

# Reducing the Risk: A Strategic Approach

## The Report of the Task Force on Sudden Cardiac Death



DEPARTMENT  
OF HEALTH  
AND CHILDREN  
AN ROINN  
SLAINTE  
AGUS LEANAÍ

# **Reducing the Risk: A Strategic Approach**

## The Report of the Task Force on Sudden Cardiac Death

Published by the Department of Health and Children  
[www.doh.ie](http://www.doh.ie) March 2006 ISBN1-873820-74-7



# Contents

## Contents

<b>Foreword</b>	6
Ms. Mary Harney T.D. Tánaiste and Minister for Health and Children	6
<b>Message from the Chairman</b>	7
Dr. Brian Maurer, Chairman of the Task Force	7
<b>Acknowledgements</b>	8
<b>Abbreviations and Glossary of Terms</b>	9
<b>Executive Summary</b>	17
<b>Chapter 1. Introduction</b>	31
1.1 Introduction	32
1.2 Terms of reference	33
1.3 Membership of the Task Force	34
1.4 Policy context and guiding principles	35
1.5 Preparing the report	36
<b>Chapter 2. Background: The Nature of the Problem</b>	41
2.1 Epidemiology of cardiovascular disease	42
2.2 Epidemiology of sudden cardiac death	43
2.3 Epidemiology of sudden cardiac death in young athletes	48
2.4 Mechanisms of sudden cardiac death	48
2.5 The main causes of sudden cardiac death	49
<b>Chapter 3. Detection and Assessment of those at High Risk of Sudden Cardiac Death</b>	57
3.1 Introduction	58
3.2 Coronary heart disease	58
3.3 Risk assessment for sudden cardiac death due to other forms of heart disease	61
3.4 Risk assessment of first degree relatives of a confirmed case of sudden cardiac death	62
<b>Chapter 4. Systematic Assessment of those Engaged in Sports and Exercise</b>	69
4.1 Introduction	70
4.2 Underlying disease associated with sudden cardiac death in athletes	70
4.3 The benefits of exercise versus the risk	73
4.4 Pre-participation screening and risk assessment	74
4.5 International recommendations	76
4.6 Use of a questionnaire	79
4.7 Performance enhancing drugs	82

<b>Chapter 5. Reducing Time to Response</b>	<b>87</b>
5.1 Introduction	88
5.2 The chain of survival	89
5.3 Early access to emergency medical services	89
5.4 Early cardiopulmonary resuscitation	92
5.5 Early defibrillation	94
5.6 Automated external defibrillators	102
5.7 Early advanced cardiac life support and reperfusion	107
5.8 Post-resuscitation care	111
<b>Chapter 6. Surveillance and Audit</b>	<b>115</b>
6.1 Information systems	116
6.2 Surveillance of mortality from sudden cardiac death	116
6.3 Risk assessment database	117
6.4 Data collection in the pre-hospital clinical setting	118
6.5 Training programmes	121
6.6 Register of automated external defibrillators	121
<b>Chapter 7. Implementation</b>	<b>125</b>
7.1 The way forward	126
7.2 Framework for implementation	126
7.3 Responsibilities for implementation	127
7.4 Critical success factors	128
<b>Summary of Recommendations and Outline Plan for Implementation</b>	<b>129</b>
<b>Appendices</b>	<b>139</b>
Appendix 1 Invitation for submissions	140
Appendix 2 Consultation	141
Appendix 3 Codes for cardiac conditions in the International Classification of Diseases	143
Appendix 4 Causes of sudden cardiac death and associated risk factors	145
Appendix 5 Management of coronary heart disease	146
Appendix 6 Communication and referral pathways for first degree relatives after sudden cardiac death	148
Appendix 7 Information and practical advice for developing community first responder programmes and the use of automated external defibrillators (AEDs)	149



## Foreword

I am very pleased to publish *The Report of the Task Force on Sudden Cardiac Death*. It is estimated that approximately 5,000 Irish people will die from sudden cardiac death this year. The majority of these deaths will occur from late middle age onwards as a result of coronary heart disease, which accounts for almost 80% of sudden cardiac deaths in most developed countries. Tragically each year a small number of our young people also lose their lives to sudden cardiac death. While all sudden death is traumatic, the loss of a young person in these circumstances is particularly distressing. The work of the Task Force on Sudden Cardiac Death has concentrated on examining the causes and devising a strategy to reduce the number of these sudden deaths.

A substantial proportion of cardiovascular morbidity and mortality is preventable. Since the publication of the *Cardiovascular Health Strategy, Building Healthier Hearts* in 1999, we have seen considerable achievements in the prevention, detection and treatment of cardiovascular disease. We must maintain this momentum, particularly in view of the changing epidemiology of coronary heart disease in Ireland over the past 30 years.

I commend the Task Force on its proposals to reduce the incident of sudden cardiac death in the Irish population, including appropriate assessment in individuals and families who may be at increased risk. I also welcome the recommendations on measures to improve early response times to sudden cardiac collapse and the enhancement of first responder programmes. I am confident that the implementation of the recommendations in this report will make a real difference and contribute significantly to improving survival rates.

It is clear from the Task Force report that reducing the numbers of sudden cardiac deaths in Ireland presents a major challenge. This challenge can only be met by a concerted effort from all involved, including the statutory and voluntary services and the community. The publication of this report is timely, given the major changes that are under way in our health service delivery system. The Health Service Executive will now be tasked with ensuring that the report's recommendations are implemented.

I wish to record my gratitude to the Chairman, Dr. Brian Maurer and the members of the Task Force for their expert contributions and for giving so freely of their time on this important work. I also wish to thank all those who made submissions to the Task Force and contributed to the consultation process. I want in particular to acknowledge the invaluable contributions of Ms. Wendy Keena, Health Service Executive, Southern Area and Dr. Emer Shelley, National Heart Health Advisor in the drafting and finalising of this excellent report.

A handwritten signature in blue ink that reads "Mary Harney". The signature is written in a cursive, flowing style.

**Ms. Mary Harney T.D.**

*Tánaiste and Minister for Health and Children*



## Message from the Chairman

Sudden death is usually unexpected and always traumatic for those bereaved. It is not always tragic as it may be the natural end of a long and fulfilled life or a chronic, painful, debilitating illness. When it occurs prematurely, especially in the young, it is a tragedy and perceived as inappropriate. Many such untimely deaths are unnatural, e.g. due to road traffic accidents and suicide, and must be addressed in a different way to those due to natural causes. As the Tánaiste writes, about 4,000 to 5,000 people die suddenly of natural causes each year, principally due to heart disease. The loss to families, community and society is enormous. The Task Force was set up to examine this problem and recommend strategies for its reduction.

Most of the cardiac causes are known and many individuals at high risk can be identified. Preventive measures can be devised with varying degrees of success. Unfortunately not all events can be prevented or postponed, even with the use of contemporary medical treatment. Unreasonable public expectations about what can be achieved may be fostered by a perception that all such deaths can be prevented. While this is not the case, measures are needed to deal promptly with those which occur despite the adoption of preventive strategies and the report makes recommendations about these. Different methods are recommended for urban and remote areas as the circumstances under which the Emergency Medical Services perform have to respond are dissimilar.

Death is inevitable but I hope that this report will reduce the burden of sudden, inappropriate death due to heart disease. I would like to thank all the members of the Task Force who have devoted so much time and effort to its preparation. It is the product of much research, exchange of information and debate and all members contributed fully not only in their own areas of expertise but by bringing their unique and extensive experience of the subject to the table. It would be invidious to single out any individuals for their scientific contribution but I would like to acknowledge in particular the patience and skills of Ms. Wendy Keena and Dr. Emer Shelley who acted as rapporteurs and drafters, for their hard work, patience and forbearance. I also thank the dedicated staff of the Health Promotion Unit of the Department of Health and Children for their unfailing support.

This report is but the beginning. It falls to others to implement it.

A handwritten signature in blue ink that reads "Brian Maurer". The signature is written in a cursive, flowing style.

**Dr. Brian Maurer**

*Chairman of the Task Force*

## Acknowledgements

The Task Force wishes to acknowledge the cooperation received and the tremendous dedication and enthusiasm of a number of sectors in bringing this report to fruition. A sincere thank you to the many people who helped us in our work. In particular:

- those services, organisations and individuals who made a submission
- the Department of Health and Children, the Health Services Executive and the Irish Heart Foundation for their support in drafting this report
- the health professionals who work to reduce the trauma of sudden cardiac death
- and finally, but certainly not least, those families and friends who through their personal experiences have highlighted the need for Ireland to systematically address this issue.

# Abbreviations and glossary of terms

## Abbreviations

<b>AAS</b>	Anabolic/androgenic steroids	<b>IOC</b>	International Olympic Council
<b>ACLS</b>	Advanced cardiac life support	<b>IRFU</b>	Irish Rugby Football Union
<b>AED</b>	Automated external defibrillator	<b>LQTS</b>	Long QT syndromes
<b>AHA</b>	American Heart Association	<b>MDD</b>	Medical Device Division
<b>AMI</b>	Acute myocardial infarction	<b>MRI</b>	Magnetic resonance imaging
<b>BLS</b>	Basic life support	<b>NCIS</b>	National Cardiovascular Information System
<b>CABG</b>	Coronary artery bypass graft	<b>NCMG</b>	National Centre for Medical Genetics
<b>CAD</b>	Coronary artery disease	<b>OLHSC</b>	Our Lady's Hospital for Sick Children
<b>CE</b>	Conformité Européene (European Conformity)	<b>PAD</b>	Public access defibrillation
<b>CHAIR</b>	Coronary Heart Attack Ireland Register	<b>PCI</b>	Percutaneous coronary intervention
<b>CHD</b>	Coronary heart disease	<b>PET</b>	Positron emission tomography
<b>CIS</b>	Clinical Indemnity Scheme	<b>PHECC</b>	Pre-Hospital Emergency Care Council
<b>CMA</b>	Cardiomyopathy Association	<b>PPE</b>	Pre-participation examination
<b>CPR</b>	Cardiopulmonary resuscitation	<b>PPS</b>	Pre-participation screening
<b>CRY</b>	Cardiac Risk in the Young	<b>PTCA</b>	Percutaneous coronary angioplasty
<b>CSO</b>	Central Statistics Office	<b>RTO</b>	Resuscitation training officer
<b>DCM</b>	Dilated cardiomyopathy	<b>RVCM</b>	Right ventricular cardiomyopathy
<b>DoH&amp;C</b>	Department of Health and Children	<b>SADS</b>	Sudden adult death syndrome
<b>ECG</b>	Electrocardiogram	<b>SCD</b>	Sudden cardiac death
<b>EMS</b>	Emergency medical services	<b>SIDS</b>	Sudden infant death syndrome
<b>EMT</b>	Emergency medical technician	<b>SLÁN</b>	Survey of lifestyle, attitudes and nutrition
<b>ESC</b>	European Society of Cardiology	<b>STEMI</b>	ST – elevation myocardial infarction
<b>FDA</b>	Food and Drug Administration	<b>UK</b>	United Kingdom
<b>FIMS</b>	Italian Sports Medicine Foundation	<b>USA</b>	United States of America
<b>GAA</b>	Gaelic Athletic Association	<b>VF</b>	Ventricular fibrillation
<b>GP</b>	General practitioner	<b>VT</b>	Ventricular tachycardia
<b>HAS</b>	Health & Safety Authority	<b>WHO</b>	World Health Organization
<b>HCM</b>	Hypertrophic cardiomyopathy	<b>WPW</b>	Wolff-Parkinson-White Syndrome
<b>HIQA</b>	Health Information and Quality Authority		
<b>HSE</b>	Health Service Executive		
<b>ICD</b>	Implantable cardioverter defibrillator		
<b>ICD</b>	International Classification of Disease		
<b>ICGP</b>	Irish College of General Practitioners		
<b>IHF</b>	Irish Heart Foundation		
<b>ILCOR</b>	International Liaison Committee on Resuscitation		
<b>IMB</b>	Irish Medicines Board		
<b>IMO</b>	Irish Medical Organisation		

## Glossary of Terms

**Ablation** – intentional destruction of a small amount of cardiac tissue to permanently isolate, interrupt or destroy an abnormal rhythm.

**Advanced cardiac life support (ACLS)** – additional interventions required to support life, for example intubation or reperfusion therapies.

**Angina (pectoris)** – discomfort or pain that is typically severe and crushing with a feeling of pressure and suffocation due to an inadequate supply of oxygen to the heart muscle. Usually located in the chest just behind the breastbone (the sternum) but can be elsewhere e.g. down the left arm.

**Angiography** – radiography of the blood vessels after introduction of a contrast medium (dye).

**Anti-coagulation** – thinning of the blood with drugs, usually warfarin, to prevent thrombosis (clots).

**Aortic aneurysm/ rupture** - bulging weak spots in the body's main artery, which could rupture and cause death.

**Arrhythmia** – an abnormality of the heart's rhythm. The heart may beat too fast, too slow or in an irregular way.

**Arteriosclerosis** – a group of diseases characterised by thickening and loss of elasticity of the arterial walls.

**Atrial fibrillation** – abnormal irregular heart rhythm arising from the atria of the heart.

**Automated external defibrillator (AED)** – small portable piece of equipment that can deliver an electric shock to a person in order to convert a cardiac arrhythmia (ventricular fibrillation) into a natural rhythm.

**Basic life support (BLS)** – emergency cardiopulmonary resuscitation, control of bleeding, treatment of shock or poisoning, stabilisation of injuries and wounds, and basic first aid.

**Brugada syndrome** – an inherited condition due to an abnormality in the sodium channels in the membranes of the heart muscle cells which can lead to life threatening ventricular arrhythmias.

**Cardiac arrest** – a medical emergency with absent or inadequate contraction of the heart usually due to ventricular fibrillation that causes circulatory failure, loss of consciousness and brain death within about 10 minutes if normal heart rhythm is not restored.

**Cardiac auscultation** – examination of the sounds of the heart through a stethoscope.

**Cardiac pathologist** – a qualified medical doctor (pathologist) specially trained to identify disease in organs and tissue, in particular in the examination of the heart.

**Cardiac rehabilitation** – a programme for people with heart disease, designed to improve function and reduce future cardiac risks.

**Cardiologist** – a qualified doctor who specialises in the prevention and treatment of disease of the heart and cardiovascular system.

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

**Cardiopulmonary resuscitation (CPR)** – the emergency substitution of heart and lung action to restore life to someone who appears dead. The two main components of CPR are chest compression to make the heart pump and mouth-to-mouth ventilation to breath for the victim.

**Chain of survival** – a process of four linked steps to be enacted to ensure an effective response to cardiac emergency.

**Channelopathy** – a disease involving dysfunction of an ion channel, due to an abnormal chemical reaction in the molecular pores in the heart's muscle cells.

**Cholesterol** – the most common type of steroid in the body, cholesterol is carried in the bloodstream as lipoproteins. Low-density lipoprotein (LDL) cholesterol is the "bad" cholesterol because elevated LDL levels are associated with an increased risk of coronary artery disease. Conversely, high-density lipoprotein (HDL) cholesterol is the "good" cholesterol since high HDL levels are associated with less coronary disease.

**Collapse** – sudden loss of posture with or without loss of consciousness.

**Commotio cordis** – sudden cardiac arrest from a blunt, non-penetrating blow to the chest.

**Coronary artery bypass graft (CABG)** – a surgical procedure which involves bypassing diseased (narrowed) coronary arteries with veins obtained from the patient's legs.

**Coronary heart disease (CHD)** – can also be referred to as coronary artery disease (CAD) or ischaemic heart disease. The coronary arteries arise from the aorta adjacent to the heart and supply the heart muscle with blood that is rich in oxygen. CHD refers to narrowing or blockages in the vessels, usually due to atherosclerosis.

**Congenital heart disease** – malformation of the heart or the large blood vessels near the heart caused by deformed development of the heart in the womb. It means "born with" or "present at birth".

**Defibrillation** – the use of a carefully controlled electric shock, administered either through a device on the exterior of the chest wall or directly to the exposed heart muscle, to restart or normalise heart rhythm.

**Echocardiography (Echo)** – use of ultrasound to provide moving images of the heart muscle and valves, to measure function and identify damaged tissues.

**Ejection fraction (EF)** – a test used to determine how well a heart pumps with each beat. The fraction of blood volume in the left ventricle that is pumped out with each heartbeat. Greater than 0.55 (55%) is normal.

**Electrocardiogram (ECG)** – a non-invasive test that is used to reflect underlying heart conditions by measuring the electrical activity of the heart. By positioning leads (electrical sensing devices) on the body in standardised locations, information about many heart conditions can be obtained by looking for characteristic patterns on the ECG.

**First degree relatives** – a person’s mother, father, sister or brother (parents and siblings).

**First responder** – a person trained as a minimum in basic life support and the use of an AED, who attends a potentially life threatening emergency. This response may be by the statutory ambulance service or complementary to it. If complementary, first responders can be linked with the statutory emergency services or they can be independent and stand alone.

**Gene mutation** – alteration in a person’s DNA causing disease.

**Genetic testing** – testing a population to identify individuals at risk for a genetic disease or for transmitting it.

**Holter monitor** – a test which measures the heart rhythm (ECG) over a 24 hour period while the patient records their symptoms and activities in a diary.

**Hypertension** – defined as a repeatedly elevated blood pressure exceeding 140 over 90 mmHg (a systolic pressure above 140 with a diastolic pressure above 90 millimeters of mercury).

**Hypotension** – blood pressure that is below the normal expected for an individual in a given environment. Hypotension is a relative term because the blood pressure normally varies greatly with activity, age, medications, and underlying medical conditions.

**Implantable cardioverter defibrillator (ICD)** – a self-contained device implanted under the skin or muscle of the upper chest wall and connected via electric leads which pass through the veins to be fixed to the muscle of the atrium and / or ventricles of the heart. The defibrillator corrects the heart rhythm by delivering precisely calibrated and timed electrical shocks, when needed, to restore a normal heartbeat.

**Ion** – positively or negatively charged electron particle which forms part of an atom.

**Ischaemic heart disease** – see coronary heart disease.

**Long QT syndrome** – an inherited defect in the heart rhythm that predisposes to syncope without warning (sudden fainting spells), dizziness, palpitations, seizures and sudden death. The name of the syndrome comes from the QT segment in the tracing on the ECG.

**Magnetic resonance imaging (MRI scan)** – a special imaging technique used to image internal structures of the body, particularly soft tissues such as the heart.

**Marfan syndrome** – a genetically determined condition of the connective tissue that can result in life threatening dilatation of the aorta and potentially sudden death if the aorta ruptures.

**Morbidity** – the incidence or prevalence of a disease or of all diseases in a population.

**Mortality rate** – the number of deaths as a proportion of the total population, frequently expressed as a rate per 100,000.

**Myocardial infarction** – death of some of the heart muscle (myocardial tissue) usually caused by arteriosclerosis with narrowing of the coronary arteries, the culminating event being a thrombosis (clot).

**Myocarditis** – inflammation of the muscular walls of the heart.

**Palpitations** – sensations of irregular and / or forceful beating of the heart. In some patients with palpitations, no heart disease or abnormal heart rhythms can be found and reasons for their palpitations are unknown. In others, palpitations result from abnormal heart rhythms (see arrhythmias).

**Pacemaker** – a system that sends electrical impulses to the heart in order to set the heart rhythm. The pacemaker can be the normal “natural” pacemaker of the heart or it can be an electronic device.

**Percutaneous transluminal coronary angioplasty (PTCA) or intervention (PCI)** – Dilatation of an occluded coronary artery (or arteries) by means of a balloon catheter to restore blood supply to the heart. A small device called a stent may be placed in the artery to keep it open after the catheter is withdrawn.

**Post-mortem or autopsy** – the examination of the body of a person who has died. The procedure is performed to verify the cause of death and / or examine the effects of treatment.

**Public access defibrillation (PAD)** – the open availability of automated external defibrillators to be used by members of the public.

**Pulmonary embolism** – the obstruction of the pulmonary artery or a branch of it leading to the lungs by a blood clot, usually from veins in the leg, or foreign material causing sudden closure of the vessel.

**Pulmonary oedema** – increased fluid within the lung that usually results from the ineffective pumping function of the heart.

**Reperfusion therapies** – interventions developed within the last two decades which have the potential to re-open obstructed coronary arteries; they include drug therapies (thrombolysis) and balloon catheters (percutaneous coronary intervention [PCI]).

**Revascularisation** – an invasive procedure to increase blood circulation such as angioplasty and stenting (see percutaneous transluminal coronary angioplasty) or a surgical procedure called coronary artery bypass graft. (see CABG).

**Risk assessment** – the qualitative or quantitative estimation of the likelihood of adverse effects that may result from exposure to specified health hazards or from the absence of beneficial influences.

**Screening** – see risk assessment.

**Statin** – medications that lower cholesterol levels.

**Sudden Adult/Arrhythmic Death Syndrome (SADS)** – a term used when sudden death occurs in an adult and no definite cause of death can be found, even after the heart has been examined by an expert cardiac pathologist.

**Sudden cardiac death** – death due to natural causes within an hour of the onset of symptoms, in the absence of any other cause and assumed to have a cardiac cause.

**Syncope** – transient, partial or complete loss of consciousness with interruption of awareness of oneself and one’s surroundings. When the loss of consciousness is temporary and there is spontaneous recovery, it is referred to as syncope or fainting.

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

**Uniformed responders** – personnel who respond to an emergency either on or off duty e.g. fire service personnel, gardaí, EMTs, voluntary and auxiliary organisations, security staff etc.

**Valvular heart disease** – a general term that applies to any abnormality of one of the heart valves.

**Ventricular fibrillation (VF)** – a disorganised heart rhythm that results in chaotic contraction of the lower chamber of the heart (ventricle) that fails to effectively eject blood from the heart.

**Ventricular tachycardia (VT)** – an abnormal heart rhythm arising from the muscle of the ventricles, rather than arising through the normal mechanism in the atrium. It is an unstable rhythm that may result in fainting, low blood pressure, shock or sudden death.

**Wolff-Parkinson-White syndrome (WPW)** – a heart condition with an additional abnormal electrical connection between the heart’s chambers which may cause the heart to race.

**Young person/young athlete** – for the purpose of this report, a person aged 14 years or older and under the age of 40.



# Executive summary

## Executive Summary

### Chapter 1 Introduction

The Minister for Health and Children established the Task Force on Sudden Cardiac Death (SCD) in the Autumn of 2004, with the following terms of reference:

- 1) Define SCD and describe its incidence and underlying causes in Ireland.
- 2) Advise on the detection and assessment of those at high risk of SCD and their relatives.
- 3) Advise on the systematic assessment of those engaged in sports and exercise for risk of SCD.
- 4) Advise on maximizing access to basic life support (BLS) and automated external defibrillators (AEDs) and on:
  - appropriate levels of training in BLS and use of AEDs, and on the maintenance of that training
  - priority individuals and priority groups for such training
  - geographic areas and functional locations of greatest need
  - best practice models of 'first responder schemes' and 'public access defibrillation', and
  - integration of such training services.
- 5) Advise on the establishment and maintenance of surveillance systems, including a registry of SCD and information systems to monitor risk assessment, and training and equipment programmes.
- 6) Advise and make recommendations on other priority issues relevant to SCD in Ireland.
- 7) Outline a plan for implementation and advise on monitoring the implementation of recommendations made in the Task Force's report.

In undertaking its work the Task Force was mindful of national health policy, relevant national strategies and of the recently reformed structures for health service delivery in Ireland. The incidence, management and monitoring of SCD were examined. Issues considered include the prevention of SCD, the detection of those at high risk, risk assessment of those engaged in sports and exercise, equipment and training programmes to improve the outcome in those suffering from sudden cardiac collapse, and the establishment of appropriate surveillance systems.

The Task Force undertook wide consultation with experts, organisations and individuals. Over 80 written submissions were received, and views and opinions were clarified during two consultation days. The issues highlighted in the consultation informed the discussions of the Task Force and the drafting of the report.

## Chapter 2

### Background: The nature of the problem

Cardiovascular disease includes coronary heart disease (CHD), stroke and other disorders of blood vessels. Ireland has a high death rate from CHD, with one in five deaths being attributed to this cause. SCD is defined as death due to natural causes within an hour of the onset of symptoms, in the absence of any other cause, and assumed or proven to have a cardiac cause. Pre-existing heart disease may have been known to be present but the time and mode of death are unexpected. The death may be witnessed or not witnessed.

