about heart disease both by producing and distributing literature, and by maintaining a telephone help line for the public which is staffed by specially trained nurses. It is also instrumental in major initiatives aimed at improving the cardiac health of the nation and the cardiovascular services available.  
[www.bhf.org.uk](http://www.bhf.org.uk)

**BPCA—British Paediatric Cardiac Association:** This fulfils many of the roles of the BCS but in the field of paediatric cardiology. It can be accessed via the BCS website.

**BPEG—British Pacing and Electrophysiology Group:** This group oversees and sets standards for pacing and electrophysiology in the UK. It is affiliated to the BCS.  
[www.heart.org.uk/bpeg](http://www.heart.org.uk/bpeg)

**BSE—British Society of Echocardiography:** This group oversees and sets standards for the practice of echocardiography in the UK. It has its own accreditation system in the subspecialty which is regarded as a template around the world. It is affiliated to the BCS.  
[www.bcs.com/bse](http://www.bcs.com/bse)

**DOH—Department of Health:** The DOH is the government department that has responsibility for all matters in the delivery of health care in England. It makes policy in conjunction with other agencies including the Royal Colleges and the specialist societies. The Scottish Executive Health Department, the National Assembly for Wales, and the Department of Health, Social Services and Public Safety (Northern Ireland) are responsible in the other parts of the UK.  
[www.doh.gov.uk](http://www.doh.gov.uk)

**ESC—European Society of Cardiology:** This body incorporates the national cardiac societies of all major European committees, including the BCS. It provides a very important degree of coordination across Europe.  
[www.escardio.org](http://www.escardio.org)

**GMC—The General Medical Council:** The GMC is the statutory body that oversees the performance of all doctors, and licences them to practice. It issues important guidelines regarding general standard of practice. Currently it is involved in devising a system to revalidate doctors in term of their fitness to practise on a regular basis.  
[www.gmc-uk.org](http://www.gmc-uk.org)

**MINAP—Myocardial Infarction National Audit Project:** This project is auditing the care of all cases of myocardial infarction in the UK. This is a revolutionary project which will give complete data for the country in the treatment of this important condition. It is part of a large and computerised database known as CCAD (Central Cardiac Audit Database). This initiative linked with CCAD is being spearheaded by the Royal College of Physicians in conjunction with CCAD.  
[www.rcplondon.ac.uk](http://www.rcplondon.ac.uk) and [www.ccad.org.uk](http://www.ccad.org.uk)

**NHF—National Heart Forum:** This is a coordinating body of over 40 national organisations working to reduce the risk of coronary heart disease in the UK.  
[www.heartforum.org.uk](http://www.heartforum.org.uk)

**NICE—National Institute for Clinical Excellence:** NICE assesses forms of treatment and decides whether they should be funded under the NHS. It tends to look at new developments, particularly when they are expensive. It has already looked at and passed many modern forms of treatment for heart patients including sophisticated drugs to prevent clotting during heart attacks, stents which are metal rings that keep arteries open after they have been opened up initially with a balloon, and implantable defibrillators.  
[www.nice.org.uk](http://www.nice.org.uk)

**RCP—Royal College of Physicians:** The RCP has an overall responsibility for the medical specialties—that is, those that do not involve surgery. It is concerned with professional organisation and training programmes for continuing professional development over the broad range of specialties it encompasses. It works in close association with the Department of Health and the specialist societies. In the case of cardiology this link is with the BCS. There is a joint committee of the RCP and the BCS.  
[www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

**RCS—Royal College of Surgeons:** The RCS fulfils the same role for surgery as the RCP does for the medical specialties.  
[www.rcseng.ac.uk](http://www.rcseng.ac.uk)

**Society of Cardiothoracic Surgeons of Great Britain and Ireland:** This has a similar role for cardiac surgery as BCS has for cardiology.  
[www.scts.org](http://www.scts.org)

## APPENDIX 6: GLOSSARY

**ACHD:** These initials stand for adult congenital heart disease. This subspecialty of cardiology encompasses the care of patients who have been born with heart disease. Many of these patients would have already undergone major corrective surgery but need continuing care into adolescence and adult life. In the UK it is also known as GUCH (grown-up congenital heart disease).