Information on SCD may be obtained from analysis of death certificates and post-mortem results, and from cardiac arrest registries. A study in the US found that 63% of all cardiac deaths were SCDs. This would have equated to 5,119 such deaths in Ireland in 2002. Rates of SCD have been decreasing in men and women in the US.

In Ireland data on all deaths is collected by the Central Statistics Office (CSO), currently using the Ninth Revision of the International Classification of Diseases (ICD). SCD is coded according to its likely underlying cause. The code for acute myocardial infarction is the one most frequently used when SCD occurs. Plans are under way to implement ICD Version 10 which has a specific code for sudden cardiac death.

A number of countries include a 'tick box' to record cardiac arrest on the death certificate. This would contribute to planning and evaluation of pre-hospital and hospital care of cardiac arrest, as well as the prevention of SCD. The changeover to ICD-10 (including the code for SCD) and any changes in the death certificate will require training of doctors.

The diseases leading to SCD have been reported from autopsy (post-mortem) studies. In a large UK series of SCD between 16 and 64 years of age, 82% of deaths were due to CHD and 12% had other cardiac pathology. In Belfast, 60% of cases had no known history of cardiac disease but severe coronary artery disease was found in 94%.

Post-mortem studies of SCD in young people have identified a number of underlying conditions, including cardiomyopathy, myocarditis and CHD. Approximately 5% of SCDs are unexplained, with no structural abnormality found at post-mortem. This is higher, 20 – 30%, in those under the age of 35 years. A genetic factor is found in only a small proportion of cases of SCD but this is expected to increase with the identification of further gene defects.

Cardiac arrest registries provide valuable information on the demographics of those who suffer a cardiac emergency, on the circumstances of the collapse, on the emergency response and on outcomes. If, as in the State of Washington, the emergency medical services (EMS) in Ireland respond to 39% of all cardiac deaths, this would have corresponded to 3,169 such deaths in 2002, or 81 per 100,000 population. This is similar to rates reported by other North European countries.

The Belfast study of sudden collapse in the community found that 78% occurred at home, 16% in a public place and the remainder in a nursing home; 93% were attended by the EMS. The following factors influence the likelihood of survival at 1 month: an initial rhythm of ventricular fibrillation (VF), shorter time to arrival by the EMS, arrest occurring outside the

home, arrest which is witnessed, one where bystander CPR is initiated and arrest occurring in younger people.

The majority of SCDs are due to the malfunction of the heart's electrical conduction system, with sudden onset of chaotic disturbance of the heart's electrical rhythm - VF. This in turn stops the output of blood from the heart and if not treated, death usually results within minutes. If treated with high voltage electrical shocks (defibrillation), normal heart rhythm can be restored.

SCD can be caused by a number of underlying heart conditions including:

- CHD
- cardiomyopathies (hypertrophic or dilated)
- cardiac channelopathies (Long QT syndrome, Brugada syndrome, Short QT syndrome, catecholaminergic polymorphic VT)
- valvular heart disease, and
- abnormal electrical pathways connecting the atrium and ventricle of the heart e.g. Wolff-Parkinson-White syndrome.

Other causes of SCD include electrocution, viral infection (myocarditis), blunt trauma to the chest (*commotio cordis*) and as an adverse effect of drugs (prescription or illicit).

Cardiomyopathy is primarily a disease of the heart muscles and is the second most common cause of SCD after CHD. There are three principal types: hypertrophic cardiomyopathy, dilated cardiomyopathy and right ventricular cardiomyopathy. Precise identification of the underlying genetic disorder by tissue sampling is helpful in a minority of cases but this is likely to increase in the future.

Cardiac channelopathies are believed to occur in 1 in 5,000 people and can trigger an abnormal rhythm, including VF. Diagnosis is difficult during life and at post-mortem. Characteristic abnormalities occur in the ECG, most commonly affecting the QT interval, but these may manifest intermittently. If the gene mutation can be identified, other members of the family can be screened.

The factors which increase risk of SCD in these underlying conditions are to be found in Appendix 4.

### **Chapter 3**

#### **Detection and assessment of those at high risk of sudden cardiac death**

Risk assessment and risk management strategies can be considered in two broad categories:

- CHD (either confirmed or unknown), and
- inherited cardiomyopathies and channelopathies

The report considers primary and secondary prevention strategies for CHD and makes several recommendations to reduce risk of SCD from this cause. Primary prevention strategies that target risk factors such as smoking, raised blood pressure and blood cholesterol levels have

contributed to the decrease in death rates from CHD in Ireland. There is no room for complacency in view of the increasing prevalence of obesity, physical inactivity and diabetes. With the implementation of the **Cardiovascular Health Strategy** there has been substantial development of cardiac rehabilitation and secondary prevention services which focus on people who already have CHD. There is strong evidence that these strategies reduce risk of a future event, including SCD. There is also evidence that providing information to patients and their families on the warning signs of a heart attack and how to deal with cardiac arrest, reduces the incidence of SCD.

Increasing public and medical awareness is a key factor in identifying potentially lethal cardiac conditions in the young, including the inherited cardiomyopathies and channelopathies. Symptoms such as unexplained fainting or blackouts, palpitations, dizziness, chest tightness or shortness of breath on exertion may indicate a serious cardiac disorder and should lead to a full cardiovascular assessment.

The priority group for risk assessment is the first degree relatives of those who have died of SCD under 40 years of age who may be at increased risk of an inherited disorder such as a cardiomyopathy or channelopathy. In older age groups the cause is more likely to be CHD and family risk assessment should be for this condition.

After a sudden death all possible steps should be taken to provide support to families, including prompt communication of medical information. Training of personnel in sympathetic and appropriate communication is essential. Counselling services and information on how to access them should be made available, including support through voluntary organisations.

First degree relatives of victims of SCD need to be informed about the cause of death as soon as possible after the event either by the physician who makes the diagnosis and signs the death certificate or by the Coroner. The Coroner should forward a copy of the pathologist's report to the deceased's GP. If an SCD occurs in hospital and the consultant physician is authorised to sign the death certificate without a post-mortem, responsibility for informing the GP of the likelihood of a familial cause of SCD rests with the physician.

The GP who has been informed of the potentially increased risk of SCD in first degree relatives should communicate with the family and provide advice on access to risk assessment services. The public health medical service could communicate with families where the deceased was not under medical care at the time of SCD.

Family risk assessment depends on accurate diagnosis in the victim of SCD. Survivors should have full medical investigation. In those who do not survive, the diagnosis may be established at post-mortem. When a post-mortem examination fails to determine the cause of SCD in a person under the age of 40 years, a further examination of the heart should be undertaken by a pathologist with cardiac sub-speciality training. In about 5% of SCD victims, no cause can be found and pathologists use the term Sudden Adult Death Syndrome (SADS) for this group. Guidelines should be developed for the conduct of a post-mortem in these cases.

The issue of organ and tissue retention is of particular concern to bereaved family members. Permission to use or retain tissue or organs for research or teaching can only be given following a specific request to relatives. Future analysis of the retained tissue, at a time remote from the actual death, may contribute to knowledge in this area and identify the underlying disease in members of the kindred. Informed consent from the next of kin for tissue retention should be sought in a sympathetic and timely fashion.

Following the recognition of SCD, all first degree family members - parents, siblings, and children - must be given the opportunity to undergo a comprehensive risk assessment. Initial assessment is done by the GP. Where indicated, relatives should be referred to the regional cardiology centre for more complex investigations. A minority will require referral to sub-specialist services. These may be provided in regional cardiac centres, in supra-regional centres or in specialist family risk assessment clinics.

Genetic analysis for inherited cardiac conditions was considered. Predictive testing on healthy family members should be carried out through a clinical genetic service, following discussion of the benefits and drawbacks of testing. Each cardiac diagnostic centre should have a link with the National Centre for Medical Genetics at Our Lady's Hospital, Crumlin to test for known cardiomyopathy and channelopathy genes.

## **Chapter 4**

### **Systematic assessment of those engaged in sports and exercise**

There has been some research and much discussion about risk assessment for those involved in sports and exercise. The evidence is weak and there are varying practices in different countries. Our understanding of the diseases underlying SCD in athletes comes from autopsy studies. Conditions found in young people who die suddenly include cardiomyopathy, myocarditis, anomalous coronary arteries and CHD. The underlying causes of sports-related SCD in Ireland have not been systematically studied in this way.

The relationship between the type of sport and the incidence of sports-related SCD is of interest. European Society of Cardiology (ESC) guidelines published in 2005 categorised sports by the level of dynamic and static intensity involved. Sports categorised as being of moderate and high dynamic intensity are the highest priority for risk assessment. Subjects taking up high static intensity sports should also be assessed. Based on the available evidence the Task Force considered that the target population for risk assessment should be all those involved in sports other than that of a low static, low dynamic nature, who are 14 years of age or older, with no upper age limit.

The health benefits of exercise are widely accepted. Regular exercise reduces the risk of developing or dying from CHD, obesity and associated conditions. There is substantial literature on the benefits of exercise in both primary and secondary prevention. In a nation where weight and the problems associated with obesity are increasing, encouraging exercise participation is highly desirable.

SCD rates in the young are increased in frequency among those involved in sports and these deaths may account for approximately one in five such deaths. These SCDs are largely the result of underlying disease, with lethal arrhythmias being triggered by exercise. Risk management strategies must achieve a balance between facilitating involvement in exercise and sports, while putting appropriate safeguards in place.

Risk assessment tests were considered - ECG testing, echocardiography, ambulatory ECG monitoring and treadmill testing. Whilst helpful in assessing those with a family history or suspicious symptoms, these tests are not sufficiently sensitive or specific for population screening for cardiomyopathy and channelopathy. The low yield and substantial number of false positive tests would lead to large numbers of normal young people being needlessly excluded from participating in physical activity and sports. The long term negative effects of labelling a young person as 'too high risk' to participate in sporting activity should not be underestimated.

There is insufficient evidence to support the implementation of a mass population screening programme for SCD. There is however a role for risk assessment for those involved in exercise or sports. Family history of SCD in a first degree relative or symptoms suggestive of cardiac disease identify individuals with a higher likelihood of having cardiac pathology than the general population. Some individuals have undetectable disease and will die suddenly and others with no disease will develop SCD due to viral myocarditis, *commotio cordis* or the use of illicit or prescription drugs.

The Task Force is of the opinion that current ESC or International Olympics Committee (IOC) guidelines have not dealt adequately with the issue of the large number of healthy athletes who have abnormal ECGs or echocardiograms which do not quite reach diagnostic criteria for cardiomyopathy or channelopathy. Abnormal findings would be likely to exclude at least 3% of young people at each round of testing from involvement in organised sports and would have implications for employment, life insurance and mortgage applications.

Considering all the evidence, a screening questionnaire about personal and family history offers the best likelihood of identifying high risk individuals while minimising the adverse effects associated with risk assessment.

There are international recommendations on participation in physical activity by people with known cardiovascular disease, including those with a genetic condition. These guidance documents differentiate between those engaged in competitive sports with pressures to attain peak performance and those taking recreational exercise. In December 2004 the IOC Medical Commission published their recommendations in regard to sudden cardiovascular death in sport. This is commonly known as the Lausanne Protocol and applies to those engaged in sports at the highest level.

Leisure activity such as walking, swimming or 'social' tennis does not require any formal pre-participation assessment. Participants should be encouraged to self-administer a questionnaire on personal and family history and to seek advice if indicated. Those with a history of heart problems or other major illness are advised to speak to their doctor before starting an exercise programme. Anyone feeling any pain or discomfort on exercising is advised to rest and to seek advice from their doctor or exercise specialist.

Individuals aged 14 years and over who wish to join a sports club, gym or other sports facility but not involved in national, provincial or county level sports, should be offered a pre-participation questionnaire. A protocol for risk assessment in this group should be agreed by the relevant sports and medical organisations, under the aegis of the Irish Sports Council.

All the major sporting organisations undertake pre-participation assessment for their players. The extent of the screening varies. Elite athletes such as those who play at national, provincial or county level are usually under the supervision of a medical officer. A protocol for risk assessment should be agreed for those involved in moderate or vigorous intensity sports at national, provincial or county level.

Concern about sudden deaths in sport has been complicated by the issue of performance enhancing drug abuse and its links with SCD. Anabolic / androgenic steroids (AAS) continue to be the most frequently abused performance enhancing drug. There is evidence of a cause and effect relationship between the abuse of such drugs and increased risk of AMI and other cardiac pathology, including SCD.

Many illicit drugs can cause cardiac arrhythmias, even in healthy subjects with no previous history of cardiac disease. Pre-participation risk assessment should include evaluation of the possibility of drug use. The discovery of an arrhythmia, especially in an individual with a structurally normal heart, mandates consideration of this also. The use of illicit drugs in the presence of undiagnosed underlying cardiac diseases, such as some of the inherited cardiomyopathies, may increase the risk of SCD.

Given the international evidence, a multisectoral approach is required to address this issue involving the Departments of Health and Children, and Education and Science, the leisure industry and sporting organisations.

Anti-inflammatory medications (NSAID) are widely used by athletes to treat a variety of musculoskeletal disorders associated with sports injury. These medications should be used with caution in older athletes, especially those with known CHD and in those at increased risk of thrombotic events (prior blood clot / family history of hypercoagulable state).

## **Chapter 5**

### **Reducing time to response**

In this chapter, the Task Force addresses the 'chain of survival', developing a coordinated first responder programme, increasing access to and setting standards for resuscitation training, ensuring optimal placement and safe operation of AEDs, clarifying legal indemnity issues and implementing robust data collection to facilitate audit and continuous improvement.

Survival rates following cardiac arrest are directly related to time to resuscitation and in particular defibrillation. A speedy and effective response is required to increase chances of survival. The ESC Task Force recommends a target time from call to defibrillation in out-of-hospital cardiac arrest of 5 minutes. The probability of successful defibrillation may be improved through the provision of early BLS.

There is considerable lack of awareness in the community as to the appropriate action to be taken in the event of a collapse. Many people still ring the GP or local hospital in the first instance. The Task Force recommends that the ambulance service should be the first to be contacted. In Ireland the contact number is 999 or 112.

The ***Ambulance Service Communications Review*** made recommendations about necessary changes to the number of communication centres, their regional operation and compatibility of technology and decision support systems. The Task Force supports these recommendations. Regardless of their purpose, all ambulances should carry an AED. The drivers of all such vehicles should be trained in BLS and AED use. Once connected to the emergency service, immediate assistance can be given by way of telephone advice. Emergency telephone information about chest pain should advise the administration of aspirin if ACS is thought to be the cause of the chest pain.

Cardiopulmonary resuscitation is a manual technique that combines external chest compressions and assisted ventilation to maintain the oxygen supply to the vital organs, in particular the brain. Early CPR improves the probability of successful defibrillation. Statutory, voluntary and private organisations are the providers of first aid and first responder training courses of varying duration and content. Statutory agencies should prioritise training their own personnel. The role of the voluntary organisations in the community should be supported and enhanced.

The Pre-Hospital Emergency Care Council (PHECC) has developed a comprehensive national standard which encompasses the provision of BLS and AED training. The more individuals who can be trained, the greater the potential to reduce the incidence of pre-hospital cardiac deaths, to educate the public about the warning symptoms of acute heart disease, the importance of quick responses and the dissemination of health promotion messages. Responsibility for accreditation and monitoring of all BLS / AED training and the maintenance of training records should be assigned to PHECC.

The following training initiatives should be prioritised:

- BLS / AED training is essential for all health care professionals
- BLS / AED training for family members of those who have suffered a non-fatal cardiac event or are at high risk of SCD
- AED training should be a requirement for occupational first aid certification
- first responders linked to the EMS, and
- BLS / AED training should be included in the curriculum for primary and secondary schools.

The time to defibrillation is the single most important determinant of survival after cardiac arrest. The Task Force is of the opinion that the challenges in meeting the ESC targets should be identified and addressed, recognising that it will take some years to achieve them. While all statutory emergency ambulances are now equipped with defibrillators, there is a need for more defibrillators strategically placed throughout the community.

The regions in Ireland which are disadvantaged for rapid access to the EMS include the North Western, Western and South Western seaboard, the peninsulas and their inhabited islands.

Such areas would benefit from well resourced and managed complementary emergency responses, such as first responder programmes.

Developing closer integration between the statutory and voluntary sectors would improve emergency response coverage.

First responder programmes are characterised by:

- trained and equipped first responders
- structured response systems based on the planned availability of first responders
- effective alerting systems, and
- defined areas of coverage.

In an Irish context the Task Force has identified seven models of first responder programmes:

- EMS
- GP first responders
- Uniformed first responders
- Community first responders – Linked or Stand alone
- Site specific
- Public access defibrillation (PAD), and
- Individual / home.

The Task Force proposes the phased strategic development of first responder programmes in Ireland. Local implementation of these programmes will require the appointment of a designated Community First Responder Coordinator in each ambulance service area, with a standard job specification. There is an urgent need to provide evidence based information to the public concerning the establishment of programmes in the community.

Appropriate support should be available for responders to receive 'critical incident stress debriefing' following a resuscitation attempt.

An AED is a small, portable piece of equipment that can deliver an electric shock in order to convert VF of the heart into its normal or usual rhythm. The AED contains computer software which analyses a cardiac rhythm and will not deliver a shock if the heart does not require it.

The Medical Devices Division (MDD) of the Irish Medicines Board (IMB) provided advice to the Task Force in relation to AEDs, including their selection, placement, storage and maintenance, traceability of devices, adverse event reporting, legal indemnity and governance. There should be a technology assessment of devices to ensure the most appropriate device is in place for the specific setting. The model chosen for use in any programme or by any individual should be compatible with the local ambulance service model.

AEDs should be placed in priority locations such as health care facilities. Geographic locations distant from emergency medical services are also a priority. The number of AEDs required to cover any given area or site is determined so as to optimise 'collapse to use' response time.

AEDs and related devices should be stored and maintained in accordance with the manufacturer's recommendations. In order to meet the requirements of the State Claims Agency's Clinical Indemnity Scheme, there must be a properly structured record on the upkeep and maintenance of AEDs involved in first responder programmes.

For traceability purposes, a national database of devices should be established. Existing AED owners and users should be encouraged to register with the national database.

National and regional governance structures, including designated responsibilities are necessary to ensure the safe and effective use of AEDs. Such quality assurance and quality improvement structures should include responsibility and accountability for device placement, regular checks and maintenance, device documentation, training, first responder groups, incident recording and audit. The HSE should ensure that these structures are established for each type of first responder programme. Clear governance structures are also essential at a local level where an AED is housed.

The legal situation should be reviewed to protect first responders from litigation. The HSE should review other aspects of insurance requirements for first responders.

It is important to establish a standardised system to record responses to sudden cardiac events, including occasions when an AED is used. It is critical that any incident in which the device malfunctions should be immediately reported to the manufacturer and to the IMB. Data collection, surveillance and audit are discussed in more detail in Chapter 6.

Task Force also recommends:

- Advanced cardiac life support training for health professionals, including those who work in a community setting
- After contacting the healthcare system (ambulance service, GP services or Emergency Department) patients with suspected AMI should:
  - have access to a defibrillator within ten minutes
  - be offered aspirin within 20 minutes (if appropriate)
  - have a completed assessment of suitability for reperfusion therapy within 30 minutes, and
  - have access to thrombolysis (if appropriate) within 60 minutes.
- Timely reperfusion therapy for patients with AMI
- Fast-tracking within Emergency Departments where patients are brought by ambulance or self-present.

## Chapter 6 Surveillance and audit

Chapter 6 deals with the fifth term of reference for the Task Force which was to advise on the establishment and maintenance of surveillance systems, including a registry of SCD and information systems to monitor risk assessment, and training and equipment programmes.

A register of people undergoing assessment for risk of SCD would provide valuable information for planning and evaluation of services, in addition to providing information on the epidemiology of conditions which increase risk of SCD in Ireland. Data collected on resuscitation in the pre-hospital and hospital settings can provide the basis for an information system to quantify the frequency and geographic spread of cardiac arrest and to support service planning. Audit of the outcome of resuscitation is important, based on data collected in the pre-hospital and hospital settings. Databases on training and on AEDs are essential for planning and monitoring coordinated responses to sudden collapse. SCD is not recorded on death certificates in Ireland. Instructions to those completing a death certificate do not allow use of the term SCD. The Task Force proposes changes to the death certificate and in the rules for completing it.

A register of people undergoing assessment for risk of SCD would provide valuable information for planning and evaluation of services, in addition to providing information on the epidemiology of conditions which increase risk of SCD in Ireland. Such a register could support follow-up of patients and would provide a valuable information base for research on these conditions. The Task Force recommends that a risk assessment database should be established, to include all patients assessed in specialist centres. The database should be maintained at the National Centre for Medical Genetics.

There is no national system to collect data on cardiac arrests. The electronic Patient Care Report being implemented by PHECC will be completed for all patients, including those who suffer cardiac arrest in the community, when attended by the EMS. While that system will not capture data on all cardiac arrests, it will provide information on trends in cardiac arrests in the community and on the outcome of such cases.

The Task Force proposes that the modified Utstein data set and definitions, as agreed by the International Liaison Committee on Resuscitation (ILCOR), be adopted as a module in PHECC's electronic reporting system. Data should be returned by all first responders, in addition to the EMS. There is currently no national systematic data collection for audit of care of cardiac arrest and resuscitation in the hospital setting. While PHECC's remit relates to care in the community, it would be most efficient if PHECC were to register response to all cardiac arrests, whether in the community or in hospital.

The Health Information and Quality Authority when established will have responsibility to oversee health information and quality initiatives in the health services, including the proposed cardiac arrest and resuscitation register.

## Chapter 7 Implementation

The Report of the Task Force on SCD comes at an opportune time. The health service is undergoing a major reform process with the establishment of the HSE. Central to this is the ability to deliver a timely and high quality service on a consistent national basis.

The Task Force sought to provide a vision for the future, with thorough analysis of the issues and clear recommendations to quickly and effectively turn the vision into a reality. The framework for the report and its implementation involves 3 levels:

**Level 1 – Overall aim**

- to reduce the incidence of SCD in the Irish population.

**Level 2 - Implementation steps**

- the delivery of effective risk assessment measures for those persons at risk of SCD
- an improvement in early response to sudden collapse through multisectoral measures and coordinated first responder programmes, and
- the development of comprehensive surveillance systems to monitor and audit SCD.

**Level 3 - Specific recommendations**

The 75 recommendations have been prioritised against implementation timeframes of immediate, medium and long-term.

In order to ensure successful implementation, several critical success factors have also been identified.

The HSE, which has responsibility for the delivery of health services in Ireland, will have overall responsibility for the implementation and monitoring of the report's recommendations. The Task Force recognises that there are other bodies, both statutory and non-statutory, which will have an important role in the implementation process. It will be a matter for the HSE to identify and interface with all such relevant organisations.

The Task Force has listed all its recommendations and their timeframes for implementation.



chapter 1

Introduction

## 1.1 Introduction

The Minister for Health and Children established the Task Force on Sudden Cardiac Death in the Autumn of 2004.

Sudden cardiac death (SCD) is defined as death due to natural causes within an hour of the onset of symptoms, in the absence of any other cause, and assumed to have a cardiac cause.<sup>1,2</sup> Pre-existing heart disease may have been known to be present but the time and mode of death are unexpected. The death may be witnessed or not witnessed.

A person who is found dead but was known to be alive and well at some time in the preceding 24 hours may be classified as having suffered an SCD if an autopsy (post-mortem examination) fails to show any other cause of death. In the majority of cases the mechanism of death is an abrupt change in the heart's electrical rhythm from normal (sinus) rhythm to a rapid uncoordinated rhythm (ventricular fibrillation [VF]).

Ireland has a high rate of death from coronary heart disease (CHD), with one in five of all deaths being attributed to this cause.<sup>3</sup> However accurate statistics are not available on the incidence of SCD in Ireland. Applying the findings of research in other countries to Irish mortality data, the Task Force estimates that SCD accounts for approximately 5,000 deaths annually in Ireland.<sup>4,5</sup> This equates to approximately 14 deaths per day across all age groups. The majority of SCDs occur from late middle age onwards as a result of CHD. Over the past few years there has been increasing awareness of sudden death in young adults, including sudden deaths in high profile athletes. The majority of these younger SCD cases are due to VF arising from one of a number of pre-existing cardiac abnormalities involving the heart muscle (cardiomyopathy), cardiac muscle cell ion channels (channelopathy) or the coronary arteries (congenital coronary artery anomalies). SCD due to arrhythmias, can also occur in the absence of any pre-existing condition, such as following the use of drugs (prescription or illicit), infection (viral myocarditis) or a blunt trauma to the chest (*commotio cordis*).

This report of the Task Force reviews SCD in its wider context, examining the incidence, management and monitoring of the condition in Ireland. Several important recommendations are made. These include strategies to reduce the incidence of SCD through prevention and the detection of those at high risk, including risk assessment of those engaged in sports and exercise. Recommendations are also made on equipment and training programmes to improve outcomes following cardiac arrest and on the establishment of appropriate surveillance systems.

The Task Force is aware that the audience for this report is diverse, including families who have been tragically affected by SCD, health professionals in the community and hospital settings, pre-hospital service providers, non-governmental organisations, and workplace and community groups planning first responder programmes. Therefore every effort has been made to explain technical terms and to make the report's contents as accessible as possible. A list of **Abbreviations** and a **Glossary of Terms** has been provided at the beginning of the report. The recommendations are numbered to reflect the chapters in the report that the recommendations arise in, for example Rec 3.1 refers to the first recommendation in Chapter 3, Rec 5.5 is the fifth recommendation in Chapter 5, etc.

## 1.2 Terms of Reference

The Task Force was asked to:

- 1) Define sudden cardiac death (SCD) and describe its incidence and underlying causes in Ireland.
- 2) Advise on the detection and assessment of those at high risk of SCD and their relatives.
- 3) Advise on the systematic assessment of those engaged in sports and exercise for risk of SCD.
- 4) Advise on maximizing access to basic life support (BLS) and automated external defibrillators (AEDs) and on:
  - appropriate levels of training in BLS and use of AEDs, and on the maintenance of that training
  - priority individuals and priority groups for such training
  - geographic areas and functional locations of greatest need
  - best practice models of 'first responder schemes' and 'public access defibrillation', and
  - integration of such training services.
- 5) Advise on the establishment and maintenance of surveillance systems, including a registry of SCD and information systems to monitor risk assessment, and training and equipment programmes.
- 6) Advise and make recommendations on other priority issues relevant to SCD in Ireland.
- 7) Outline a plan for implementation and advise on monitoring the implementation of recommendations made in the Task Force's report.

### 1.3 Membership of the Task Force

The Task Force membership consisted of:

Dr. Brian Maurer, Irish Heart Foundation (Chairperson)

Prof. Gerard Bury, Department of General Practice, University College Dublin

Mr. Ken Figgis, Irish Society for Immediate Care

Mr. Chris Fitzgerald, Health Promotion Unit, Department of Health and Children

Dr. Joe Galvin, Connolly and Mater Misericordiae Hospitals, Dublin

Ms. Wendy Keena, Health Service Executive, Southern Area and National Cardiovascular Information Systems Steering Committee

Dr. Geoff King, Pre-Hospital Emergency Care Council

Dr. Conor O'Brien, Faculty of Sports and Exercise Medicine

Dr. Emer Shelley, National Heart Health Advisor, Department of Health and Children

Mr. Brian Dowling, Mr. Peter Henshaw and Ms. Marie Kinsella, Department of Health and Children, assisted the work of the Task Force.

## 1.4 Policy Context and Guiding Principles

The vision and guiding principles for the health services in Ireland set out in the ***National Health Strategy, Quality and Fairness***<sup>6</sup> provided direction for the work of the Task Force.

The vision:

- a health system that supports and empowers you, your family and community to achieve your full health potential
- a health system that is there when you need it, that is fair, and that you can trust, and
- a health system that encourages you to have your say, listens to you, and ensures that your views are taken into account.

The guiding principles:

- equity and fairness
- a people-centred service
- quality of care, and
- clear accountability.

A major reform of the Irish health care system is under way to implement the national strategy, with the establishment of the Health Services Executive (HSE) to manage and deliver all publicly funded health services.

The Health Information and Quality Authority (HIQA) is an essential component of the new structures. Its role is to support the Health Strategy's aim of delivering high quality, evidence-based services. The responsibilities of HIQA will be:

- to develop health information
- to promote and implement quality assurance programmes nationally, and
- to oversee health technology assessment.

***The Cardiovascular Health Strategy, Building Healthier Hearts*** guides the development of cardiovascular services in Ireland.<sup>7</sup> The overall aim of the Strategy is to improve the heart health of the population by:

- reducing the risk profile in the general population
- detecting those at high risk
- dealing effectively with those who have clinical disease, and
- ensuring the best survival and quality of life outcome for those who recover from an acute attack.

In March 2003, the ***Second Progress Report on the Implementation of the Cardiovascular Health Strategy, Ireland's Changing Heart*** described progress across the range of activities and service settings, namely health promotion, primary care, pre-hospital care, hospital services and cardiac rehabilitation, as well as information systems, audit and evaluation.<sup>8</sup>

A major development in pre-hospital care was the replacement on a statutory basis of the National Ambulance Advisory Council by the Pre-Hospital Emergency Care Council (PHECC) in May 2000.<sup>9</sup> The Council has responsibility for developing professional and performance standards for ambulance services and personnel. It is also tasked with developing standards for training and other aspects of pre-hospital care.

The work of the Task Force on SCD complements the ongoing implementation of the ***Cardiovascular Health Strategy***. It will also facilitate the work of PHECC to improve outcomes in those suffering an acute cardiac event.

## 1.5 Preparing the Report

### 1.5.1 The work of the Task Force

As a result of increasing public awareness and concern, the Minister of Health and Children established the National Task Force on Sudden Cardiac Death which held its inaugural meeting on 12th November 2004.

The Task Force met on 12 occasions in plenary session. In addition, sub-groups were established to examine specific issues and to consult with relevant parties.

The Health Promotion Unit in the Department of Health and Children which has overall responsibility for implementation of the *Cardiovascular Health Strategy* supported the work of the Task Force.

Ms. Wendy Keena, a member of the Task Force was seconded from the Health Service Executive (HSE) to draft the report for the Task Force, working with Dr. Emer Shelley, National Heart Health Advisor, Department of Health and Children. The Chairman and Task Force members contributed material for the sections of the report in which they had particular expertise.

### 1.5.2 The consultation process

The Task Force sought to consult as widely as possible with those experts, organisations and individuals who wished to contribute to the report (Figure 1).

The Task Force placed an advertisement in the national media on 11th February 2005 (Appendix 1) inviting written submissions from interested members of the public, private, professional and voluntary organisations, and other parties. In addition, the Task Force wrote to a number of organisations seeking their views on key issues relating to the Task Force's objectives and their proposals to overcome these challenges. Over 80 written submissions were received, which mainly centred on the third and fourth terms of reference.

Although many of the submissions received were detailed and unambiguous, the Task Force invited some of those who had responded to a consultation day to clarify a number of complex issues. This was held on 7th April 2005. During the morning the Task Force listened to and discussed presentations from a number of organisations. In the afternoon there were facilitated discussions involving 'uniformed' groups, staff working within the health services and others.

The fifth term of reference needed special consideration in view of the technical issues involved. Therefore a second consultation day was held on the 13th May 2005 when the Task Force met with relevant experts and organisations.

A full list of organisations consulted and from whom submissions were received can be found in Appendix 2.

**Figure 1.**  
Groups involved in consultation



### 1.5.3 Main issues highlighted during consultation

Many complex issues were raised during the Task Force's consultation process including :

**First Term of Reference - *Define SCD and describe its incidence and underlying causes in Ireland.***

- the difficulty of obtaining accurate statistics on the incidence of SCD in Ireland
- variations in the definition of SCD and the number of different causes, and
- a substantial proportion of cardiovascular mortality and morbidity is preventable.

**Second Term of Reference - *Advise on the detection and assessment of those at high risk of SCD and their relatives.***

- the challenges in identifying and targeting high risk groups and the feasibility of performing mass population risk assessment
- the role of various stakeholders, for example primary and secondary care services, in the management of SCD
- the timely notification of families and the quality of information provided after a close relative has died of SCD
- difficulties in accessing assessment and diagnostic services, and
- uncertainty as to what investigative tests should be undertaken, how and where they should be provided and whether there is a need to develop specialist family assessment centres for SCD.

**Third Term of Reference - *Advise on the systematic assessment of those engaged in sports and exercise for risk of SCD.***

- the groups to be considered and the age at which young people should be assessed
- whether professional sports competitors require a different approach from amateurs
- concern about possible links between drug misuse (performance enhancing drugs and recreational drugs) and SCD
- the appropriate settings and methods for conducting risk assessments
- responsibility for undertaking the assessment i.e. the duty of care of the person and their guardians, the sporting organisations and the medical profession
- concerns regarding the financing of risk assessments
- the issues regarding 'consent' to testing and its implications
- the information and advice that should be given to those identified as being at risk, and
- ensuring a balance between the benefits and the risks of exercise.

**Fourth Term of Reference - *Advise on maximizing access to basic life support (BLS) and automated external defibrillators (AEDs) and on: appropriate levels of training in BLS and use of AEDs and on the maintenance of that training; priority individuals and priority groups for such training; geographic areas and functional locations of greatest need; best practice models of 'First Responder Schemes' and 'Public Access Defibrillation', and integration of such training services.***

- the public's awareness of SCD and its capacity to recognise and respond to an emergency situation
- the need to develop an Irish national standard for BLS training; re-certification requirements and concerns that regulation of training could lead to the imposition of costly and inflexible programmes that would be a heavy burden on the voluntary sector
- the lack of coordination in delivering training programmes in BLS / AED and the monitoring of the programmes
- financing pre-hospital programmes and the priorities for allocation of resources
- the need to support those geographic areas of greatest need for early response
- confusion over the term 'first responder' and the variety of programmes that are being developed, with inadequate coordination
- concerns about AEDs, including regulation of their use, maintenance requirements, monitoring and insurance
- the perception that communities tend to prioritise access to an AED, rather than considering the whole 'chain of survival', and
- the lack of counselling and debriefing services.

**Fifth Term of Reference - *Advise on the establishment and maintenance of surveillance systems, including a registry of SCD, and information systems to monitor risk assessment, and training and equipment programmes.***

- the purpose of an information system and whether a registry is the appropriate mechanism for the surveillance and monitoring of SCD
- the challenges in establishing a register of SCD – data collection, maintenance, ownership of data, links with other cardiac IT systems and quality assurance
- problems due to international classification of diseases not permitting the specification of SCD as the underlying cause of death on the death certificate
- the collection of pre-hospital data to monitor response times
- concerns about the establishment and maintenance of national registers of training and equipment, and
- the role of HIQA and of the National Cardiovascular Information System (NCIS) in surveillance of SCD.

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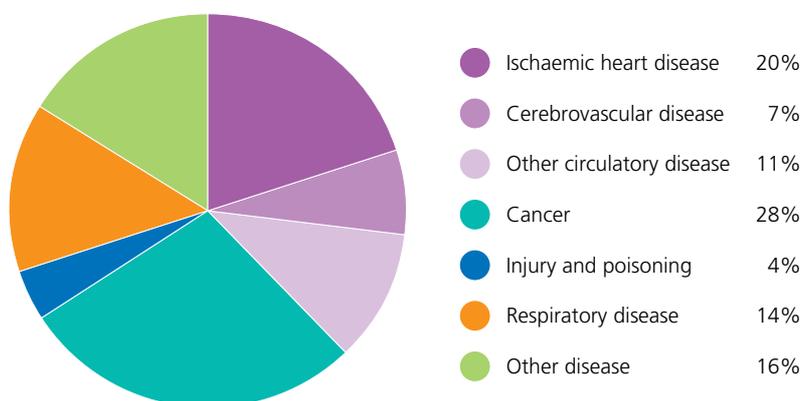
# chapter 2

## Background: The nature of the problem

## 2.1 Epidemiology of Cardiovascular Disease

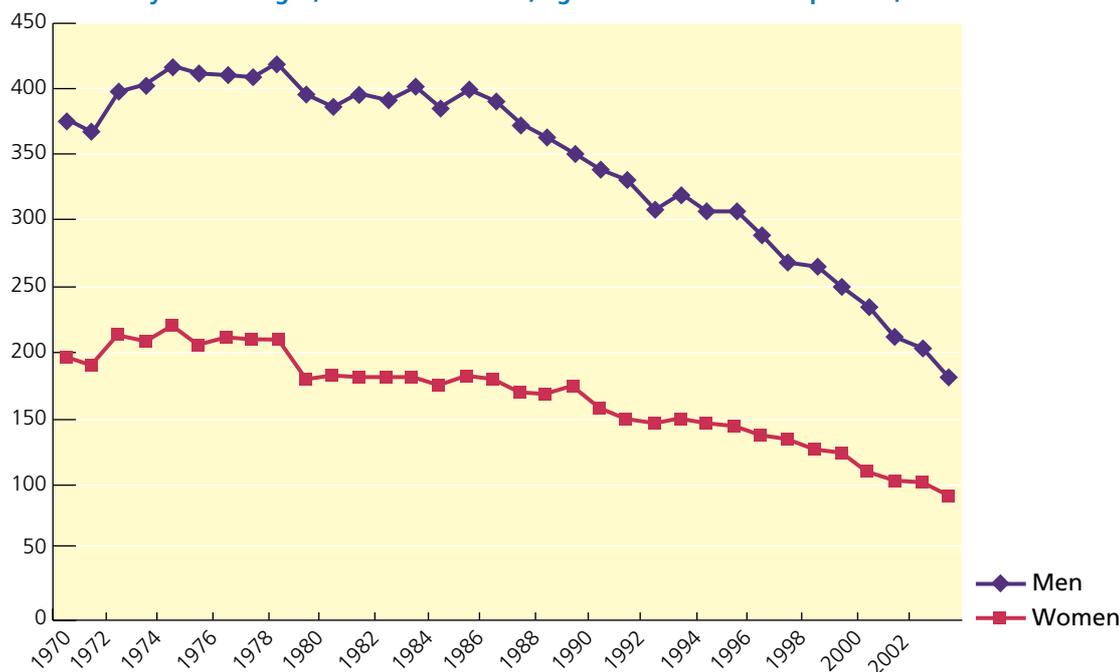
Cardiovascular disease, which includes coronary heart disease (CHD), stroke and other disorders of blood vessels, is the most common cause of death in this country and an important cause of premature mortality (Figure 2).<sup>1</sup> While death rates from CHD have decreased (Figure 3), the number of people living with cardiovascular disease has increased, with substantial numbers suffering chronic ill-health and reduced quality of life. A large proportion of cardiovascular mortality and morbidity is preventable.

**Figure 2.**  
Principal causes of death at all ages, Ireland 2004



Source: Vital Statistics Report, CSO, 2004

**Figure 3.**  
Mortality CHD all ages, Ireland 1970-2003, age-standardised rates per 100,000



Source: WHO Regional Office for Europe, European Health for All Database  
Note: 2003 data are provisional

## 2.2 Epidemiology of SCD

SCD is defined as death due to natural causes within an hour of the onset of symptoms, in the absence of any other cause, and assumed or proven to have a cardiac cause.<sup>2,3</sup> Pre-existing heart disease may have been known to be present but the time and mode of death are unexpected. The death may be witnessed or not witnessed.

There are three sources of information on the incidence of SCD and its underlying causes :

- death certificate and death register data
- post-mortem studies, and
- cardiac arrest registries.

Death certificate data is collected routinely and has the potential to provide information on trends over time and to facilitate international comparisons. Analysis of post-mortem results can provide more detailed information on the underlying pathology. Cardiac arrest registries provide information on the circumstances of the collapse and the underlying heart rhythm, on the emergency response and on outcomes.

### 2.2.1 Death certificate data

In the United States an analysis of death certificates estimated that the overall SCD rate in 1999 was 3 per 100,000 from birth to age 34 (3,976 deaths), 75 per 100,000 (78,456 deaths) in the 35 to 64 year age group and 1,100 per 100,000 (379,869 deaths) in those aged 65 years or older.<sup>4</sup> Of all SCDs in 1998 in those aged 35 or over, CHD was the underlying cause on 62% of death certificates.<sup>5</sup>

The analyses in the US found that 63% of all cardiac deaths were SCDs, occurring out-of-hospital (47%), or in emergency departments or 'dead on arrival' (16%), with almost all of the remaining cardiac deaths occurring as non-sudden deaths in hospital.<sup>4</sup> SCD accounted for 74% of all cardiac deaths in the 35 to 44 year age group, 73% in those 45 to 54, 66% in those 55 to 64, 58% in those 65 to 74 and 69% in those aged 85 or over.<sup>5</sup> Between 1989 and 1998, rates of SCD in those aged over 35 years decreased by 12% in men and by 6% in women.<sup>5</sup>

According to the CSO, 11,652 people died of diseases of the circulatory system in 2002 in Ireland (10,608 in 2004), including 8,126 deaths attributed to cardiac causes.\* Assuming that, as in the United States, 63% of cardiac deaths are SCDs, this would translate into 5,119 such deaths in Ireland in 2002. Apart from this method of estimation, it is not possible at present to obtain the number of SCDs from Irish vital statistics reports.

In Ireland data on all deaths is collected by the Central Statistics Office (CSO), on the basis of medical certificates and death registration information collected by local Registrars' Offices or on the basis of Coroners' report forms. Death rates for a particular condition are estimated from the information recorded on death certificates and subsequently coded by the CSO. This information is subject to inaccuracies for a variety of reasons. For many causes of death the data are sufficiently accurate for the purposes of identifying high risk groups, tracking trends and planning health services. The nature of SCD makes it more subject to misclassification than other causes of death.

\* International Classification of Diseases Version 9, codes 390-398, 402, 410-414, 415-417, 420-429, 745 and 746 (See Appendix 3).

Currently the CSO is using the Ninth Revision of the International Classification of Diseases (ICD).<sup>6</sup> Code 410 (acute myocardial infarction) is the most frequently used code when SCD occurs. The code for 'cardiac arrest' or 'cardiorespiratory arrest', code 427.5 is not used in this country, though 463 deaths in 2002 were coded as 427, 'cardiac dysrhythmias'. Code 798, sudden death, cause unknown, was used for 48 deaths in that year.

The CSO has informed the Task Force that it plans to introduce ICD Version 10 for coding cause of death. This version has a specific code for Sudden Cardiac Death (146.1). Relevant ICD-9 and ICD-10 codes are listed in Appendix 3.

Attempting to quantify the incidence of SCD without a specific code is unsatisfactory. Instructions to those completing a death certificate do not allow use of the term SCD. Instructions on death certificates in Ireland forbid recording the mode of death, such as cardiac arrest. Instead, the certifier must state the underlying cause e.g. acute myocardial infarction (AMI).

For the purposes of completing death certificates from which national statistics are compiled, SCD is therefore coded according to its likely underlying cause, including AMI, coronary thrombosis, angina, heart failure, pulmonary oedema (fluid in the lungs), ruptured aortic aneurysm (a split in the wall of the main blood vessel from the heart), or myocarditis (infection of the muscle of the heart). A post-mortem is not carried out in all cases and so a 'best guess' may be made as to the underlying cause of death. Even where a post-mortem is carried out, there may be difficulty in identifying the cause of death.

With the introduction of ICD-10 it will be possible to estimate the total number of SCDs from death certificate data. In calculating the number of SCD cases it will be important to exclude victims who were not actively resuscitated because of end stage disease. These cases are not relevant to planning emergency medical services in the community.

A number of countries such as the USA, France and Italy, now include a 'tick box' to record cardiac arrest on the death certificate. Similar information for this country would contribute to planning and evaluation of pre-hospital and hospital care of cardiac arrest, as well as the prevention of SCD. Death certificate data will not include those who survive a cardiac arrest. Although this number is currently small, it is likely to grow over the coming years. Such data could be collected in a cardiac arrest registry (see Sections 2.2.3 and 6.4).

The changeover to ICD-10 (including the code for SCD) and any changes in the death certificate to allow recording of cardiac arrest will require training of doctors to inform them about these changes and to reinforce the importance of accurate coding of the cause of death.

### 2.2.2 Post-mortem studies

Several retrospective autopsy (post-mortem) series have been reported. These do not include SCDs where a general practitioner (GP) certified (without a post-mortem) a patient with known CHD who died suddenly as having died, for example, of a 'myocardial infarct'. This is usually done with the knowledge of the coroner.

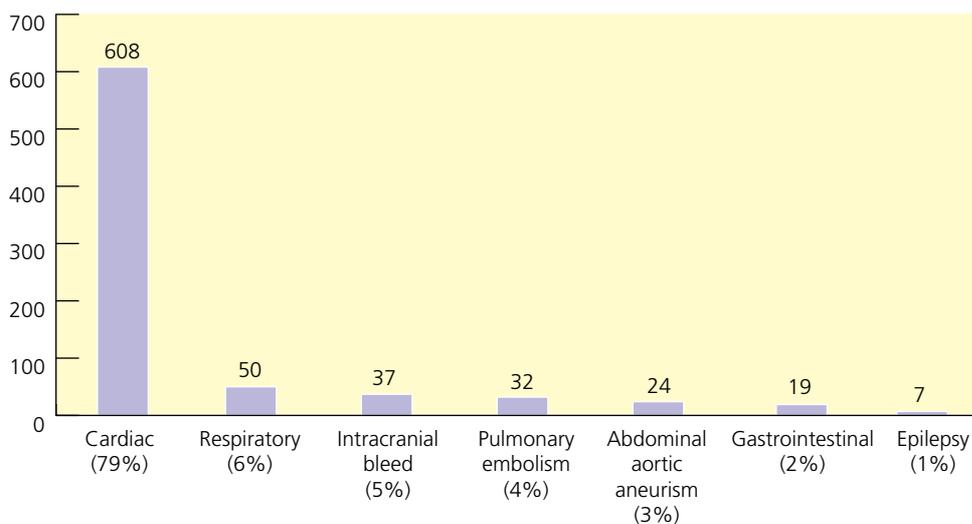
In one series in the UK, 692 SCD autopsy results were analysed for white Caucasians between 16 and 64 years of age with no history of cardiac disease.<sup>7</sup> Eighty-two per cent of deaths were due to CHD and 12% had other cardiac pathology. Of the remainder, 2% had a history of some other condition but in 4% no cause of death could be identified. The annual rate of SCD (including unidentified causes) in this population was 11 per 100,000.

A study in Belfast identified SCDs from EMS and autopsy reports. There were autopsy reports for 37% of cases.<sup>8</sup> In the autopsy group, 60% had no known history of cardiac disease but severe coronary artery disease was found in 94%.

Nearly 2,000 reports were analysed of post-mortems at Connolly Hospital, Dublin between January 1987 and December 2001.<sup>9</sup> Of these, 777 (69% male, 31% female) were performed because of sudden, unexpected, out-of-hospital death occurring within 1 hour of symptom onset. The underlying cause of death was cardiac in 608 subjects (78%). In these, a possible mechanical cause of death was found in 28%, therefore an arrhythmia was the presumed mechanism of death in 72%.

**Figure 4.**

**Causes of sudden death at autopsy at Connolly Hospital 1987 – 2001<sup>9</sup>**



There has been particular interest in the findings at post-mortem of SCD in young people. In a retrospective series looking at 72 SCDs under 35 years of age in Dublin between 1993 and 2002, death was most frequently attributed to CHD, followed by hypertrophic cardiomyopathy (HCM) (24% of deaths).<sup>10</sup> Patients with congenital heart disease and those younger than 10 years of age were excluded from this study.

Between 1992 and 1999 the Swedish national database of forensic medicine recorded 181 cases of SCD in the 15 to 35 year age group, 73% male and 27% female.<sup>11</sup> The incidence rate of 0.93 / 100,000 was stable over time. A cardiomyopathy was found in 23%, CHD in 18% and myocarditis in 11%. No structural cardiac abnormality was found in 21%.

An autopsy series of 193 cases of SCD aged 35 or younger in Sydney, Australia between 1994 and 2002 found CHD in 24%, cardiomyopathy in 15% and myocarditis in 12%.<sup>12</sup> No structural abnormality was found in 31% and death was presumed to be due to a disorder leading to a fatal cardiac arrhythmia.