**Angioplasty:** See PCI.

**CABG:** CABG is the abbreviation for coronary artery bypass grafting. This is the operation which is carried out to “bypass” blocked coronary arteries in patients suffering from coronary heart disease. In certain circumstances this treatment is life saving. This procedure is carried out by cardiac surgeons in tertiary centres.

**Cardiac surgeons:** A cardiac surgeon is a surgeon who carries out operations on the heart. Cardiac surgeons work in close conjunction with cardiologists. Many, but not all, cardiac surgeons also practice as thoracic surgeons and operate on abnormalities of other structures in the chest, such as the lungs.

**Cardiologists:** A cardiologist is a physician who diagnoses and treats patients with heart disease. The treatment may involve the use of drugs, the use of tubes and small balloons inserted into the body by the cardiologist to clear blockages, and also the implantation of pacemakers and defibrillators. The role of the cardiologist stops short of open heart surgery, which is carried out by the cardiac surgeon. Cardiologists and cardiac surgeons have a very close relationship. In general patients are not referred directly to cardiac surgeons but reach cardiac surgeons via cardiologists. Cardiologists all have a general knowledge of cardiology. Many of them extend their knowledge within a subspecialty of cardiology such as percutaneous coronary intervention (PCI), electrophysiology, echocardiography, grown-up congenital heart disease (GUCH), etc.

**CCAD:** The Central Cardiac Audit Database is being actively set up at the present moment. Initially it is going to record information from paediatric cases and myocardial infarction. It is intended to extend its use to all areas of cardiology. It was initially set up in 1995 as a cooperation between the British Cardiac Society, the Society of Cardiothoracic Surgeons, and other interested bodies that have already helped to develop relevant databases. It is now being developed under the umbrella of the NHS Information Authority.

**CCSO:** This stands for Cardiac Clinical Scientific Officer and is the term now used for cardiology technician. A cardiology technician carries out tests involved in treating heart disease. These tests are technical in nature and are mainly involved in the diagnosis of heart disease.

**CHD:** This stands for coronary heart disease, and is also known as coronary artery disease. This is a disease that leads to angina and heart attacks and is caused by narrowing of the coronary blood vessels.

**Clinical governance:** This is the careful scrutiny of medical practice. It involves development and audit of services for treating patients, the assessment and management of risk, the investigation of adverse incidents, and the establishment of standards for services. It is the cornerstone of modern medical practice.

**Coronary artery bypass surgery:** See CABG.

**CPD:** This stands for continuing professional development. All health care workers should be involved in CPD. This is made up of learning derived from going on courses that deal with particular aspects of cardiac care, attending educational meetings within the workplace, and private study. The level of CPD is monitored closely and doctors now have to submit annual returns as to how much CPD they undertake. In the

past CPD was also called CME, which stands for continuing medical education.

**DGH:** The district general hospital is the hospital that serves a particular area. It provides what is known as a secondary care. This is hospital care for patients who are referred by their general practitioners. For many patients all their treatment can be carried out in a DGH. Occasionally patients need to be referred to other hospitals having more specialised facilities (see Tertiary care).

**Echocardiography:** This is a study of the heart using ultrasound (sound beams). The sound beams (which are not audible) are reflected from the heart and produce a picture, which is interpreted by the cardiologist. Many of these procedures are carried out by echocardiography technicians under the supervision of a cardiologist. Most investigations are carried out by placing an ultrasound probe on the chest wall and obtaining a picture by shining the sound beams at the heart. Occasionally this does not provide adequate images because the wall of the chest obstructs the sound beams. Under these circumstances a probe can be swallowed by the patient, who is lightly sedated. This probe can be pointed at the heart from inside the gullet (oesophagus). This produces very much better pictures. This is known as transoesophageal echocardiography.

**Electrophysiology:** Electrophysiology is the assessment of the mechanism underlying abnormalities of cardiac rhythm. This is done by introducing thin wires through the veins to the heart under x ray control. Electrical impulses within the heart can be measured through the wires.

**GUCH:** See ACDH.

**Heart attack:** See MI

**HDU:** This stands for high dependency unit, and is where patients are looked after when too ill for an ordinary ward and not ill enough for ITU.