Approximately 5% of SCDs are unexplained, and no structural abnormality is found at post-mortem.<sup>13</sup> The proportion rises to 20 – 30% in those under the age of 35 years.<sup>11,12</sup> The percentage in whom no structural abnormality is found is higher in young women than in young men, 50% compared to 24% in one series of cases in the 35 to 44 year age group in the US.<sup>14</sup> In the 28% of cases in whom no structural abnormality was found in an Italian series of cases aged 35 or younger, two-thirds were men and one-third women.<sup>15</sup> A genetic factor can be identified in only a small proportion of cases at present but it is expected that this will increase with the identification of further gene defects.<sup>13</sup>

The Royal College of Pathologists has published guidelines on autopsy practice in sudden death with likely cardiac pathology.<sup>16</sup> The contribution of specialist cardiac pathologists to the surveillance of SCD in Ireland is discussed in Section 6.2 of this report.

### 2.2.3 Cardiac arrest registries

Cardiac arrest registries can provide valuable information on the demographics of those who suffer a cardiac emergency, on the circumstances of the collapse, on the emergency response and on outcomes. Registry data can estimate the likely incidence of cardiac arrests requiring response by the EMS. Registries however underestimate the total number of SCDs as they do not include arrests that were not witnessed. Neither do they include events for which no cardiac arrest is called, for example in sudden collapse of someone with other serious morbidity.

Death certificate data and data compiled by the EMS were analysed for the State of Washington in the year 2000.<sup>17</sup> There were 3,577 deaths from cardiac disease in this population of nearly 2 million. The EMS responded to 39% of all heart disease deaths, representing 57% of out-of-hospital events (including 128 people who were successfully resuscitated and discharged from hospital).

Using multiple sources of information, SCD incidence was 53 per 100 000 (median [central] age 69 years, 57% male) in 2002 in Multnomah County in Oregon, representing 6% of annual mortality.<sup>18</sup> Resuscitation was attempted in two-thirds of cases and 8% survived to hospital discharge. One in five cases was identified using sources other than first responders. A retrospective analysis of death certificates for 2002 using ICD-10 codes and location of death gave an estimated SCD rate of 153 per 100,000 (median age 81, 51% male) which would have greatly overestimated the required EMS response.

The Helsinki Cardiac Arrest Registry reported an incidence of out-of-hospital cardiac arrest of 80 per 100,000 inhabitants per year between 1994 and 1999.<sup>19</sup> A similar rate (9.2 / 10,000) was reported for 1997 – 2000 by the Maastricht Circulatory Arrest Registry.<sup>20</sup> Sudden death represented 19% of all deaths.

If, as in Washington State, the EMS in Ireland respond to 39% of all cardiac deaths, this would have corresponded to 3,169 such deaths in 2002, or 81 per 100,000 population, similar to rates reported by other North European countries.

There have been several studies of the circumstances of sudden collapse. The Belfast study of out-of-hospital deaths in 2003 – 2004 used multiple sources of information to identify SCDs.<sup>21,22</sup> There were 297 such deaths in 12 months, 66% of which were in men. The mean age was 68 years (65 in men and 72 in women). The majority, 78%, occurred at home, 16% were in a public place and the remainder in a nursing home; 93% were attended by the EMS. The mean 'call to response' interval was 8 minutes and 27% were in ventricular fibrillation (VF) when the EMS arrived. This was higher (53%) in witnessed arrests. In those attended by the EMS, nearly one in ten were resuscitated to reach hospital alive and 7% survived to hospital discharge.

Several studies have examined the factors associated with successful resuscitation. When resuscitation was attempted in the Helsinki Registry, fifty-seven patients (17%) survived to discharge.<sup>20</sup> Nearly one-third survived when collapse was bystander witnessed and the diagnosis was cardiac arrest with VF as the initial rhythm.

The Swedish Cardiac Arrest Registry found the following factors influenced the likelihood of survival at 1 month: an initial rhythm of VF, shorter time to arrival by the EMS (below the median i.e. better than the response time in the middle when ordered sequentially), arrest occurring outside the home, arrest which was witnessed, one where bystander CPR was initiated and in younger (below the median) people.<sup>23</sup>

In Seattle, Washington, the annual incidence of cardiac arrest with VF as the first identified rhythm decreased from 0.85 per 1,000 population in 1980 to 0.38 per 1,000 in the year 2000.<sup>24</sup> The Swedish Cardiac Arrest Registry reported that between 1992 and 2003 the mean age of out-of-hospital cardiac arrests increased from 68 to 70 years and percentage of females increased from 29% to 32%.<sup>25</sup> There was a decrease in cases of cardiac origin from 75% to 61% and a decrease from 36% to 25% of arrests with VF as the initial rhythm. These changes reflect the changing patterns of mortality in many developed countries, with decreasing death rates and a smaller proportion of deaths being attributed to cardiovascular disease.

Some studies of cardiac arrest use data from cardiac arrest registries; others add supplementary data from other sources. The case definition for registration may vary, to include all cases of sudden collapse or only those cases where resuscitation was attempted. The International Resuscitation Network registry aims to study emergency response and outcomes.<sup>26</sup> Audit of emergency response in Ireland will be facilitated by the establishment of a cardiac arrest registry, with data collection to international standards. Chapter 6 of this report considers information systems and surveillance, and makes recommendations to improve the collection of data relevant to SCD in Ireland.

## 2.3 Epidemiology of Sudden Cardiac Death in Young Athletes

In reviewing SCD as it relates to young athletes, the exact incidence is difficult to ascertain, mainly because many studies have relied on reporting by physicians and media accounts of deaths.

The National Federation of State High School Associations in the USA estimates 10 to 25 cases of SCD per year per million population in individuals younger than 30 years.<sup>27</sup> Even when comprehensive medical assessment is employed, as in recruitment to the US Air Force, the incidence of sudden death is 1 per 735,000 per annum.

A study of Minnesota high schools revealed three SCDs during a 12-year period, giving a risk of 1 death per 200,000 athletes per year.<sup>29</sup> The incidence of sudden death during recreational exercise in unscreened people younger than 30 years was estimated to be 1 death per 280,000 per year in Rhode Island.<sup>30</sup>

In a landmark study, Maron et al detailed the clinical, demographic, and pathologic profiles of 134 young, competitive athletes in the US experiencing SCD from 1985 through 1995.<sup>31</sup> The mean age was 17 years (range 12 to 40 years); 90% were male and 44% were black. Basketball and football players accounted for 68% of the deaths.

The National Centre for Catastrophic Sports Injury Research in the US identified that between June 1983 and June 1993, 160 athletes participating in high school and college sports died from non-traumatic causes, of which 78% of deaths were from cardiac causes. The estimated death rate of male athletes was 5-fold higher than for female athletes (7.5 versus 1.33 per million athletes per year), and 65% of the deaths occurred during participation in basketball or football. Male college athletes had twice the estimated death rate of their high school counterparts (14.5 versus 6.6 per million athletes per year).

Chapter 4 has additional information on the epidemiology of SCD in athletes.

## 2.4 Mechanisms of Sudden Cardiac Death

The majority of SCDs are due to the sudden onset of chaotic disturbance of the heart's electrical rhythm called ventricular fibrillation (VF). If not treated, death usually results within minutes. If treated with high voltage electrical shocks (defibrillation), normal heart rhythm can be restored. Other mechanisms of SCD include asystole and pulseless electrical activity (PEA), neither of which will respond to defibrillation but may respond to other resuscitation measures. Both are rare causes of cardiac arrest in the absence of pre-existing severe and symptomatic heart disease. The likelihood of PEA and asystole increases with a delay in response to a cardiac arrest.

Massive pulmonary embolism and aortic rupture, although extra-cardiac, can cause sudden cardiovascular collapse and death. Marfan syndrome, a cause of aortic rupture, may be genetically determined. Therefore all first degree relatives of index cases should be assessed for risk of sudden death.

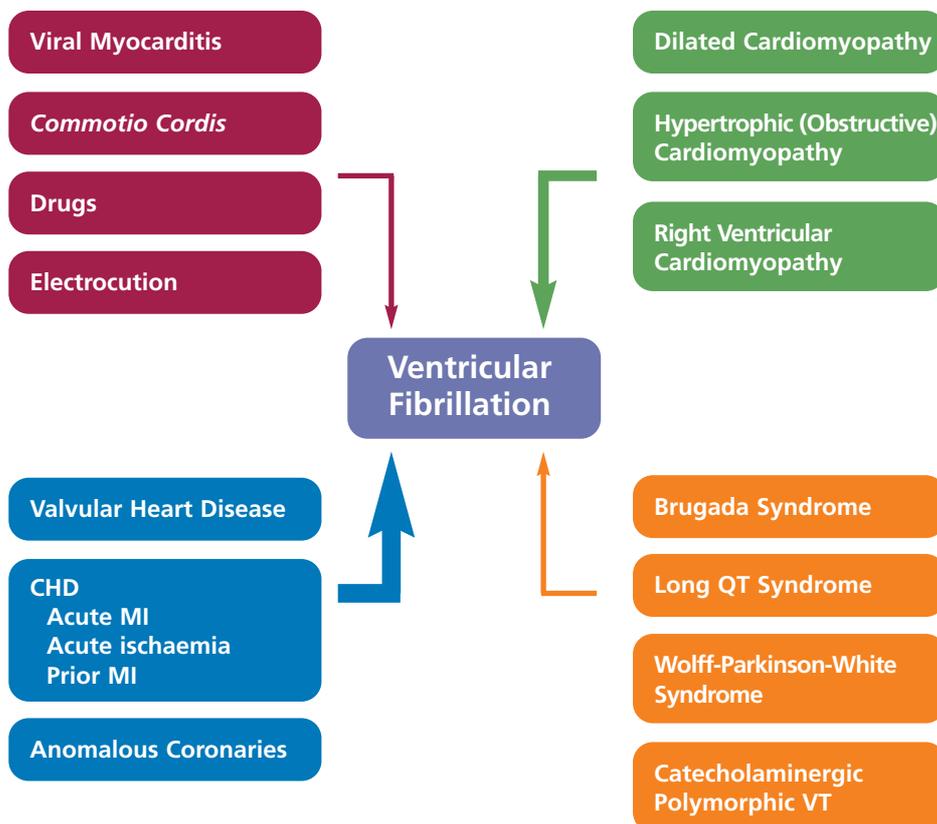
## 2.5 The Main Causes of Sudden Cardiac Death

SCD can be caused by a number of underlying heart conditions including:

- coronary heart disease (CHD)
- cardiomyopathies (hypertrophic or dilated)
- cardiac channelopathies (Long QT syndrome, Brugada syndrome, Short QT syndrome, catecholaminergic polymorphic VT)
- valvular heart disease, and
- abnormal electrical pathways connecting the atrium and ventricle of the heart e.g. Wolff-Parkinson-White syndrome.

SCD due to cardiac arrhythmia can also be due to other causes, for instance illicit or prescription drugs, electrocution, viral infection (myocarditis) and blunt trauma to the chest (*commotio cordis*) (Figure 5).

**Figure 5.**  
**Causes of Ventricular Fibrillation**



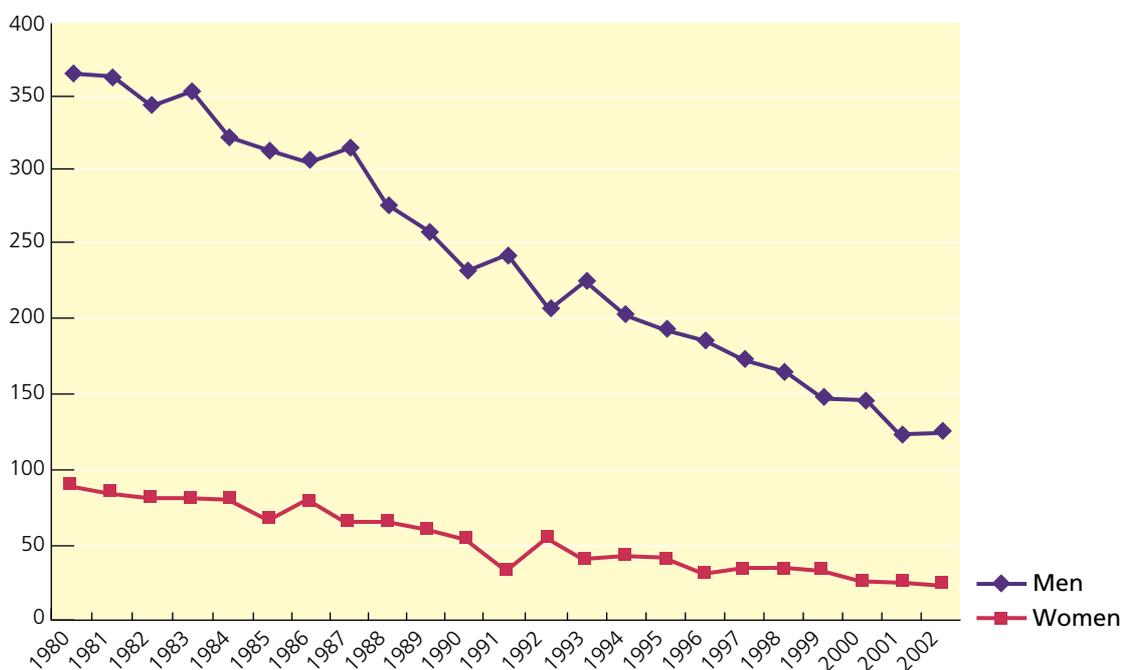
Most SCDs are due to a sudden malfunction of the heart's electrical conduction system, leading to VF. This in turn stops the output of blood from the heart and unless corrected rapidly, results in death. VF may be preceded by a very fast but still organised rhythm, called ventricular tachycardia (VT). This may last for some time but usually deteriorates into VF.

### 2.5.1 Coronary heart disease

In 75 – 80% of cases in developed countries, such as Ireland, SCD is caused by CHD.<sup>33</sup> The commonest mechanism of SCD is VF.<sup>34</sup> Fibrillation may occur as the first manifestation of a heart attack. It is a serious threat during the acute phase of a myocardial infarct or may be initiated by scar tissue from a previous heart attack. It has been estimated that 50% of patients who suffer an acute coronary event die suddenly with little or no advance warning.

The *Cardiovascular Health Strategy* addresses the prevention, treatment and rehabilitation of patients with CHD, including a reduction in the incidence of SCD. Continued implementation of the Strategy will maintain the decreasing trend in death rates from CHD which has occurred over the past twenty years. The decrease has been particularly striking in those aged between 45 and 60 years and was especially marked in men (Figure 6). There is some evidence that SCD has not fallen at the same rate as all deaths from CHD.<sup>21</sup>

**Figure 6.**  
**CHD Mortality age 45-59, Ireland 1980 – 2002 Age standardised rates per 100,000**



Source: Central Statistics Office

### 2.5.2 Cardiomyopathies

Cardiomyopathy is primarily a disease of the heart muscles and is the second most common cause of SCD (Figure 7). There are three principal types:

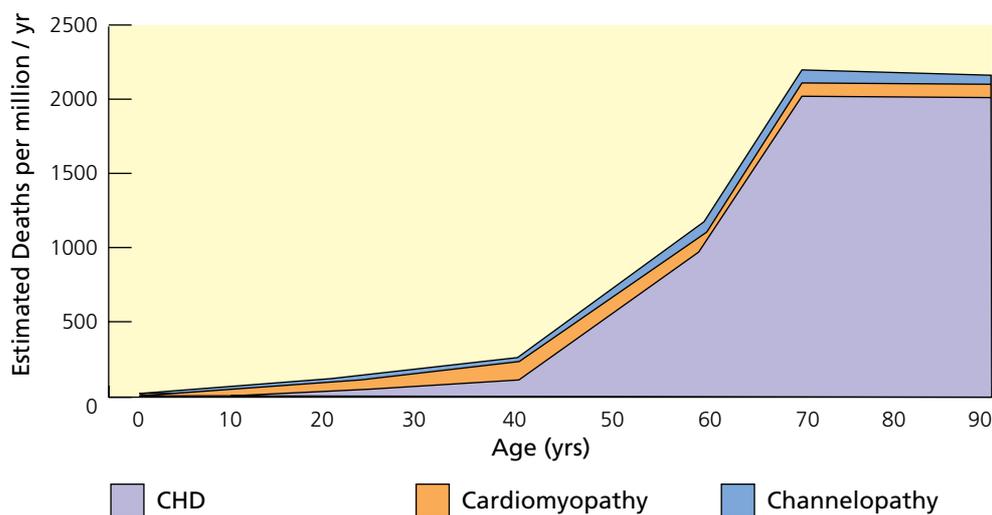
- Hypertrophic cardiomyopathy (HCM)
- Dilated cardiomyopathy (DCM), and
- Right ventricular cardiomyopathy (RVCM).

**Hypertrophic cardiomyopathy (HCM):** The most common form, hypertrophic cardiomyopathy is a genetic disease which may lead to thickening and scarring of the heart muscle, and affects about 1 in 500 of the population.<sup>36</sup> Clinical diagnosis is usually confirmed by echocardiography. Risk of death varies from less than 1% per year in asymptomatic patients to up to 6% in patients with high risk characteristics.<sup>37</sup> Many individuals are asymptomatic, some develop symptoms and progressive disability, and a very small number die suddenly of VF.

**Dilated cardiomyopathy (DCM):** Dilated cardiomyopathy results in progressive dilatation and reduced contraction of the left ventricle. It may be genetically determined, the result of a viral infection (myocarditis) or toxic (e.g. alcohol or drugs). The diagnosis is made by echocardiography.

**Right ventricular cardiomyopathy (RVCM):** Like HCM, this is a genetically determined condition. Gene mutation can currently be identified in about 40% of patients. It is less common than HCM or DCM, but its true incidence and prevalence are unknown. Diagnosis is established by ECG and echocardiography.

**Figure 7.**  
Causes of SCD by age



The last decade has seen rapid advances in our knowledge of the underlying pathology and genetic basis of all three forms of cardiomyopathy. Precise identification of the underlying genetic disorder by tissue sampling is helpful in a minority of cases but this number is likely to increase in the future.

Other diagnostic techniques include cardiac biopsy, cardiac magnetic resonance imaging (MRI scan) and positron emission tomography (PET scan).

### 2.5.3 Cardiac channelopathies

One of the principal mechanisms in the development of cardiac rhythm disturbances is thought to be a disturbance of the normal pattern of transport of ions across cell membranes. This transport is an essential part of the maintenance of normal cell function of each cell in the body. Increasingly it is recognised that such an abnormality in any tissue may result in disease. The term channelopathy is used to describe disorders of ion channels in cell membranes. This is the mechanism of disease in conditions such as epilepsy and cystic fibrosis.

Cardiac channelopathies can trigger an abnormal rhythm, including VF. These are believed to occur in 1 in 5,000 people. The prevalence may be higher because the genetic basis is not yet fully described. Consequently diagnosis is difficult during life and at post-mortem. Diagnosis is made by recognising abnormalities in the ECG but such ECG changes may manifest intermittently. Characteristic changes may be found, most commonly affecting the QT interval. A number of different abnormalities occur. Amongst conditions recognised are Congenital Long QT syndrome, Brugada syndrome, Short QT syndrome and Catecholaminergic Polymorphic VT. There may be other forms which are not yet recognised.

**Long QT Syndromes (LQTS):** This is the commonest form of channelopathy in the Irish population. First described in the 1950s, at least eight different types are now recognised with between 5 and 90 genetic mutations responsible for each type. The diagnosis is initially made on ECG findings. Primary risk factors for SCD in LQTS include prior cardiac arrest, syncope, family history of SCD in a first degree relative and documented VT. Identification of the gene can be difficult. Once the culprit mutation has been identified, other members of the family can be screened.<sup>38</sup>

### 2.5.4 Other causes of SCD

**Myocarditis:** It is known that viral infections can affect the heart and cause myocarditis. This may lead to electrical irritability and ventricular arrhythmias at the time or scar tissue and late arrhythmias. Either may result in SCD. The incidence of myocarditis, its causes and why it only affects some individuals are poorly understood.<sup>39,26</sup>

**Anomalous coronary arteries:** The coronary arteries, the blood vessels supplying the heart muscle may be placed in an abnormal location and this can cause arrhythmias.

**Drugs (prescription and illicit):** Certain anti-arrhythmic drugs, antibiotics and anti-psychotic

medications may result in QT prolongation and an acquired form of the Long QT syndrome. Patients with Long QT syndrome are at particular risk of life-threatening cardiac arrhythmias if they take these drugs and should mention their condition to a physician before accepting any medications. A comprehensive list of QT prolonging drugs can be found on the website [www.qtdrugs.org](http://www.qtdrugs.org).

A wide variety of street drugs, including cocaine, ecstasy and amphetamines may cause cardiac arrhythmias and SCD. This may happen even when there is no underlying heart disease but is probably more common in individuals with a pre-existing abnormality.

**Commotio cordis:** This refers to a blunt trauma to the chest. If this is of sufficient intensity and occurs at a particular moment in the cardiac cycle, VF can result. This can occur in the absence of structural heart disease and with no evidence of any abnormality on post-mortem examination. It has important implications for the provision of AEDs at sports facilities where contact sports are played.<sup>40,41,27,28</sup>

The factors which increase risk of SCD in these underlying conditions are to be found in Appendix 4.

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# chapter 3

## Detection and assessment of those at high risk of sudden cardiac death

## 3.1 Introduction

The first part of this report reviewed the incidence of SCD and its underlying causes. The second term of reference asked the Task Force to advise on the detection and assessment of those at high risk of SCD and their relatives.

A major concern for health services is how to detect and identify those individuals at risk.

Risk assessment can be considered in two broad categories:

- CHD (either confirmed or unknown), and
- inherited cardiomyopathies and channelopathies.

## 3.2 Coronary Heart Disease

As identified in the previous chapter, the majority of SCDs occur as a result of CHD in people over the age of 50. Factors which increase the risk of developing CHD are well documented<sup>1</sup> and include:

- |                           |   |
|---------------------------|---|
| - smoking                 | - physical inactivity   |
| - high blood pressure     | - male gender   |
| - high cholesterol levels | - family history of premature CHD (in a close male relative under age of 55 or female under 65) |
| - obesity                 |   |
| - diabetes                |   |

### 3.2.1 Primary prevention strategies

The evidence shows that primary prevention strategies have contributed to the falling incidence of CHD deaths in Ireland. Between 1985 and 2000, CHD mortality rates fell by 47% in both men and women aged 25 to 84.<sup>2</sup> Nearly half of the observed decrease in mortality was attributed to treatment effects and half to risk factor changes in the population.

A number of Government led health promotion strategies have been implemented over the last decade. Those aimed at preventing CHD have focused on decreasing smoking, improving nutrition and increasing physical activity. Recently attention has focussed on combating the increased prevalence of obesity and diabetes.

#### Smoking

The use of tobacco is the major avoidable cause of death and disability in Ireland. Approximately 7,000 deaths each year can be attributed to tobacco related illness, including CHD. The chronic illnesses which result from active and passive smoking impose an enormous burden on our health care system.

Ireland has made substantial progress in reducing the prevalence of smoking. It decreased from 43% of the population in the early 1970s, to 31% in 1998, to the current level of 23.7%.<sup>3,4</sup> Government tobacco control measures have made a large contribution to this, including:

- raising of the age limit for sale of cigarettes from 16 to 18 years
- ending of advertising of tobacco products in newspapers and magazines
- ending of sponsorship of events by the tobacco industry
- establishment of the Office of Tobacco Control to coordinate a national tobacco control programme
- development of smoking cessation services, and
- legislation to control smoking in the workplace and in public places.

### Diabetes and Obesity

Four hundred thousand (400,000) people in Ireland are thought to have diabetes, but only half of them are aware of their condition.<sup>5</sup> Another 250,000 people have impaired glucose tolerance and up to half of these are likely to develop diabetes in the next 5 years. The fact that one-sixth of our population have or may develop a disorder so closely associated with CHD and SCD poses a major challenge for prevention and therapeutics.

Closely related to diabetes is an increase in obesity and in the average weight of the Irish population.<sup>6</sup> The increasing prevalence of overweight and obesity has been described by the World Health Organization (WHO) as a global epidemic. Nearly 40% of Irish adults are overweight and a further 18% are obese.<sup>7</sup> This is consistent with trends in other developed countries.<sup>8,9</sup> The National Taskforce report *Obesity the Policy Challenges* made 93 recommendations aimed at tackling this problem.<sup>6</sup>

### Physical Activity

Physical *inactivity* is now recognised as an independent risk factor for CHD. Studies have shown that physical activity plays an important role in cardiovascular health, lowering blood pressure and preventing cardiovascular disease. Primary prevention mandates an increase in activity at all ages but particularly amongst children and young adults.

The Obesity Taskforce<sup>6</sup> recommended that:

- adults require 45 to 60 minutes of moderate intensity activity to prevent transition to overweight or obesity; 60 to 90 minutes per day for weight loss and the maintenance of weight loss, and
- children should be involved in at least 60 minutes of moderate physical activity each day.

#### 3.2.2 Secondary prevention strategies

Secondary prevention does not differ in principle from primary prevention but it focuses on people who already have CHD. It is logical to target such individuals more intensively as their risk of a further event, including SCD, is considerably higher than that of the general population.<sup>1</sup>

Secondary prevention and rehabilitation are an integral part of the treatment of patients with CHD in the hospital and community settings. Cardiac rehabilitation is an essential component of secondary prevention. It is the process through which people with diagnosed cardiac disease are encouraged and supported to achieve and maintain optimal physical and psychosocial health.<sup>12</sup>

Cardiac rehabilitation programmes in Ireland's acute hospitals have increased in recent years. In 1998, only 29% of hospitals provided a programme, whereas by October 2003 this had increased to 77%.<sup>13</sup>

One of the aims of rehabilitation is to empower patients and their families to deal effectively with further ischemic events and SCD. Nearly 70% of out-of-hospital arrests occur in the home, in males over the age of 50, during the day time (approximately  $\frac{3}{4}$  between 8am and 6pm).<sup>14</sup> There is evidence that providing information to patients and their families on the warning signs of a heart attack and how to deal with cardiac arrest, reduces the incidence of SCD.

The National Programme in General Practice for Secondary Prevention of Cardiovascular Disease, known more commonly as *Heartwatch*<sup>15</sup> was established in October 2002 and is implementing many of the primary care recommendations of the *Cardiovascular Health Strategy*.

The Task Force welcomes the *Primary Care Strategy*<sup>16</sup> and the development of well structured and properly resourced primary care teams and networks. These developments in primary care with improved access to secondary care services, including direct access to diagnostic facilities, will be important in the secondary prevention of CHD and SCD.

The increased provision of prevention and rehabilitation services is encouraging and will contribute to a reduction in SCD.

### 3.2.3 Risk assessment and management

When CHD is confirmed or suspected, the degree of risk to the person is assessed on the basis of the symptoms, signs and diagnostic test results, with treatment then planned according to the individual's needs.

Additional information on treatment and secondary prevention of CHD can be read in Appendix 5. Appropriate support early on in the care pathway is an essential component and has been shown to reduce anxiety and depression, encourage behaviour change and reduce the use of health resources.<sup>17</sup>

### ▶ The Task Force recommends that:

- R 3.1: Primary prevention strategies to prevent CHD should continue to be developed and implemented.
- R 3.2: Secondary prevention programmes, including cardiac rehabilitation services and primary care based secondary prevention programmes, should continue to be developed in order to provide access for all patients.
- R 3.3: Family members of those who have suffered a cardiac event should be offered basic life support (BLS) and automated external defibrillator (AED) training.
- R 3.4: Information and continuing education on risk assessment for SCD should be made available to general practitioners.
- R 3.5: As outlined in the *Primary Care Strategy*, GPs should have improved access to diagnostic facilities and other secondary care services for their patients.

### 3.3 Risk Assessment for SCD due to other forms of Heart Disease

These conditions are in the main the inherited cardiomyopathies and channelopathies. Increasing public and medical awareness is one of the key factors in diagnosing potentially lethal cardiac conditions in the young. Symptoms such as unheralded syncope (fainting, blackouts), pre-syncope associated with palpitations (dizziness), exertional chest tightness or shortness of breath may indicate a serious cardiac disorder, principally inherited cardiomyopathy or a channelopathy. When present they should lead to a full assessment, including a cardiovascular examination and ECG. Frequently an echocardiogram, treadmill exercise test or Holter monitoring will be needed to complete the assessment.

Everyone joining a sports club or organisation should complete a questionnaire about the presence of a family history of SCD and a personal history of cardiac symptoms. This will be discussed in greater detail in the next chapter.

ECG testing, echocardiography, ambulatory ECG monitoring and treadmill testing are helpful in assessing those with a family history or suspicious symptoms. However these tests are not sufficiently sensitive or specific for population screening for cardiomyopathy and channelopathy. The low yield and substantial number of false positive tests would lead to more harm than good because large numbers of normal young people would be prevented from participating in physical activity and sports. It is hoped that more sensitive and specific tests will be developed in the future. There is currently insufficient evidence to support the implementation of a mass population screening programme for risk of SCD.

Risk assessment is recommended for high risk populations because up to 50% of first degree relatives of individuals who have experienced SCD at a young age are found to suffer from cardiomyopathy or channelopathy. Full cardiological assessment in this group is not only justified but is strongly recommended by the Task Force.

### 3.4 Risk Assessment of First Degree Relatives of a Confirmed Case of Sudden Cardiac Death

The Task Force believes that the priority group for risk assessment should be the first degree relatives of those who died of SCD under 40 years of age. When an SCD occurs in the absence of CHD in someone under the age of 40 years, other family members may be at increased risk. In older age groups the cause is more likely to be CHD and family risk assessment should be for this condition.

The sudden death of an apparently healthy young person traumatises the family, friends and community. Failure to find a physical cause adds to the trauma and may raise questions about lifestyle, such as suspicion of drug misuse. Expert examination of an apparently normal heart may take a long time. Inability to find a cause for SCD despite autopsy or delay in communicating the findings adds to the distress of family and friends.

The Task Force recommends that all possible steps should be taken to provide appropriate support, including prompt communication of medical information. Training of personnel providing emergency medical services (EMS), GPs, Gardaí, hospital emergency department staff and staff in the coroner's office, in sympathetic and appropriate communication is essential. Counselling services and information on how to access them should be made available. This includes support through voluntary organisations by families who have suffered an SCD. Further information on these organisations can be obtained from the Internet, including:

[Irish Cardiomyopathy Group - www.irishheart.ie](http://www.irishheart.ie)

[Cardiomyopathy Association - www.cardiomyopathy.org](http://www.cardiomyopathy.org)

[Cardiac Risk in the Young - www.c-r-y.org.uk](http://www.c-r-y.org.uk)



#### The Task Force recommends that:

- R 3.6: A national education campaign to raise awareness of the symptoms which indicate increased risk of SCD should be developed and implemented.
- R 3.7: An education programme should be developed and implemented for all personnel involved in the immediate and post-event management of SCD.
- R 3.8: Training of personnel in the management of SCD should include a module on appropriate psychological support.

### 3.4.1 Notification of families

As first degree relatives of victims of SCD may themselves be at increased risk of dying suddenly, they need to be informed about the cause of death as soon as possible after the event. The primary responsibility for providing this information to the relatives rests with the physician who makes the diagnosis and signs the death certificate or, much more frequently in these circumstances, with the Coroner.

As the law requires that all sudden, unexplained deaths be referred to the Coroner's Office, the diagnosis will usually be made following a post-mortem examination carried out by a pathologist on the instructions of the Coroner. When SCD is established as the likely cause of death, whether following a post-mortem or by the decision of the Coroner, it is essential that families be notified immediately.

It is suggested that following confirmation from the pathologist the Coroner should notify the next of kin. The Coroner should specifically inform them of the possible risk of SCD in first degree relatives of the deceased.

The Coroner should also forward a copy of the pathologist's report to the deceased's GP. This should not be delayed by the need to hold an inquest which may take several months. Delay is unacceptable as family members may be at risk during this period.

In some cases a post-mortem examination may not be done, such as when a person was known to have a condition which increased risk of SCD. Should such a death occur in hospital, the consultant physician may be in a position to sign the death certificate without a post-mortem. In this situation the responsibility for informing the GP of the likelihood of a familial cause of SCD rests with the physician. The importance of screening family members for the specific cause of SCD should be conveyed to the GP.

The GP who has been informed of the potentially increased risk of SCD in first degree relatives should communicate with the relatives and provide advice on access to risk assessment services.

Difficulties may arise in informing all relevant family members. Estrangement or poor communication within families, and reactions such as protectiveness, denial or fear may need to be addressed with sympathy.

More than one GP may be involved in the care of the kindred. If the next of kin or family member with whom initial communication is established is not willing to contact other family members or to communicate with them, the Coroner, hospital physician or GP primarily involved may have to try and trace such individuals. The HSE Public Health medical service could also provide information to family members. This service could also support communication where the deceased was not under medical care at the time of SCD. The Public Health service should be involved if there is evidence that a contaminated illegal drug may have been a factor and the possibility of an increased risk to other potential users in the population may need to be investigated.

### 3.4.2 The role of the pathologist

Family risk assessment depends on accurate diagnosis in the victim of SCD. In the case of survivors this will depend on full medical investigation. In those who do not survive, the diagnosis may be established at post-mortem.

In about 5% of SCD victims, no cause can be found even at post-mortem. Pathologists use the term Sudden Adult Death Syndrome (SADS) for this group. Precise figures are not available for Ireland as current death certification protocols do not code for SADS.

Guidelines for the conduct of a post-mortem in SADS cases should be developed as has already been done for Sudden Infant Death Syndrome (SIDS).

When initial autopsy does not provide evidence of disease or abnormality sufficient to explain the death, a more detailed cardiac post-mortem should be performed. In such cases the heart should be examined by a specialist cardiac pathologist. If, after such examination there is no evidence of structural heart disease, SADS should be diagnosed and appropriate tissue samples should be taken and frozen with a view to subsequent DNA extraction and analysis.

The sensitive issue of organ and tissue retention has been the subject of professional and public debate in recent years. The public and particularly bereaved family members have serious concerns about this. These sensitivities need to be addressed with tact but in cases where the Coroner directs that a post-mortem take place, consent from the next of kin is not required. Permission to use or retain tissue or organs for *research or teaching* is not covered by the Coroner's jurisdiction but can only be given following a specific request to the relatives. Data obtained in the future and at a time remote from the actual death may be vitally important for increasing knowledge in this area and particularly helpful in determining the underlying cause of the disease and its prevention in members of the kindred. In seeking permission for long-term tissue retention these issues need to be explained in a sympathetic and timely fashion to family members.

### ▶ The Task Force recommends that:

- R 3.9: Following certification of SCD in individuals less than 40 years of age, the Coroner should notify the next of kin and the patient's GP of a potential increased risk of SCD in first degree relatives.
- R 3.10: The Coroner and all medical professionals involved should encourage the next of kin to communicate this information to other first degree relatives as appropriate, and risk assessment of each relative should ensue.
- R 3.11: Protocols should be formalised for informing GPs and families of the results of post-mortems and the implications for families in terms of risk assessment.
- R 3.12: In cases of SCD, pathology reports should be forwarded to the GP as soon as possible in order to avoid delays in notifying family members who may be at risk.
- R 3.13: Guidelines for the conduct of a post-mortem in SADS cases should be developed as has already been done for Sudden Infant Death Syndrome (SIDS).
- R 3.14: When a post-mortem examination fails to determine the cause of SCD in a person under the age of 40 years, a further examination of the heart should be undertaken by a pathologist with cardiac sub-speciality training, in a specialist referral centre. This will necessitate the appointment of at least two cardiac pathologists in Ireland.

#### 3.4.3 The risk assessment process

Following the recognition of SCD, all first degree family members - parents, siblings, and children - must be given the opportunity to undergo a comprehensive risk assessment. In the case of minors, parents or guardians should be informed of the risk. This assessment should take place in a number of stages:

**Stage 1** – The initial assessment of first degree family members by the GP.

**Stage 2** – Where indicated following the initial assessment, relatives should be referred to the regional cardiology centre for more complex investigations. These should include the comprehensive evaluation of the family history, the individual's personal history, physical examination and investigations – ECG, chest X-ray and echocardiogram. If no evidence of the disease as diagnosed in the index case is found, the patient should be referred back to general practice for primary care follow-up. If the family member has evidence of the disease, further investigations and treatment may be required.

**Stage 3** – A minority of individuals will require referral to sub-specialist services. These may be provided in regional cardiac centres, in supra-regional centres or in specialist family risk assessment clinics. Direct referral links with such centres should be established by all cardiology services to ensure that an individual that requires it will be assessed by a cardiologist who has specialist knowledge of cardiomyopathy or channelopathy. Paediatric

risk assessment may be required for children or younger family members and referral to a clinical genetic service may be needed for some. Follow-up care should be undertaken as appropriate.

A diagram illustrating the referral pathways for first degree relatives of a victim of SCD can be found in Appendix 6.

#### **3.4.4 Medical genetic services**

The National Centre for Medical Genetics (NCMG) is based in Our Lady's Hospital for Sick Children (OLHSC) in Crumlin. Its multidisciplinary staff, including trained genetic counsellors, provide outreach clinics in Temple Street Children's Hospital, Dublin, and in Cork, Limerick and Galway for both children and adults.

In hereditary cardiomyopathies and in Long QT syndrome, genetic testing is becoming increasingly possible on a sample from a confirmed affected patient. Such testing is time consuming and will only find a specific gene mutation in between 20 to 50% of affected families, depending on the disorder involved. Where a definite gene mutation has been found in an affected person, then the test has confirmed the diagnosis of a genetic disorder, and also allows predictive genetic testing for those healthy family members who wish to determine their own genetic status.

Such predictive testing on healthy family members should be carried out through a clinical genetic service, where a full discussion of the benefits and drawbacks of genetic testing can take place. If a person does not have the gene alteration, they are not at risk of having the genetic cardiac disorder and their own children are also not at risk. If the person does have the gene alteration, they can be assessed, their risk of cardiac disease estimated, and therapeutic interventions considered.

Genetic analysis of patients suspected of having inherited cardiac abnormalities is currently coordinated through the NCMG, with specimens for analysis sent to one of a number of laboratories in the UK or Europe.

It is the Task Force's view that genetic testing and predictive genetic testing should continue to be performed through the NCMG. In order to achieve efficient use of resources, samples will continue to be referred outside the country for analysis for the foreseeable future.

**▶ The Task Force recommends that:**

- R 3.15: There is insufficient evidence to support the implementation of a mass population screening programme for SCD. The first degree relatives of those who have died of SCD under 40 years of age are the priority group for risk assessment.
- R 3.16: In cases of SCD under the age of 40, initial assessment of first degree family members should be by the GP, with referral to a regional cardiology centre for investigation when indicated.
- R 3.17: All cases of possible cardiomyopathy or channelopathy identified in a regional centre should be assessed by a cardiologist with expertise in these conditions. Supra-regional centres should be identified for assessment and treatment of children with a family history of SCD.
- R 3.18: As access to a geneticist is an integral part of the service, each regional and supra-regional cardiac referral centre should have a link with the National Centre for Medical Genetics at Our Lady's Hospital, Crumlin for testing for known cardiomyopathy and channelopathy genes.

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chapter 4

Systematic assessment of  
those engaged in sports  
and exercise

## 4.1 Introduction

The sudden death of a young athlete is a rare event that draws substantial public attention and concern. A number of such deaths have occurred in Ireland in recent years and have attracted considerable publicity. The majority of these were due to an abnormal heart rhythm (cardiac arrhythmia) which may be associated with a disorder of the heart muscle (cardiomyopathy). There is an argument that some of these deaths might have been prevented if risk assessment or screening had been carried out before participating in sport. Some research and much discussion concerning the evidence for risk assessment or screening has taken place. Different conclusions have led to the development of varying practices in different countries.

The third term of reference asked the Task Force to consider all the evidence available and give advice on risk assessment for people engaged in sport and exercise.

## 4.2 Underlying Disease Associated with SCD in Athletes

Our understanding of the underlying diseases that lead to SCD in athletes comes from a number of autopsy series. The wide variety of conditions that have been found at autopsy among young people who die suddenly is shown in Table 1. There is substantial variability in the prevalence of underlying conditions between the groups studied, with a different condition being most common (shown in bold) in each of the four groups. It is unclear what the most common underlying cause of sports-related SCD is in Ireland as this has not been systematically studied to date.

**Table 1.**  
**Causes of SCD in high school and college athletes, and military recruits in the USA.**

	D Corrado et al <sup>1</sup>			
	Athletes	Non-athletes	Eckart et al <sup>2</sup>	Maron et al <sup>3</sup>
<b>(Number in study)</b>	<b>(49)</b>	<b>(220)</b>	<b>(126)</b>	<b>(387)</b>
Anomalous coronaries	12.2%	2.6%	<b>33%</b>	13.7%
<b>Hypertrophic CM</b>	2%	6.3%	13%	<b>26.4%</b>
<b>Coronary atherosclerosis</b>	18.4%	<b>16.7%</b>	16%	2.6%
<b>RV cardiomyopathy</b>	<b>22.4%</b>	10.8%	2%	2.8%
Commotio cordis	0%	0%	0%	19.9%
Conduction system disease	8.2%	8.9%	0%	0%
Mitral valve prolapse	10.2%	9.7%	0%	2.3%
Myocarditis	6.1%	8.2%	20%	5.2%
Myocardial bridging	4.1%	2.6%	3%	2.8%
Aortic dissection	2%	4.5%	0%	3.1%
Dilated cardiomyopathy	2%	3.7%	2%	2.3%
Pulmonary embolus	2%	1.5%	0%	0%
Coronary artery hypoplasia	0%	5%	0%	0%
Coronary aneurysm	0%	3%	0%	0%
Coronary dissection	0%	2%	0%	0%
Bicuspid aortic valve	0%	2%	0%	0%
Embolio myocardial infarction	0%	2%	0%	0%
LV hypertrophy	0%	0%	0%	7.5%

#### 4.2.1 Incidence of SCD among sports participants

The largest series of systematically collected data comes from Italy. Systematic screening of competitive athletes under 35 years of age has been performed there since 1979 when it was mandated through legislation. In the setting of this screening programme SCD incidence rates have been published for the Veneto region of Northern Italy.<sup>1</sup> The total population of 4.4 million people with 2 million under 35 years of age is similar to Ireland. Over 17 years, there were 269 sudden unexpected cardiac deaths among those under 35 years of age, with 49 occurring in athletes (1.6 / 100,000 / yr) and 220 occurring in non-athletes (0.75 / 100,000 / yr). Despite the pre-participation screening (PPS) programme in the region, the rate of SCD in the athletes was 2.1 times greater than that in non-athletes. However, SCD in athletes accounted for only 18% of the total number of SCDs in those under 35 years of age. The findings remained unchanged when the series was extended to include 300 cases of SCD (55 deaths in athletes [2.3 / 100,000 / year] and 245 deaths in non-athletes [0.9 / 100,000 / year]).

Incidence rates in other populations are shown in Table 2. Of particular interest is the data from Rhode Island where over a 7.25 year period there were 75 deaths while taking leisure exercise in those aged 30 or more, e.g. during golf, jogging and swimming and predominantly due to CHD.<sup>7</sup> There were 6 deaths (1 per 250,000 / year) during leisure exercise in those under 30 years of age. This compared to 1 death per 7,620 joggers / year in joggers between 30 and 65 years of age.<sup>8</sup> Of the 12 deaths in joggers at all ages, 11 were attributed to CHD.

**Table 2**  
**Rates of sudden death in different populations**

Population Group	Age Distribution	Incidence
Organised High School /College athletes <sup>5</sup>	15-23 yrs	7.47 per million/yr (male) 1.33 per million/yr (female)
US Air Force recruits <sup>6</sup>	17-28 yrs	1.4 per million / yr
Rhode Island, recreational exercise <sup>7</sup>	< 30 yrs	3.6 per million / yr
Rhode Island, joggers <sup>8</sup>	30-65 yrs	131 per million joggers / yr
Marathon runners <sup>9</sup>	37 (mean)	20 per million marathons

#### 4.2.2 The target population

These data suggest that to focus purely on screening competitive athletes under 35 years of age would exclude the bulk of those under 35 years of age (four out of five) who will die suddenly and would also exclude a group of sports participants (those aged 30 to 65) who are 35 to 40 times more likely to die suddenly. Any strategy to identify those at risk of dying suddenly during sports and exercise should be inclusive and cover a larger segment of the population than has been previously targeted.

It has been suggested that PPS should begin at about 14 (Italy) or 15 (USA) years of age. SCD rates below the age of 14 are lower than in those over 14, symptoms and ECGs are more difficult to interpret, and exercise tends to occur in a less organised, less intense and more informal manner.

Little data exists for the relationship between the type of sport and the incidence of sports-related SCD. The European Society of Cardiology (ESC) guidelines for competitive sports participation *in athletes with cardiovascular disease* published in 2005 categorised sports by the level of dynamic and static intensity involved (Table 3).<sup>10</sup> Sports categorised as being of moderate and high dynamic intensity are the highest priority for risk assessment. Subjects taking up high static intensity sports should also be assessed. Consideration should be given to screening pre-participants for some moderate / low dynamic intensity sports and pre-participants do not need to be screened for low static / low dynamic intensity sports e.g.

bowling, cricket, riflery and golf. In addition, contact sports (Table 3 with \*) carry a risk of *commotio cordis* or induction of fatal arrhythmias following blunt trauma to the chest. Though this risk is very low, the only strategy to prevent such deaths is immediate access to a defibrillator as they occur in people with completely normal hearts. There is no doubt that such immediate access to defibrillation would reduce sports-related SCD in all of the disease categories in Table 1, with the exception of those due to pulmonary embolism and aortic dissection.

**The Task Force considers that the target population should be all those involved in sports other than that of a low static, low dynamic nature who are 14 years of age or older, with no upper age limit.** It is difficult to estimate the number of people involved in organised sports and exercise. Based on the Italian experience the Task Force estimates that 10% of the population may participate in such activity in any one year. This is likely to be higher among teenagers, particularly those involved in school sports and lower in people over 40. A reasonable estimate would be some 320,000 people aged 14 years or older in Ireland. Any form of risk assessment programme for such a large cohort must be easy to administer. It must not be associated with a high false positive rate in order to ensure that the benefits of risk assessment are not outweighed by adverse effects.

**Table 3**  
**Classification of sports into low, moderate and high dynamic and low, moderate and high static intensity.<sup>10</sup>**

Classification of Sports			
	Low Dynamic	Moderate Dynamic	High Dynamic
<b>Low Static</b>	Bowling Cricket Golf Riflery	Fencing Table Tennis Tennis (doubles) Volleyball Baseball* / softball*	Badminton Race walking Running (marathon) Cross-country skiing (classic) Squash* / Racquetball* Gaelic handball
<b>Moderate Static</b>	Auto racing* Diving Equestrian* Motorcycling* Gymnastics* Karate / Judo* Sailing Archery	Field events (jumping) Figure skating* Lacrosse* Running (sprint)	Basketball* Biathlon Ice hockey* Field hockey* Rugby* Soccer* Cross-country skiing (skating) Running (mid / long) Swimming Tennis (singles) Team handball* Gaelic Football*
<b>High Static</b>	Bobsledding* Field events (throwing) Luge* Rock climbing* Waterskiing* Weightlifting* Windsurfing*	Body building* Snow boarding* Downhill skiing* Wrestling*	Boxing* Canoeing, kayaking Cycling* Decathlon Rowing Speed skating Triathlon* Hurling*

\* Danger of bodily collision

### 4.3 The Benefits of Exercise Versus the Risks

The health benefits of exercise are widely accepted.<sup>11</sup> Regular exercise reduces the risk of developing or dying from CHD, obesity and associated conditions. There is substantial literature on the benefits of exercise in both primary and secondary prevention i.e. in the general population and in those with known CHD or a related condition. In a nation where weight and the problems associated with obesity are increasing, encouraging exercise participation is highly desirable. In this context the publicity associated with the sudden death of sports participants may discourage public participation and particularly participation of young people in sports and exercise. Such publicity needs to be balanced by providing information on the benefits of exercise.

There have been a number of initiatives in recent years promoting exercise in the general population. The kinds of exercise promoted e.g. walking, leisure cycling, swimming, require no specific medical clearance because of their non-strenuous nature. Promoting the participation of young people in athletics, team sports, and high level endurance activities requires a somewhat different approach in order to address the concerns raised by the small number of SCDs in participants. Recommendations are also needed to reassure older individuals who wish to embark on fitness programmes that they can do so with safety. The remainder of this section will address the evidence that exercise is desirable and consider the safeguards that need to be put in place to ensure the safety of the individual.