**ICD:** An implantable cardioverter-defibrillator is an electrical device which is the size of a large pacemaker. It can be inserted under the skin and connected to the heart. It delivers an electric shock to the heart if the heart goes into a dangerous rhythm. An ICD is used in patients who have had serious life threatening cardiac arrhythmias, have previously experienced sudden cardiac death from which they have been resuscitated, or are in danger of suffering a life threatening arrhythmia. They are implanted to correct the heart rhythm should a cardiac arrest occur.

**ITU (ICU):** This stands for intensive therapy (care) unit, and is where patients are looked after when very unwell and usually when critical ventilation or other support of breathing is needed.

**MI:** MI stands for myocardial infarction. This is when a coronary artery becomes blocked and part of the heart muscle dies as a result. This is treated by urgent unblocking of the artery either by a balloon (PCI) or by thrombolysis. Other names for this condition are *heart attack* and *coronary thrombosis*.

**Myocardial infarction:** See MI.

**National Service Framework:** See NSF for CHD.

**NICE:** This stands for the National Institute for Clinical Excellence. This body was set up by the government to look at various forms of treatment and decide whether they are of proven benefit and can be funded by the National Health Service. NICE is also responsible for writing guidelines to inform medical practice.

**NSF for CHD:** This is the National Service Framework for coronary heart disease. It sets standards by which coronary heart disease should be treated within England in primary, secondary, and tertiary care.

**Nurse consultant:** This is a new grade. Nurse consultants are similar to nurse practitioners but with a wider range of responsibility and autonomy.

**Nurse practitioner:** A nurse who takes over a role which was formally undertaken by a doctor and takes clinical decisions about a patient's care. This is usually carried out within strict guidelines.

**Paediatric cardiologists:** Paediatric cardiologists are paediatricians who specialise in cardiology. Like the adult cardiologists described under "cardiologists", their duties encompass all aspects of care of children with heart disease, stopping short of open heart surgery.

**PCI:** PCI stands for percutaneous coronary intervention. This is where a tube is passed in through the skin into an artery, and then manipulated as far as the heart. The tube is then used to introduce balloons and other equipment that can clear the coronary arteries from inside. This technique is also called angioplasty or PTCA (percutaneous transluminal coronary angioplasty).

**Primary care:** Primary care is another term for general practice. This is the care to which any patient can refer themselves.

**Radiofrequency ablation:** This is when a radiofrequency impulse is passed into the heart and in doing so puts right an abnormality of electrical conduction within the heart. This allows the heart to return to a normal rhythm and to prevent dangerous or distressing rhythm disturbances occurring in the future.

**Revascularisation:** Revascularisation is the restoration of blood flow through the arteries to the heart (the coronary arteries) using either CABG or PCI.

**Risk factors:** Risk factors are the factors that can be identified in a particular patient that make them at risk, for example, from having coronary heart disease. The most important coronary risk factors are smoking, high cholesterol, hypertension (high blood pressure), obesity, diabetes, and a strong family history of premature heart disease.

**Secondary care:** Secondary care refers to care carried out in a DGH. This is the first port of call for patients who are referred by their general practitioner except in certain circumstances when the general practitioner may go straight to the tertiary centre. Because tertiary centres usually have surrounding populations, they take on the role of secondary care for the population—that is, they act as a DGH for their local population.

**SHO:** This stands for senior house officer. The SHO usually has between one and four years of medical experience. This is a grade that people enter before deciding upon which specialty they are going to devote their career.

**SpR:** This stands for specialist registrar. The SpR is someone who has been selected for training in the specialty of cardiology. This training takes six years after completion of the SHO grade, and at the end of this the SpR will be appointed to a consultant post.

**Tertiary care (centre):** Tertiary care is very specialised care given to patients with heart disease. Patients are referred to tertiary care centres if they have a problem that is too complex for the local DGH. Most types of care are provided both in DGH and tertiary centres, but the tertiary centres sometimes have more sophisticated equipment and specialists with interest in very specialised areas of cardiology diseases. In particular, tertiary care is where cardiac surgery is performed. Cardiac surgery is not carried out in hospitals which are not tertiary centres.

**Technician:** See CCSO

**Thrombolysis:** Thrombolysis is the administration of drugs which dissolve clots to patients who are having heart attacks. Dissolving the clot improves the function of the heart and saves many lives. In some patients the blood clot is cleared with a balloon (PCI) rather than by thrombolysis.