Heart disease is more common amongst those with a sedentary lifestyle.<sup>12,13</sup> The British Heart Foundation National Centre for Physical Activity and Health in the UK quotes the following statistics:<sup>14</sup>

- thirty seven percent of CHD deaths are related to inactivity
- inactivity is the most prevalent risk factor for CHD. Seventy percent of women and 60% of men in the UK are not active enough to achieve the health benefits of physical activity, and
- nine percent of deaths from CHD in the UK could have been avoided if people increased their activity to a moderate level.

In the USA, one third of deaths from CHD have been attributed to insufficient physical exercise.<sup>15</sup>

Even in childhood there is substantial evidence that regular physical activity positively affects body composition and musculo-skeletal development and reduces risk factors for CHD, providing immediate health benefits.<sup>16,17,18</sup>

Paradoxically, SCD rates in the young are increased in frequency among those involved in sports, with a two to two and a half fold increased risk among young people involved in organised sporting activity.<sup>1,4</sup> It should be stressed that these SCDs are largely the result of underlying disease, with the lethal arrhythmias being triggered by exercise.

## 4.4 Pre-participation Screening and Risk Assessment

Pre-participation risk assessment (screening) is not meant to exclude individuals from sporting activities but is intended to be a positive intervention to enable safe participation. A balanced approach to risk assessment is essential. Otherwise there may be a danger of excluding a large number of healthy participants or those with minor abnormalities from participating in a healthy activity.

Wen (2004) considered the principles of population screening in the context of SCD and stated that the following criteria must be fulfilled:<sup>19</sup>

- **the prevalence of the condition screened should be sufficiently frequent in the population**
- **the tests used to screen for the condition should be cheap and have a relatively high positive and negative predictive value, and**
- **treatment should be available which is cost effective and if instituted prevents or corrects the condition being screened for.**

Current screening techniques used or proposed include:

- questionnaire
- medical examination
- ECG and exercise ECG, and
- echocardiogram.

### 4.4.1 Questionnaire

Some currently available screening questionnaires are quite detailed. An example of one, based partly on symptoms, recently published by the International Olympic Committee (IOC) is shown in Appendix 7.<sup>20</sup> Unfortunately, less than 60% of individuals who die suddenly have antecedent symptoms; in about half of these the symptoms are either mild or non-specific, such as fatigue or influenza type symptoms.<sup>21</sup> In addition, the specificity or positive predictive value of symptom-related questionnaires reaches very low rates when non-specific questions such as 'have you ever experienced skipped heart beats?' or 'have you experienced dizzy spells?' are included. Despite this, a questionnaire may pick up important symptoms of underlying heart disease in a small number of pre-participants. There is also value in asking pre-participants if they have a known heart condition or a family history of SCD in a first degree relative under the age of 40.

### 4.4.2 Physical Examination

Physical examination can be of benefit, for example, to identify hypertension, the stigmata of Marfan syndrome and valvular heart disease. Its usefulness however is limited by the high prevalence of benign flow murmurs, 'white coat hypertension' and variable levels of expertise among physicians in distinguishing benign from significant murmurs and in identifying the physical signs of Marfan syndrome. In addition there is an extremely low association between abnormalities on physical examination and subsequent SCD. To overcome some of these difficulties, PPS has become a major undertaking involving hundreds of specially trained physicians throughout Italy, even though the programme has been

limited to those engaged in organised sports aged 14 to 34 years. Review of the evidence on the evaluation of young athletes has concluded that resources should focus on examining those who have suggestive, even if minor, symptoms and those with a positive family history.<sup>22</sup>

#### 4.4.3 ECG and echocardiography

ECG and echocardiography may appear to be abnormal in about 10% of healthy individuals. Abnormal findings occur in an even higher percentage of athletes, reflecting physiological changes in the heart muscle as a result of training, so called 'athlete heart syndrome'. A review of 1,005 ECGs in trained athletes from the Italian screening programme, 75% male and average age 24, found that only 60% had ECGs that were completely normal or showed only minor abnormalities.<sup>23</sup> Most of the remainder had changes compatible with athletic training. Even in a sub-group with striking ECG abnormalities, the changes were considered to reflect long-term intense training. The authors concluded that such false positive ECGs 'represent a potential limitation to routine ECG testing as part of pre-participation screening'.

A recent study of 91 Irish professional rugby players found apparently abnormal ECGs and echocardiograms in 24%.<sup>24</sup> While this group was unusual in that they were already highly trained, the findings cast serious doubt on the validity of using these tools for universal risk assessment. The following concerns have also been identified:

- in addition to the high false positive rates with these tests, there is in addition a significant false negative rate. This means that a high proportion of those with a positive test result will be considered to have an essentially normal heart after further investigations. Conversely, test results appear normal in an important proportion of those who later suffer an SCD
- the variability of ECG findings in cardiomyopathy and in particular in cardiac channelopathies may lead to false negative screening tests; the commonest cause of SCD amongst US army recruits was anomalous coronary arteries which are not detected by conventional ECG and echocardiography<sup>2</sup>
- some conditions, such as viral myocarditis and *commotio cordis* arise in previously healthy individuals and could not be predicted by screening of athletes, and
- screening cannot address the effects of subsequent taking of prescription or illicit drugs which may contribute to SCD.

In Italy, 9% of those aged 14 to 34 screened by history and physical examination were referred for ECG examination.<sup>25</sup> Echocardiography, the main diagnostic test for cardiomyopathy was not used, being too expensive and impractical for screening large populations. Overall, 3% of those screened in the Italian series were excluded from sporting activity. Cardiomyopathy was definitively identified in 0.07% of those screened. It is difficult to interpret the prevalence of HCM identified in the Veneto series<sup>25</sup> partly due to the use of ECGs as opposed to echocardiography and partly because the athletes are screened annually. The estimate of exclusion from activity in the Veneto series is likely to underestimate the problem at a population level, as those barred from activity in previous years are not included in the annual screening.

The prevalence of HCM in the Veneto Region was comparable to that identified by once-off echocardiography in 4,111 people aged 23 to 35 years in the USA.<sup>26</sup> Probably or definite HCM was identified in 7 people (4 black men, 1 black woman, 1 white man and 1 white woman). The overall prevalence was 0.17% (95% confidence interval 0.07% to 0.35%); the prevalence was 0.26% in men and 0.09% in women, 0.24% in blacks and 0.10% in whites.

If, as estimated, 10% of the Irish population aged 14 or over are involved in sporting activity, some 320,000 people (approximately 140,000 aged 14 to 34 years) would need to be screened. The experience of assessing all those engaged in organised sport in Italy would translate into 29,000 of those screened by questionnaire and physical examination in Ireland requiring further assessment and tests, including possibly referral to a cardiologist. Over 4,000 people aged 14 to 34 would be excluded from participating in organised sports. In addition they and their families would have to deal with the uncertainty of potentially having a life shortening condition. The long-term negative effects of labelling a young person as 'too high risk' to participate in sporting activity should not be underestimated. This must be put in perspective with the likely identification of 140 cases of probable or definite HCM, only a proportion of whom would succumb to SCD if they continued to participate in organised sports.

It is the Task Force's opinion that for the reasons described, the currently available screening tests fail to fulfil Wen's criteria for universal population screening. There is insufficient evidence to support the implementation of a mass population screening programme to identify risk of SCD. However, the Task Force does advise a pre-participation questionnaire for those aged 14 or older who wish to join a sports club or engage in organised activity (Section 4.5.1).

## 4.5 International Recommendations

There are international recommendations on competitive sports participation in people with known cardiovascular disease,<sup>10</sup> and on recreational activity in young patients with genetic cardiovascular diseases.<sup>27</sup> They provide expert opinion to physicians who advise patients about participation in exercise. These guidance documents recognise the important balance to be struck in those with an identified cardiac condition between the benefits of being regularly active on the one hand and minimising the risk of sudden death on the other. They differentiate between those engaged in competitive sports with pressures to attain peak performance and those taking recreational exercise. The European Society of Cardiology (ESC) recommendations<sup>10</sup> only apply to those with cardiovascular disease participating in competitive sports; they do not apply to activities, even of moderate or vigorous intensity, which do not involve systematic training or the pursuit of excellence. While important for the care of individual patients, these guidance documents do not contribute to the discussion about identifying those at high risk of SCD in those participating in sports.

Other consensus statements and guidelines address the problem of SCD in young competitive athletes and PPS in older athletes, over the age of 40.<sup>25,28,29</sup> There are recommendations also on screening, staffing and emergency policies at gyms and fitness facilities.<sup>30</sup>

In 1996, the American Heart Association (AHA) published a consensus statement and recommendations for screening high school and college athletes for conditions that could lead to sudden death.<sup>28</sup> It concluded that history and physical examination were the 'best available and most practical approach'.

In December 2004 the IOC Medical Commission published their recommendations in regard to sudden cardiovascular death in sport. This is commonly known as the Lausanne Protocol.<sup>20</sup> This included a detailed questionnaire on personal history and symptoms, and on family history. The lack of specificity of the IOC questionnaire would likely result in a high rate of positive responses and is probably not applicable to large populations for screening purposes. It could potentially be used in small numbers of high performance athletes. The protocol also includes physical examination and a resting ECG. Depending on the results of the questionnaire, physical examination and ECG, some athletes would require additional evaluation. The IOC has stipulated that participation in future Olympic Games will require participants to pass this screening protocol.

A Study Group of the ESC has taken a more vigorous view.<sup>31</sup> In February 2005, it recommended that every young athlete (at the age of 12 to 14 years) involved in organised sport should have a rigorous physical examination, a detailed investigation of their personal and family medical history, and a 12-lead ECG, repeated every two years. It should be performed by a physician with specific training who could reliably identify clinical symptoms and signs associated with cardiovascular diseases responsible for exercise related sudden death. Apparently abnormal children should be referred for more extensive tests and if these confirmed suspicions, barred from competition and training.

The European Study Group relied heavily on the results of Italy's twenty-five year experience of PPS in reaching its conclusions.<sup>25</sup> An editorial on the European proposal noted that six million athletes (about 10% of the population) participating in organised sports are screened annually in Italy by history, physical examination and ECG.<sup>32</sup> It acknowledged that inclusion of the ECG at initial assessment stage would be 'expected to be fraught with the major limitation of many false positive test results and re-evaluations which would negatively impact available resources and increase the psychological burden on the athletes, families, coaches, and institutions'. It was considered that the European proposed screening was 'unlikely to be exported to the United States'.

As noted in Section 4.4.2 a review of the evidence on the evaluation of young athletes concluded that resources for physical examination should focus on those who have suggestive, even if minor, symptoms and those with a positive family history.<sup>22</sup> The high percentage of false positive ECGs when used for ongoing monitoring of highly trained athletes has called into question the value of routine ECGs in assessing large numbers of athletes (Section 4.4.3).

The methods used for pre-participation evaluation (PPE) in athletes under the age of 36, including student athletes, have been reviewed.<sup>33</sup> Most of the literature on the PPE consisted of type III evidence i.e. case-based opinion papers and position papers from respected authors, sports medicine societies and reports of expert committees. The review found that the format of the PPE is not standardised and does not consistently address the AHA

recommendations. The studies which looked at screening methods were divided on the effectiveness of history, physical examination, ECG and echocardiography for detecting risks for SCD in athletes. It was concluded that research on the effectiveness of the PPE is very limited and that in the United States PPE is not implemented adequately or uniformly.

Another review of published studies on high school and college PPS programmes in the USA concluded that the PPS for athletes did not satisfy the basic requirements for medical screening as described by the United States Preventive Services Task Force.<sup>34</sup> It also stated that 'While current research fails to demonstrate whether the PPE has an effect on the overall morbidity and mortality rates in athletes, other objectives may be fulfilled by these examinations. Furthermore, no harmful effects of these examinations have been reported. The practice of providing pre-participation medical screening for athletes is neither supported nor refuted by the current medical literature due to the inadequacies of research data available'.

#### 4.5.1 The Irish situation

Population screening programmes have not been developed in Ireland. Leisure activity such as walking, swimming or 'social' tennis do not require any pre-participation assessment. A public awareness and education programme to encourage physical activity advised a gradual increase in activity levels.<sup>35</sup> Light or moderate activity was advised for those who have been inactive for a long time. Anyone feeling any pain or discomfort was advised to rest and to seek advice from their doctor or exercise specialist. Those with a history of heart problems or other major illness were also advised to speak to their doctor before starting an exercise programme. Overall, the slogan was 'If in doubt, talk to your doctor'.

All the major sporting organisations undertake pre-participation assessment for their players. The extent of the screening varies. For example the Irish Rugby Football Union (IRFU) in addition to its questionnaire and physical examination and irrespective of family history and symptoms, require all its professional players and IRFU Academy players to undergo an ECG and an echocardiogram, on a once-off basis.

Elite athletes such as professionals and those who play at national, provincial or county level are usually under the supervision of a medical officer. This is not just for risk assessment but also to treat and prevent injuries and, working with team coaches and physiotherapists, to maximise fitness and performance. Such individual medical attention is likely to increase in the future, with amateur sports organisations adopting more of the methods of the professionals. It is appropriate that all those involved in moderate or vigorous intensity sports at national, provincial or county level should receive on-going medical attention, including risk assessment with physical examination, 12 lead ECG and further tests such as echocardiography if indicated. Expert opinion may be required for up to 40% of this group, to distinguish ECG changes as a result of 'athlete heart syndrome' from those due to cardiac disease.

There is no national policy on what should be advised for those involved at the middle levels in sports, between the recreational and the elite. Because the majority of sudden deaths in athletes do not occur in elite athletes but rather at school and sports club level, it was the opinion of the Task Force that to focus on high level competitive athletes under 35 years

only would not be adequate. It seems reasonable to advise that all those joining organised sports from the age of 14 onwards should complete a pre-participation questionnaire (Section 4.6), with medical assessment and physical examination in those with a positive questionnaire. Many sports clubs and gym facilities already administer a pre-participation questionnaire.

It is accepted that many, if not most, of the conditions that lead to SCD are often asymptomatic and have minimal or no physical abnormalities.<sup>19</sup> In the absence of cardiac symptoms or a positive family history, the sensitivity and specificity of ECG abnormalities in predicting SCD is poor. It is difficult to recommend it as part of PPS unless one or both of these risk factors (symptoms and / or family history) are present. The Task Force is of the opinion that current ESC or IOC guidelines have not dealt adequately with the issue of the large number of healthy athletes who have abnormal ECGs or echocardiograms which do not quite reach diagnostic criteria for cardiomyopathy or channelopathy. This will likely occur in at least 3% of subjects and may have major implications for employment, life insurance and mortgage applications for that individual.

The Task Force therefore recommends that a questionnaire be used to risk assess those who wish to participate in sports and exercise. This should not be limited to the under 35 year population but should be used in all those aged 14 years or older who wish to participate in organised sports or exercise, particularly those sports classified as being of a moderate or high dynamic intensity.

## 4.6 Use of a Questionnaire

### 4.6.1 Questionnaire design and administration

Family history of SCD in a first degree relative or symptoms suggestive of cardiac disease identify individuals with a much higher likelihood of having cardiac pathology than the general population. It must however be pointed out that some individuals have undetectable disease and will die suddenly and that others with no disease will develop SCD on the basis of viral myocarditis, *commotio cordis* or the use of illicit or prescription drugs. Given these deficiencies, risk assessment questionnaires appear to offer the best hope of identifying high risk individuals. This is in accordance with the views of the AHA / American College of Sports Medicine Scientific Statement on cardiovascular screening in health and fitness facilities, providing risk management while not acting as a disincentive to participation in exercise.<sup>30</sup>

As described in Section 4.4.1, a number of PPS questionnaires have been developed for those who wish to become involved in sport. The IOC questionnaire is longer than some others.<sup>30</sup> The purpose of a questionnaire in this context is to identify those who:

- have cardiac symptoms
- have a personal history of heart disease
- have a family history of premature sudden death of cardiac or unknown cause
- take prescribed or illicit drugs.

All four categories warrant some form of medical clearance because of their association with the substrate conditions for SCD.

The questionnaire should be designed so as to be easily understood and administered, with the questions as specific as possible to avoid large numbers of false positives. Positive responders to these questions should be assessed by a GP before participating in organised sports and exercise and if required, referred to a cardiologist.

While the Task Force accepts that the scientific basis for administering such a questionnaire is limited, it considers that the benefits to the population would outweigh the risks. Benefits include:

- increasing awareness of the importance of cardiac symptoms
- identifying a cardiac history
- identifying a family history of premature sudden cardiac death, and
- highlighting the dangers of taking performance enhancing or other illicit drugs when involved in sports.

A risk assessment questionnaire could be widely disseminated among a variety of organisations including schools, sports clubs gyms, and sports facilities. In addition, it could be used in poster form for educational purposes in the same settings.

#### **4.6.2 Consent**

The issue of consent was raised by many organisations during the consultation process. Organisations varied in obtaining written consent to risk assessment from participants. Complex legal issues have arisen in other countries, mainly in professional sport, when non-significant cardiac abnormalities are detected that prevent sports participation. Athletes and their families must be made aware that consenting to a PPS assessment may lead to findings which affect some types of mortgage, health insurance / life insurance applications and even careers.

### ▶ The Task Force recommends that:

- R 4.1: Those with a history of heart problems or other major illness are advised to speak to their doctor before starting an exercise programme. Otherwise leisure activities such as walking, swimming or tennis do not require any formal pre-participation assessment (See R 4.2). Anyone feeling any pain or discomfort during exercise is advised to seek advice about exercising safely from their doctor or exercise specialist.
- R 4.2: Those aged 14 years or older who engage in recreational activity without joining a club or organisation should be encouraged to self-administer a risk assessment questionnaire (see R 4.5) and to seek advice from the GP if the questionnaire is positive.
- R 4.3: Individuals aged 14 years or older who wish to join a sports club, gym or other sports facility but not involved in national, provincial or county level sports, should be offered a pre-participation questionnaire. Informed consent to risk assessment should be sought. Those with a positive questionnaire should be advised to contact their GP.
- R 4.4: Following assessment by the GP, those with family histories of SCD, cardiac symptoms or abnormal cardiac examination should be referred to a cardiologist for further assessment.
- R 4.5: A protocol for risk assessment should be agreed by the major sports and sports medicine organisations, and the Irish Cardiac Society and Irish College of General Practitioners under the aegis of the Irish Sports Council, for those who wish to join a sports club, gym or other sports facility but are not involved in national, provincial or county level sports. The protocol should include methods for obtaining informed consent, a model questionnaire and procedures for its administration and referral for medical assessment if indicated, as well as guidelines on physical examination and diagnostic tests, including referral to cardiac and specialist centres if required.
- R 4.6: A protocol for risk assessment should be agreed by the major sports and sports medicine organisations, and the Irish Cardiac Society and Irish College of General Practitioners under the aegis of the Irish Sports Council, for those involved in moderate or vigorous intensity sports at national, provincial or county level. (The protocol in R 4.5 should apply to those engaged in low intensity sports at this level.) The protocol should include methods for obtaining informed consent, a model questionnaire and procedures for its administration, and guidelines on physical examination for all athletes at this level and on further tests and referral to cardiac and specialist centres if required.
- R4.7: The Irish Sports Council should support the development and delivery of training courses for sports and medical personnel, including general practitioners, on the implementation of protocols for risk assessment of athletes.

## 4.7 Performance Enhancing Drugs

Concern about sudden deaths in sport has been complicated by the issue of performance enhancing drug abuse and its links with SCD. Research has shown a steady increase in usage at both competitive and non-competitive levels. Competitive athletes have been the greatest abusers of performance enhancing drugs with international pick up rates of 1 to 2% in most national drug programmes and rates of 20% reported anecdotally.

The most commonly abused performance enhancing drugs are anabolic steroids, stimulants, growth hormones, peptide hormones and masking agents. Anti-inflammatory agents are also regularly used in exercise to reduce symptoms of injury. The illicit drug classes banned by the IOC and updated yearly by the World Anti-Doping Agency are available on the website: [www.wada-ama.org](http://www.wada-ama.org)

Scientific evidence points to a potential cause and effect relationship between the abuse of performance enhancing drugs and SCD.

### 4.7.1 Anabolic steroids and their effects

Anabolic / androgenic steroids (AAS) continue to be the most frequently abused performance enhancing drug. In monitoring surveys in the US, 3.4% of high school 12th graders reported in 2004 that they had used AAS at some time in the past, 2.5% reported using at least once in the previous year and 1.6% in the 30 days before the survey.<sup>36</sup> At least one third of elite US powerlifters in the early 1990s reported use of AAS to enhance performance.<sup>37</sup> One in seven gay men surveyed in central London gyms admitted to using AAS in the previous year.<sup>38</sup> The cardiovascular risk of anabolic steroids is considerable. A number of case studies have linked anabolic steroid abuse with sudden death.<sup>39</sup> A 12 year follow up study in Finland of 62 male powerlifters suspected of AAS abuse found a mortality rate of 13% in the power lifters compared to 3% in the control group.<sup>40</sup> Three of the 8 deaths were attributed to AMI.

AAS can cause direct cardiac damage. Heart muscle hypertrophy, elevation in blood pressure and interference with the normal rhythm and conductivity of the heart have been reported.<sup>41,42,43</sup> Almost all illicit drugs may cause a wide range of cardiac arrhythmias, even in healthy subjects with no previous history of cardiac disease.<sup>44</sup>

Pre-participation risk assessment should include evaluation of the possibility of drug use. The discovery of an arrhythmia, especially in an individual with a structurally normal heart, mandates consideration of this also. The use of illicit drugs in the presence of undiagnosed underlying cardiac diseases, such as some of the inherited cardiomyopathies, may increase the risk of SCD.

There is also strong evidence to suggest a significant association between the abuse of performance enhancing drugs and street drugs, with 20% of anabolic steroid abusers also using street drugs, particularly cocaine. Cocaine misuse should be investigated when a young person presents with ischaemia or an AMI.<sup>45</sup> Internationally, several SCDs in professional athletes have been attributed to cocaine abuse.

The Task Force are aware that the sensitivities surrounding this issue are very complex, unpalatable and not easy to address. However given the international evidence, there is an obligation to address this issue in order to prevent further risk of SCD to young Irish men and women engaged in sports and exercise. A multisectoral approach is required between the various stakeholders including the Departments of Health and Children, and Education and Science, the leisure industry, sporting organisations etc.

#### 4.7.2 Anti-inflammatory (NSAIDs) and their effects

Anti-inflammatory medications (NSAID) are widely used by athletes to treat a variety of musculoskeletal disorders associated with sports injury. In early 2004 it became apparent that COX 2 NSAIDs increase the risk of thrombosis, with increased risk of AMI and of stroke.<sup>46</sup> A number of COX 2 selective NSAIDs have been withdrawn from the market. The high use of NSAIDs in older athletes with a history of CHD is a matter of considerable concern. These medications should be used with caution in this population and in those at increased risk of thrombotic events (prior blood clot / family history of hypercoagulable state).

#### The Task Force recommends that:

- R 4.8: Multisectoral strategies are required to achieve safe participation in sports and exercise. Education programmes should emphasise the dangers of using performance enhancing, recreational and other drugs.
- R 4.9: Pre-participation assessment should explore the use of performance enhancing and illicit drugs.
- R 4.10: If sudden cardiac death occurs in an athlete, risk assessment should be offered to training colleagues and team members.

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# chapter 5

## Reducing time to response

## 5.1 Introduction

Survival rates following cardiac arrest are directly related to time to resuscitation and in particular defibrillation. If defibrillated within 5 minutes, survival rates are approximately 50% and potentially higher with younger patients. If time to defibrillation is 10 minutes or more, virtually no one survives without cardiopulmonary resuscitation (CPR). This increases to 10 to 20% if CPR is used.<sup>1</sup> A speedy and effective response is required if the chances of survival are to be increased.

In the absence of an effective emergency response system, survival from cardiac arrest is less than 1%. Recent data confirms that when response systems are optimised, survival rates increase. Overall survival from cardiac arrest in a Belfast study was 7.2%.<sup>2</sup> Where the arrest was witnessed and the emergency medical services arrived within 7 minutes and the rhythm was VF, the survival rate rose to 41%.

In a Dublin study, the Mater Hospital Group found an overall survival to hospital discharge rate of 3.6% (13 out of 388 patients).<sup>3</sup> In AED equipped sites, 7 out of 13 (54%) patients whom resuscitation was attempted survived to discharge. By contrast only 6 out of 375 (1.6%) survived arrest where an AED was not available.

These data are compatible with data from the United States where survival rates of more than 30% have been documented among cardiac arrest victims in Seattle, Washington.<sup>4</sup> Taken together, the data supports the hypothesis that prompt defibrillation improves survival.

The ESC Task Force recommends a target time from call to defibrillation in out-of-hospital cardiac arrest of 5 minutes.<sup>5</sup> The probability of successful defibrillation may be improved through the provision of early basic life support (BLS).

This Task Force was asked to review and make recommendations on improving the emergency response in geographic areas and locations of greatest need, by maximizing access to BLS and AEDs. Technological advances in the design of AEDs have made them suitable for use, not just by healthcare professionals, but also by suitably trained lay responders.<sup>6,7,8,9</sup>

The Task Force was also asked to identify priority individuals and groups suitable for training in BLS and the use of an AED in order to augment the statutory emergency medical services (EMS). Work has already been done towards establishing first responder programmes in Ireland. For these programmes to be effective they must be co-ordinated and integrated with the existing EMS, thus establishing a 'chain of survival'. In rural areas, the dispersed population, nature of the terrain and availability of resources lead to longer ambulance response times.<sup>10</sup> A national strategy should be implemented so that such areas where the EMS are unable to meet target response times are prioritised for first responder programmes.

In this chapter, the Task Force discusses and outlines its recommendations relating to developing and strengthening the 'chain of survival', developing a coordinated first responder programme, increasing access to and setting standards for resuscitation training,

ensuring optimal placement and safe operation of AEDs, clarifying legal indemnity issues and implementing robust data collection to facilitate audit and continuous improvement.

## 5.2 The Chain of Survival

The chances of survival following cardiac arrest are considerably improved if there is a rapid, coordinated response to the emergency. The Task Force supports the concept of the 'chain of survival', with each component of the chain being only as strong as its supporting link.<sup>11</sup>

The components in the 'chain of survival' are:

- early access to emergency medical services (EMS)
- early cardiopulmonary resuscitation (CPR)
- early defibrillation, and
- early advanced cardiac life support (ACLS).

## 5.3 Early Access to Emergency Medical Services (EMS)

### 5.3.1 Accessing emergency services

There is considerable lack of awareness in the community as to the appropriate action to be taken in the event of a collapse. The Task Force recommends that the ambulance service should be the first to be contacted. In Ireland the contact number is 999 or 112.



In line with the Council of Europe recommendation, the emergency telephone number throughout Europe is to be 112. However, many countries have not yet implemented this recommendation.<sup>12</sup>

Many people still ring the GP or local hospital in the first instance. In some areas, discrepancies in protocol also extend to health care professionals i.e. contacting the local ambulance station directly, rather than contacting the emergency number.

Figure 8.  
Ambulance Centres

HSE Ambulance Services



Dublin Fire Brigade  
Communications Centre & Fire Stations



Once an emergency call is received at an emergency call centre, the relevant services are immediately contacted and dispatched e.g. Ambulance, Garda Síochána, Fire Brigade, Mountain Rescue, Cliff and Coastal Rescue, Lifeboat, etc. In the case of a medical emergency the call is transferred to one of 14 ambulance control centres. The *Ambulance Service Communications Review* made recommendations about necessary changes to the number of communication centres, their regional operation and compatibility of technology and decision support systems.<sup>13</sup> The Task Force supports these recommendations. The Task Force has considered other means of improving the public reaction to an emergency and makes the following recommendations.

### ▶ The Task Force recommends that:

- R 5.1: The Task Force welcomes the establishment of the Health Service Executive National Ambulance Service and recommends that it should lead a national education programme on contacting the EMS.
- R 5.2: Signage on all emergency vehicles should include “*In an emergency phone 999 or 112*” analogous to the Garda Síochána confidential telephone number on Garda Síochána vehicles.
- R 5.3: Regardless of their purpose, all ambulances should carry an AED. The drivers of all such vehicles should be trained in BLS and AED use.
- R 5.4: The recommendations in the *Ambulance Service Communications Review, 2005*, concerning the function and role of communication centres should be implemented expeditiously.

#### 5.3.2 Pre-arrival advice and early interventions

Once connected to the emergency service, immediate assistance can be given by way of telephone advice.

**Sudden death** – although less effective than BLS provided by a trained rescuer, telephone-assisted CPR has been shown to improve survival from cardiac arrest. There are substantial disparities across the country in the delivery of pre-arrival advice and telephone-assisted CPR.<sup>13</sup> A national standard is required for the delivery of this advice by the EMS.

**Chest pain** – patients with chest pain of cardiac origin may be suffering an acute coronary syndrome (ACS), for example a heart attack. The early administration of aspirin to such patients has been shown to save lives. There is evidence that aspirin is not being administered to a substantial proportion of those who may benefit in the pre-hospital setting.<sup>15</sup> Emergency telephone information about chest pain should advise the administration of aspirin if ACS is thought to be the cause of the chest pain.

### ▶ The Task Force recommends that:

- R 5.5: All providers of pre-hospital emergency care who are contacted by the public should provide pre-arrival advice including telephone-assisted CPR according to a national standard.
- R 5.6: The early administration of aspirin should be encouraged if chest pain, not collapse, is the problem and ACS is thought to be the cause.

## 5.4 Early Cardiopulmonary Resuscitation (CPR)

### 5.4.1 The role of CPR

The second link in the chain of survival is the provision of early CPR. Cardiopulmonary resuscitation is a manual technique that combines external chest compressions and assisted ventilation to provide some oxygen to the vital organs, in particular the brain. Although the provision of CPR alone is not effective in restoring spontaneous circulation, a number of trials has shown that early CPR has improved the probability of successful defibrillation.<sup>11</sup> Unfortunately, bystander CPR is only used in a minority of cases. Increasing the numbers of people trained in CPR was recommended in the *Cardiovascular Health Strategy*.

### 5.4.2 Training courses and standards

The Irish Heart Foundation (IHF) is the franchise holder for American Heart Association (AHA) training and trainer courses in Ireland (Table 4).<sup>16</sup> The majority of statutory and voluntary bodies in Ireland have aligned themselves to this standard. These standards are compatible with the Basic Life Support Working Group of the International Liaison Committee on Resuscitation (ILCOR). Other international organisations also provide training courses which differ from the AHA in minor ways.

**Table 4.**  
**AHA accredited BLS and ACLS courses in Ireland**

Courses for General Public	Courses for Health Care Providers	Instructor Courses
CPR for Family and Friends	BLS Healthcare Provider	BLS Instructor
'Heartsaver' CPR	ACLS Provider	BLS Instructor Trainer
'Heartsaver' AED	ACLS Experienced Provider	ACLS Instructor
	PALS Provider	ACLS Experienced Provider Instructor
		Paediatric Advanced Life Support Instructor

Statutory, voluntary and private organisations are the providers of first aid and first responder training courses of varying duration and content. Given limited resources, a strategy to maximise the benefits of this training is necessary. The Task Force are of the opinion that statutory agencies should prioritise training their own personnel. The role of the voluntary organisations in the community should be supported and enhanced.

In Ireland, apart from the standard for occupational first aid laid down by the Health and Safety Authority (HSA), there are no national standards for first aid training and first aid trainers. PHECC has developed a comprehensive draft national standard which encompasses the provision of BLS and AED training.<sup>17</sup> If adopted it will facilitate access to accreditation by training providers. All statutory, voluntary and private training providers should be required

to conform to this standard. The more individuals who can be trained, the greater the potential to reduce the incidence of pre-hospital cardiac deaths, to educate the public about the warning symptoms of acute heart disease, the importance of quick responses and the dissemination of health promotion messages.

Responsibility for accreditation and monitoring of all BLS/AED training and the maintenance of training records should be assigned to PHECC.

### 5.4.3 Priority groups for training

Training in BLS needs to be of a high standard and readily accessible. Other than the EMS, the following are priority groups for BLS training:

#### 1. Health care professionals

The appointment of additional resuscitation training officers (RTOs), who in the main provide BLS training to health care professionals in the hospital setting, was a welcome development arising out of the *Cardiovascular Health Strategy*. However not all acute hospitals in the country have appointed such staff. Additional RTOs, hospital and community, should be appointed to ensure that all health care professionals receive ongoing BLS training. Access to similar training should also be provided for GPs.

#### 2. Family members

Cardiac rehabilitation coordinators are ideally placed to provide BLS training to family members of those who have suffered a non-fatal cardiac event.

#### 3. Occupational first aid

Current training for occupational first aid which includes BLS training should be extended to include AED training.

#### 4. First responder programmes

Priority for training should be given to those programmes which are linked with the EMS, particularly uniformed responders as discussed in a later section.

#### 5. Young persons

- primary schools – BLS training, focussing on the first two links in the chain of survival should be provided as part of the core curriculum in all national schools.
- secondary schools – BLS and AED training should be included in the school curriculum.

Additional strategies are required to increase BLS skills in the population. For example, during the consultation process it was proposed that BLS training should be a requirement for obtaining or renewing a driving licence.

## The Task Force recommends that:

- R 5.7: The respective roles of the statutory and voluntary organisations in BLS / AED training should be agreed and operationalised to maximise benefit to the public.
- R 5.8: Irish standards for BLS and AED courses and trainers should be published by PHECC. Statutory, voluntary and private training providers should be accredited according to these standards.
- R 5.9: The following training initiatives should be prioritised:
- BLS / AED training is essential for all health care professionals
  - BLS / AED training for family members of those who have suffered a non-fatal cardiac event or are at high risk of SCD
  - AED training should be a requirement for occupational first aid certification
  - first responders linked to the EMS
  - BLS / AED training should be included in the curriculum for primary and secondary schools.
- R 5.10: Responsibility for accreditation and monitoring of all BLS / AED training and the maintenance of training records should be assigned to PHECC.

## 5.5 Early Defibrillation

### 5.5.1 Recommended times to defibrillation

In the majority of cases, SCD occurs due to the sudden disturbance of the heart's electrical conduction system, resulting in a chaotic heart rhythm, called ventricular fibrillation (VF). If VF is not treated, death ensues within minutes. The treatment for VF is the delivery of an electric shock to stabilise the heart's rhythm. This is known as defibrillation.

As discussed earlier, the chances of successful defibrillation decrease with each minute that passes. It is now generally accepted that the time to defibrillation is the single most important determinant of survival after cardiac arrest. The ESC Task Force recommended that out-of-hospital defibrillation should be delivered within 5 minutes of receipt of the EMS call. In the hospital setting shock delivery should be within 3 minutes of collapse. The Task Force is of the opinion that the challenges in meeting the ESC targets should be identified and addressed, recognising that it will take some years to achieve them.

While all statutory emergency ambulances are now equipped with defibrillators, there is a need for more defibrillators strategically placed throughout the community to enhance coverage and to meet recommended response times. Early defibrillation can be achieved through the delivery of well structured and coordinated first responder programmes.

**▶ The Task Force recommends that:**

R 5.11: Access to defibrillation should be optimised to meet European recommendations. The challenges in meeting the ESC targets should be identified and addressed, recognising that it will take some years to achieve them.

**5.5.2 Developing a national early defibrillation strategy**

Rural communities are disadvantaged in accessing the links in the 'chain of survival'.<sup>19</sup> Spatial analysis has identified geographic locations most at risk.<sup>20</sup> The regions in Ireland which are disadvantaged include the North Western, Western and South Western seaboard, the peninsulas and their inhabited islands. The study highlights areas in the country that would benefit from well resourced and managed complementary emergency responses, such as first responder programmes.

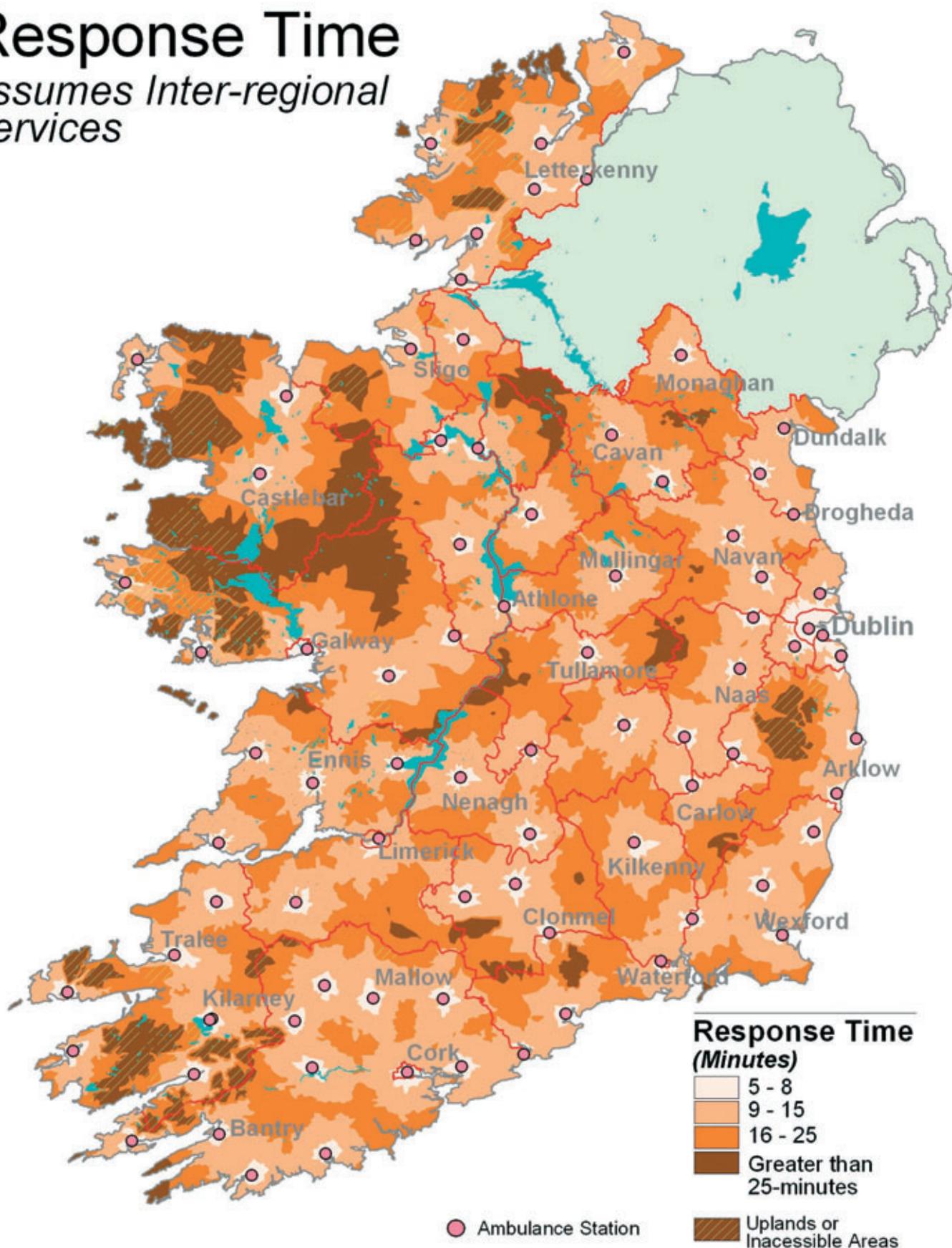
Further consideration should be given to the role of voluntary organisations and the use of their ambulances. Developing closer integration between the statutory and voluntary sectors would improve emergency response coverage.

**▶ The Task Force recommends that:**

R 5.12: Closer integration should be encouraged between the statutory and the voluntary ambulance services.

# Response Time

*Assumes Inter-regional Services*



### 5.5.3 First responder programmes

For the purpose of this report a 'first responder' is:

*'A person trained as a minimum in BLS and the use of an AED, who attends a potentially life threatening emergency. This response may be by the statutory ambulance service or complementary to it. If complementary, first responders can be linked with the statutory emergency services or they can be independent and stand alone. In any single event the first responder may be an individual who happens to be present or part of a first responder programme. Trained first responders may or may not participate in a first responder programme'.*

In the context of this report, first responder programmes are characterised by:

- trained and equipped first responders
- structured response systems based on the planned availability of first responders
- effective alerting systems, and
- defined areas of coverage.

The ESC recommends that programmes for early defibrillation should be tailored to specific environments and that it is essential to achieve a compromise between the widespread distribution of AEDs and the economic feasibility of the programme in terms of available resources.<sup>21</sup> The ESC suggests three main programme strategies outside of the EMS:

- community programmes
- in hospital and on-site programmes, and
- home programmes.

Published literature suggests that rapidly deployable 'uniformed' first responder schemes are more effective than lay community member first responder schemes and public access defibrillation schemes.<sup>8</sup> During the consultation process the Task Force was advised that with regard to lay community member models it can be difficult to sustain and retain motivation on an ongoing basis.

The UK launched its National Defibrillator Programme in July 1999 to install AEDs in busy public places such as railway stations, underground stations, airports, coach stations and ferry ports, and to train people employed at the site of their use in basic life support. The overall aim of the programme is to increase the proportion of people who survive an arrest to one in five. Since February 2000, nearly 700 AEDs have been placed at 110 locations across England and Wales and more than 6,000 volunteers have been trained in BLS and AED use. In 2005 an audit was undertaken of the first 250 deployments, of which 182 were for confirmed cardiac arrest. Of these, 177 were witnessed, whilst 5 occurred in situations that were remote or initially inaccessible to the responders. Of the 177 witnessed cases, 44 (25%) are known to have survived to hospital discharge.<sup>22</sup> Most of the witnessed arrests occurred where the density of AEDs was greatest – in airports (101 cases) and railway stations (58 cases). The estimated time from collapse to start of resuscitation, whether by CPR or the application of an AED, was a mean of 3.3 minutes for 112 cases in which information was available. Further information on the programme can be obtained from [www.dh.gov.uk](http://www.dh.gov.uk)

#### 5.5.4 Proposed programmes for first responders in Ireland

In an Irish context the Task Force has identified seven models of first responder programmes (Table 5).

**Table 5.**  
**First Responder Programmes**

First Responder Programmes	
• EMS	• Site specific
• GP	• Public access defibrillation (PAD)
• Uniformed (on and off-duty)	• Individual / home
• Community	

- **EMS** – In Ireland, emergency ambulance services are provided by the HSE and Dublin Fire Brigade.
- **GP first responders** – A GP first responder programme is one whereby GP practices are equipped and trained to use an AED to respond to an acute cardiac event. In rural Ireland in particular, GPs are often the first to arrive at the scene of an acute cardiac event. The UK Resuscitation Council advises that all members of the Primary Health Care Team should be equipped and trained to an appropriate level for their expected role to resuscitate patients who suffer cardiac arrest in the community. The minimum standard should be proficiency in BLS and the majority of the team should be trained to use an AED. To ensure an effective response, such a programme should be linked to the EMS.
- **Uniformed first responders** – There are two types of uniformed programmes, for 'on-duty' and 'off-duty' personnel.
  - **On-duty** – these include the gardaí, fire brigade (full-time, part-time and retained personnel) and other emergency personnel acting as first responders during the course of their work. Examples of this type of programme include:
    - Dublin Fire Brigade provides a first response service and an ambulance service
    - Dublin Airport Fire Brigade provides first response supported by the HSE Ambulance Service.
    - Some retained fire services currently provide a first response supported by the HSE Ambulance Services. *For example in Co. Sligo all the first line fire trucks in the county have been fitted with an AED and 95% of fire fighters are now trained in BLS and the use of AEDs.*
    - The Emergency Response Team was the only Garda unit with any team members trained in AED use. *A pilot project with the Garda Síochána has recently been initiated in Co. Kilkenny and in Blanchardstown, Dublin, which involves training of all Gardaí in BLS and AED, instructor training, placement of AEDs in Garda vehicles and strategic locations, and linking of Gardaí with the EMS.*
  - **Off-duty** – off-duty health professionals, including Emergency Medical Technicians (EMTs) and members of voluntary and auxiliary organisations who are used to responding to emergencies, are an ideal group to organise on a voluntary basis as first responders linked to the EMS.

- **Community first responders** – A community first responder programme can stand alone or be linked with the EMS. In either of the community models it is suggested that recruitment of ‘uniformed’ first responders i.e. members of the community who are used to responding to emergencies in their working environment, should be a priority.
- **Linked** – in a linked model, the ambulance service on receiving the 999 or 112 call, in addition to the usual ambulance / EMS personnel, simultaneously dispatches a rostered on-call community-based first responder. The ambulance service has developed comprehensive guidelines to support linked models.
- **Stand alone** – a stand alone model would consist of defibrillators that are easily accessed by trained people in the community. In an event, after contacting 999 or 112, the local response would be according to locally agreed protocols. This may involve setting up an on-call rota, carrying a mobile phone / pager, designated contact points, etc.
- **Site specific** – this is similar to a community programme but is site specific, in a defined area / facility e.g. workplace, sports club, airport, shopping centre, etc. The first responders could be uniformed or non-uniformed but models using uniformed people have been shown to be effective, e.g. cabin attendants in aircrafts, security personnel in shopping centres and sports grounds.<sup>6,23,24</sup> Priority locations are identified later in this chapter.
- **Public access defibrillation (PAD)** – AEDs accessible for use by members of the public. Internationally there are very few true public access defibrillator programmes, and those that are in place are mainly in the USA. The majority of so called ‘public access’ defibrillation programmes involve training identified personnel and are usually site specific. Whilst not recommending PAD as a priority, the Task Force recognises that there may be certain venues or locations where it may be of benefit.
- **Individual / home** – support should be available to all individuals at high risk if they wish to establish a home programme.<sup>25</sup>

### 5.5.5 Priority first responder programmes

In recent years there has been a substantial increase in awareness and demand for community / public access defibrillation. This has been introduced sporadically and in an uncoordinated fashion across the country.<sup>26</sup>

When planning the development of programmes and allocating resources it is essential that a structured and coordinated approach using the most appropriate of the above programmes is initiated. It is evident from the consultation process that there is considerable enthusiasm across all sectors - health professionals, voluntary organisations and communities - to be involved in such a national approach.

The Task Force proposes the following phased strategic development of first responder programmes in Ireland (Box 1).

#### Box 1.

##### Priority First Responder Programmes

Priority 1 – EMS, health services personnel, GPs and associated personnel
Priority 2 – all uniformed 'on duty' first responders Fire Brigade, Gardaí, Coast Guard, etc., integrated as appropriate into the EMS response
Priority 3 – site specific programmes
Priority 4 – information and advice for communities and family members

Local implementation of these programmes will require the appointment of a designated Community First Responder Coordinator in each ambulance service area, with a standard job specification.

There is an urgent need to provide evidence-based information to the public concerning the establishment of programmes in the community, particularly for those communities or organisations who do not wish to be integrated into regional programmes. Information should be available for distribution at local level to inform and guide communities, local councils, site specific groups, etc. One such guide has been developed in the HSE Southern Area (Cork and Kerry) in partnership with PHECC (Appendix 8).

### 5.5.6 Follow up after an event

Responding to an emergency may be stressful for all concerned. This is particularly so if the person dies. It is essential that support is available for the first responders involved. During the consultation process the issue of whose responsibility it is to provide this type of service was raised, as currently the main support is provided by the BLS trainers and / or the EMS. Occasionally this support may involve access to formal services such as counselling.

### The Task Force recommends that:

- R 5.13: In establishing first responder programmes, priority should be given to programmes, geographic locations and facilities identified as having the greatest need. All such programmes should be coordinated by the HSE ambulance service, with best practice guidance from PHECC.
- R 5.14: First responder programmes must include standardised quality assurance / quality improvement structures (see Section 5.6.8).
- R 5.15: All AEDs and trained personnel available to voluntary aid organisations should be integrated immediately within first responder programmes associated with the statutory ambulance services.
- R 5.16: First responder programmes outside the voluntary aid organisations should be integrated where appropriate with the statutory ambulance service.
- R 5.17: Community first responder coordinators should be appointed in each ambulance service region to coordinate all programmes. A standard job specification should be agreed for such posts.
- R 5.18: All community-based health personnel, particularly health professionals, should be trained to manage a cardiac emergency. All community health facilities, including general practice premises, should be equipped to deal with such an emergency. This includes the provision and maintenance of an AED.
- R 5.19: A tiered response system should prioritise the training and equipping of rapidly deployable 'uniformed responders' such as:
- full time fire services in urban communities
  - retained fire services in rural communities
  - the evaluation of the pilot programme of Garda patrol car AEDs should be concluded prior to such programmes being implemented nationally
  - auxiliary and voluntary providers
  - security personnel at large shopping centres / sports grounds / public amenities, and
  - local first responder programmes should facilitate participation by off-duty trained health services and uniformed personnel.
- R 5.20: All priority facilities should be encouraged to provide first responder programmes and consideration should be given to requiring this on a statutory basis.
- R 5.21: Management of other site specific locations should be advised of the potential benefits of implementing programmes e.g. leisure centres, sports clubs (GAA, golf courses, etc).
- R 5.22: A template should be developed urgently for the provision of local information and advice to communities, councils, organisations, etc. who wish to establish first responder programmes in their area.
- R 5.23: Appropriate support should be available for responders to receive 'critical incident stress debriefing' following a resuscitation attempt.
- R 5.24: The HSE ambulance service should be required to establish structural links to first responder programmes.

## 5.6 Automated External Defibrillators (AEDs)

An automated (more correctly 'advisory') external defibrillator (AED) is a small, portable piece of equipment that can deliver an electric shock in order to convert VF of the heart into its normal or usual rhythm. The AED contains computer software which analyses a cardiac rhythm and will not deliver a shock if the heart does not require it.

The Medical Devices Division (MDD) of the Irish Medicines Board (IMB) provided advice to the Task Force in relation to AEDs, including their selection, placement, storage and maintenance, traceability of devices, adverse event reporting, legal indemnity and governance.

### 5.6.1 Selection and technology assessment

There are many models of AEDs available. They are relatively inexpensive but the ongoing costs of consumables need to be taken into consideration when purchasing a model.

It is essential that any device purchased carries a recognised and applicable CE mark. In considering its specification, an AED must be reliable, low weight, require little maintenance, have a long battery life, a lengthy warranty and most importantly should be easy to use. A model with recording facilities is beneficial in facilitating evaluation and audit.

The IMB has advised that there should be a technology assessment of devices both currently in place and those proposed to ensure the most appropriate device is in place for the specific setting. The assessment should review device performance and optimal location of the device in terms of accessibility and security. It is particularly important that the model chosen for use in any programme or by any individual is compatible with the local ambulance service model.

### 5.6.2 Placement of AEDs

The number of AEDs is increasing exponentially in Ireland. There are no restrictions on who can purchase an AED or where they may be placed.

There is good evidence that some locations are more appropriate than others. Published literature has identified facility types at which the incidence of cardiac arrest is highest.<sup>27,28,29,30</sup>

Priority locations include:

- inpatient health facilities
- GP surgeries and primary care facilities
- airports, shopping centres, major sports venues and golf courses, bus / rail terminals, ferries / ferry terminals, concert and conference venues
- universities and colleges
- gyms and fitness clubs, and
- other venues for major public events.

Geographic locations distant from emergency medical services are also a priority. People who have suffered from heart disease and are identified as being at high risk may be advised to purchase an AED for their home.

The number of AEDs required to cover any given area or site is determined so as to optimise 'collapse to use' response time.

### 5.6.3 Storage and maintenance of AEDs

AEDs and related devices should be stored in conditions that comply with the manufacturer's recommendations. Devices should be stored securely in order to prevent misuse or theft. Whilst requiring easy access, it is recommended that an AED in a public place should be stored in a purpose built cabinet that incorporates an alarm which is activated when opened to remove the defibrillator. In some sites, this alarm system could also be connected to the EMS services. A designated person should oversee these arrangements and be responsible at a local level for choosing the most appropriate storage point and ensuring appropriate storage conditions for the AED.

National signage for defibrillators should be agreed and used in all locations.

Maintenance is critical to ensure that medical devices operate safely and perform effectively in all settings. AEDs need to be regularly maintained and serviced in a method approved by the manufacturer. Most models have a 5 to 7 year warranty with a maintenance contract available after that period of time. The manufacturer should provide advice in the instruction manual on maintenance requirements for the model of AED.

It is essential that maintenance protocols are in place, that maintenance schedules are observed and recorded, regular checks and refurbishment of consumables are performed, and clear roles and lines of responsibility are identified. A designated person in each location should ensure that these objectives are achieved.

In order to meet the requirements of the State Claims Agency's Clinical Indemnity Scheme (CIS), there must be a properly structured record on the upkeep and maintenance of AEDs involved in first responder programmes (see Section 5.6.7 and 5.6.8).

### 5.6.4 Traceability of devices

It is critical that AEDs distributed to a wide variety of settings are readily traceable. While the distributor of the device may keep a record of where they have supplied the device, they are not legally obliged to do so under medical devices legislation. At present only manufacturers have a legal responsibility. The IMB has responsibility for post-market surveillance of medical devices.

For traceability purposes, a national database of devices should be established. Responsibility for the establishment and maintenance of a devices / customer register should be clarified. Existing AED owners and users should be encouraged to register with the national database.

### 5.6.5 Information collection and audit

It is important to establish a standardised system to record responses to sudden cardiac events, including occasions when an AED is used. It is especially important to know if the collapse was witnessed, what time it occurred, when help arrived, when CPR commenced, when defibrillation was attempted and how many times. Many AEDs now come with a software package which records data that can be downloaded after an event.

All cardiac arrests should be reported whether they happen in a hospital or community setting. Cases to be included in such a register should be agreed at national level. The establishment of a national cardiac arrest register is considered in Chapter 6.

As part of the National Defibrillator Programme in the UK, a universal report form was designed for use by lay-responders using an AED.<sup>31</sup> The UK Resuscitation Council coordinates the collection of all reports on resuscitation attempts initiated by a lay person using an AED. It also established a national computerised database to analyse the data returned. The forms are distributed through the Resuscitation Council, the British Heart Foundation and the distributors of AEDs. The distributors inform all new customers about the database and include copies of the report form with each AED sold. Copies of the forms are also included with each set of defibrillator electrode pads.

A template for first responder use, to collect appropriate data on cardiac arrest, has been prepared by PHECC.<sup>32</sup> Those involved in first responder programmes should record this information as an integral part of each programme's procedures.

### 5.6.6 Adverse event reporting

A reporting system is required for events in which medical devices malfunction or do not perform effectively, resulting in actual or potential injury or harm to patient, user or bystander. The IMB informed the Task Force that the Food and Drug Administration (FDA) received over 5,000 reports of adverse events relating to the use of AEDs in the US in 2003. The IMB is aware of several such incidents involving AEDs in Ireland.

The information collected on each occasion when the device is deployed should include device data and any adverse events. It is critical that any incident in which the device malfunctions, does not perform as expected or has the potential to, or actually causes harm to patient, user or bystander should be immediately reported to the manufacturer and to the IMB. Data collection, surveillance and audit are discussed in more detail in Chapter 6.

### 5.6.7 Legal indemnity

One of the main stumbling blocks to many organisations or communities progressing with their purchase of AEDs and developing subsequent programmes has been concern over the legal indemnity of their use.

Ireland has no 'Good Samaritan' law to protect members of the public who go to the aid of another person. Similarly there is no general legal requirement or obligation for a lay person

to go to the aid of another. Although credible legal opinion has advised that the likelihood of successful litigation arising from a 'Good Samaritan' act is remote,<sup>33</sup> the Task Force recommends that the legal situation should be reviewed to protect rescuers from any possible litigation.

For those employed in pre-hospital services, the two principal areas of liability are trespass to the person and negligence. Both are torts – civil wrongs committed by one person against another. Legal opinion was sought by PHECC, which advised that *'should a pre-hospital emergency care provider act in accordance wholly with their training status and not act in a grossly negligent fashion, then it is unlikely that any litigious claim would be successful.'*<sup>33</sup> This conclusion is in keeping with the position of the Resuscitation Council in the UK.<sup>34</sup>

The CIS has agreed that members of the public / volunteer first responders participating in a *'formalised scheme, who have been trained in the use of AEDs and CPR in a formal, structured way and post-training remain under the supervision and control of the HSE Ambulance Service, or other appropriately qualified personnel will be indemnified'*.<sup>35</sup> This indemnity does not apply however to members of the public or uniformed responders who receive CPR training outside such formal structures.

The CIS also indemnifies health professionals employed by the HSE who provide pre-hospital emergency care when off duty. General Practitioners are advised to ensure cover under their own indemnity arrangements.

Other insurance aspects e.g. employer liability and public liability are operational issues for consideration by the HSE Ambulance Service.

### 5.6.8 Governance

National and regional governance structures, including designated responsibilities are necessary to ensure the safe and effective use of AEDs. Quality assurance and quality improvement structures should include responsibility and accountability for device placement, regular checks and maintenance, device documentation, training, first responder groups, incident recording and audit. The HSE should ensure that these structures are established for each type of first responder programme. Clear governance structures are also essential at a local level where an AED is housed.

PHECC (in consultation with HIQA when established) should develop and implement a national programme of audit of emergency cardiac response. This should include regular regional audit meetings of personnel and organisations involved in each type of first responder programme. These meetings should include a review of each event.

## The Task Force recommends that:

- R 5.25: A technology assessment should be conducted of devices currently in place and those proposed, to ensure the most appropriate device is in place for the specific setting.
- R 5.26 AEDs should be placed in facilities where the incidence of cardiac arrest is highest, including:
- inpatient health facilities
  - GP surgeries and primary care facilities
  - airports, shopping centres, major sports venues and golf courses, bus / rail terminals, ferries / ferry terminals, concert and conference venues
  - universities and colleges
  - gyms and fitness clubs, and
  - other venues for major public events.
- R 5.27: National signage for AEDs should be agreed and used in all locations.
- R 5.28: Individuals and organisations who purchase an AED should be informed by the vendor about procedures to ensure that the AED is maintained in a state of operational readiness.
- R 5.29: A designated person in each location where an AED is housed should ensure that clear roles and lines of responsibility are identified, maintenance schedules are observed and recorded, and regular checks / refurbishment of consumables are performed.
- R 5.30: Responsibility for the establishment and maintenance of a devices / customer register should be assigned to the IMB. This should include a system for recording adverse events associated with the use of AEDs.
- R 5.31: Vendors should notify the sale of each AED to a national register. Manufacturers and vendors must notify the IMB in the event of a product recall or requirement to provide technical information to AED owners.
- R 5.32: An AED purchaser should be required to provide the following information at the time of purchase:
- a registration form with all contact details for submission to a central register
  - a training form stating that the purchaser understands the responsibility that owning an AED brings and a recommendation that they complete a BLS / AED training course, and
  - a community response form notifying their local EMS station that they have an AED and specifying whether they wish to become part of an integrated community response programme, have a limited role in such a response programme or have no role in such a programme.
- R 5.33: The standardised form developed by PHECC should be used to report sudden cardiac events, including data on AED use. Those involved in first responder programmes should record this information as an integral part of each programme's procedures.
- R 5.34: The legal situation should be reviewed to protect first responders from litigation. The HSE should review other aspects of insurance requirements for first responders.
- R 5.35: PHECC, in consultation with HIQA, should develop and implement a national programme of audit of emergency cardiac response.

## 5.7 Early Advanced Cardiac Life Support (ACLS) and Reperfusion

ACLS is outside the Task Force's terms of reference. However, it is the critical last link in the 'chain of survival'. In addition to BLS and ACLS, reperfusion therapies are important immediate treatment for patients with heart attack. Therefore, the Task Force considered that it was important to address ACLS and reperfusion therapies and to make recommendations in relation to them.

### 5.7.1 ACLS

The 'chain of survival' concept provides an effective framework for dealing with VF and emphasises the role of early defibrillation. Some patients with cardiac arrest require further medical support in addition to BLS. ACLS includes:

- ECG monitoring and arrhythmia recognition and treatment
- establishment and maintenance of intravenous access, and
- emergency treatment of patients with cardiac and respiratory arrest.

In Ireland ACLS training is usually provided for hospital-based personnel. Such training should be readily accessible to health professionals as appropriate, including those who work in a community setting.

### 5.7.2 Reperfusion therapies

Reperfusion therapies are interventions developed within the last two decades which have the potential to re-open obstructed coronary arteries; they include drug therapies (thrombolysis) and balloon catheters (percutaneous coronary intervention [PCI]). Those heart attacks which are likely to respond to one of the currently available reperfusion therapies are known as ST elevation myocardial infarctions (STEMIs). There is evidence that reperfusion therapies reduce the risk of VF and death, and improve cardiac function after the event.

Thrombolysis is the administration of a 'clot-dissolving' drug to break down a clot, restore the patency of the coronary artery and allow arterial blood flow to resume to the myocardium (heart muscle).

The benefits of thrombolysis are critically dependent on time – the best results are achieved when the drug is administered within two hours after the onset of the heart attack. A 1994 overview of published studies of thrombolysis showed that on average, at one month, thrombolysis had saved 18 lives per 1,000 people treated.<sup>36</sup> A 1996 study showed that when thrombolytic treatment is initiated within 30 to 60 minutes of symptom onset, 60 to 80 additional patients per 1,000 will be alive at one month compared with those not given thrombolysis.<sup>37</sup> If the treatment is initiated within one to three hours, 30 to 50 additional patients per 1000 will be alive at one month. As the hours pass, the benefit falls significantly, so that by 12 hours after onset of symptoms there is limited benefit to giving a thrombolytic drug.

Other reperfusion strategies are also effective in restoring patency to a blocked coronary artery. These usually involve inserting a balloon catheter directly into the blocked artery and then inflating it to clear the obstruction. When used for the treatment of STEMI this

technique is known as primary PCI. The benefits of early PCI are becoming increasingly clear and when it can be delivered within 90 minutes of symptom onset, it is the treatment of choice. However, when thrombolysis can be delivered early (within a maximum of three hours) its benefits and side effects are equivalent to those of early PCI, but without many of the complexities of providing a PCI service. Approximately one quarter of patients who receive early thrombolysis would also benefit from or require PCI within 24 hours.<sup>38</sup>

### 5.7.3 Targets for the delivery of care

While early PCI might be the ideal intervention, the provision of cardiac catheterisation laboratories on the basis of round-the-clock availability for treatment of most patients within 90 minutes of the onset of heart attack symptoms is very challenging.

In Ireland at present, the key issue in initiating reperfusion therapy or indeed any effective cardiac care is patient delay. Doyle et al<sup>39</sup> have shown median delays of four to five hours in Irish patients with heart attacks arriving to hospital. Disappointingly, these figures have shown little change between 1994 and 2003.

Within three hours of symptom onset, the benefits of thrombolysis are equivalent to those of PCI. A small number of patients will be suitable only for PCI and a proportion of those receiving early thrombolysis will require 'rescue' PCI within 12-24 hours. In most parts of the country, early thrombolysis should continue to be the first priority in the provision of reperfusion therapies.

Thrombolysis may be delivered in the hospital or pre-hospital settings but the norm in Ireland at present is for hospital treatment. Doyle et al's survey of CCUs in 2003 demonstrated that 44% of confirmed acute myocardial infarction (AMIs) received thrombolysis; only 29% of patients received thrombolysis within 90 minutes of calling for professional help. The timely provision of reperfusion therapies to patients in Ireland requires innovation.

When patients with suspected AMI contact the health services, the following response time targets should apply:

- access to a defibrillator within ten minutes
- be offered aspirin within 20 minutes (if appropriate)
- have a completed assessment of suitability for reperfusion therapy within 30 minutes, and
- have access to thrombolysis (if appropriate) within 60 minutes.

By 2010, 90% of patients presenting with suspected AMI should have access to the strategies outlined above within the response time targets.

When the diagnosis of AMI is confirmed:

- patients should receive reperfusion therapy within 90 minutes of contact with the health services, regardless of their contact point, and
- in line with international recommendations, the medium term target is for patients to receive reperfusion therapy within 60 minutes of contact with the health services.

The initial assessment for suitability should enable activation of pre-hospital thrombolysis or transport of the patient to a facility (Emergency Department or Intensive / Coronary Care Unit) where thrombolysis (or in some cases PCI) can be delivered within 15 minutes of arrival.

Pre-hospital thrombolysis should be delivered either by registered medical practitioners or advanced paramedics with suitable training and supports. In general, if transfer time to hospital for a confirmed AMI patient who is suitable for thrombolysis is likely to exceed 30 minutes, that patient should be offered pre-hospital thrombolysis.

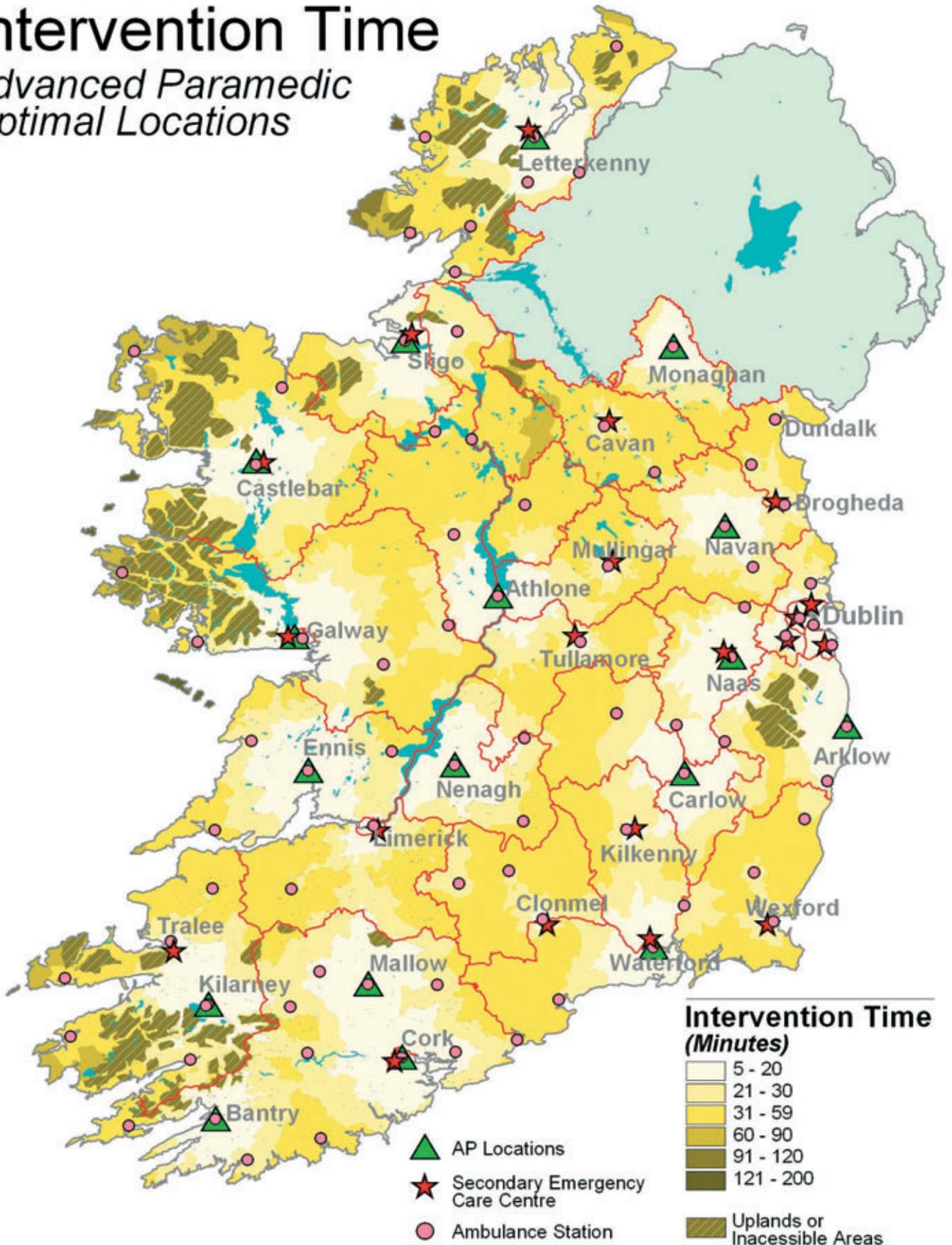
The Merit Project (Medical Emergency Responders Integration and Training - a pilot project established December 2004 in University College Dublin [UCD] in conjunction with PHECC and the HSE) will address the provision of specific forms of advanced care, including pre-hospital thrombolysis, by small groups of trained and well-supported doctors working in close cooperation with the ambulance services.

In the last year, PHECC in association with the National Ambulance Training School and UCD introduced an advanced paramedic training programme. Spatial analysis research has identified potential optimal locations for the early deployment of advanced paramedics.<sup>20</sup>

The development of regional and local structures to provide services meeting these targets by general practice, ambulance services and hospital practitioners must be undertaken on a collaborative basis. Treatment protocols, communications procedures, pharmacy arrangements and out-of-hours systems must all form part of the structures and procedures to be established.

# Intervention Time

*Advanced Paramedic  
Optimal Locations*



## 5.8 Post-resuscitation Care

While much attention has been focused on teaching the skills necessary to resuscitate a patient during cardiac arrest, the goal of treatment is to restore the individual to their pre-arrest state without any lasting neurological deficit. The continuum of care does not stop with the successful return of spontaneous circulation. There is evidence that the current level of post-resuscitation care is inadequate. In several studies reporting survival from out-of-hospital cardiac arrests, fewer than half of patients who had a return of spontaneous circulation and were deemed to have been 'successfully resuscitated', survived to hospital discharge. In some studies the figures were considerably worse.<sup>40</sup>

Although several contributory factors have already been identified, the underlying causes for these unacceptably poor results remain largely unknown.<sup>41</sup> Developing a standardised, evidence-based approach to post-resuscitation treatment remains an important challenge in resuscitation care.<sup>42</sup>

While the management of cardiac arrest survivors in hospital remains outside its terms of reference, the Task Force acknowledges that without improvements in post-resuscitation treatment, the mortality figures from out-of-hospital cardiac arrest are likely to remain poor.

### The Task Force recommends that:

- R 5.36: Advanced cardiac life support training should be readily accessible to health professionals as appropriate, including those who work in a community setting.
- R 5.37: After contacting the healthcare system (ambulance service, GP services or Emergency Department) patients with suspected AMI should:
- have access to a defibrillator within ten minutes
  - be offered aspirin within 20 minutes (if appropriate)
  - have a completed assessment of suitability for reperfusion therapy within 30 minutes, and
  - have access to thrombolysis (if appropriate) within 60 minutes.
- R 5.38: Timely reperfusion therapy for patients with AMI should involve:
- pre-hospital thrombolysis via GP services or advanced paramedic units of the ambulance service where hospital assessment for reperfusion is unlikely within 30 minutes or hospital provision of reperfusion is unlikely within 90 minutes of the patient contacting the health services; the medium term target is for patients to receive reperfusion therapy within 60 minutes of making contact, and
  - fast-tracking within Emergency Departments where patients are brought by ambulance or self-present, and
  - if possible primary angioplasty.
- R5.39: Best practice guidelines for the management of cardiac arrest survivors during the post-resuscitation phase should be developed and implemented.

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chapter 6

# Surveillance and audit

## 6.1 Information systems

In its fifth term of reference, the Task Force was asked to ‘advise on the establishment and maintenance of surveillance systems, including a registry of SCD and information systems to monitor risk assessment, and training and equipment programmes’.

Accurate mortality data is essential to monitor trends in SCD. A register of people undergoing assessment for risk of SCD would provide valuable information for planning and evaluation of services, in addition to providing information on the epidemiology of conditions which increase risk of SCD in Ireland. Data collected on resuscitation in the pre-hospital and hospital settings would quantify the frequency and geographic spread of cardiac arrest and support service planning. Such data would also provide a basis for audit of the outcome of resuscitation. Databases on training and on AEDs are essential for planning and monitoring coordinated responses to sudden collapse.

## 6.2 Surveillance of mortality from SCD

The aim of surveillance of mortality is to systematically collect and review information on the epidemiology of SCD in Ireland. This would provide estimates of the incidence of SCD, and identify the causes and the demographic characteristics of those who died. Such surveillance should be done in accordance with international methods.

SCD is not recorded on death certificates in Ireland. As discussed in Section 2.2.1, instructions to those completing a death certificate do not allow use of the term ‘sudden cardiac death’. The Task Force proposes changes to the death certificate and in the rules for completing it. A ‘tick box’ on the death certificate completed by a medical practitioner would identify deaths occurring within one hour of onset of symptoms. A similar box could be added to the forms completed by the Registrar of Deaths and to the Coroner’s Certificate.

The rules for completion of the death certificate should be altered. Version 10 of the International Classification of Diseases (ICD) which is being introduced in Ireland permits use of the terms ‘sudden cardiac death’, and ‘other sudden death, cause unknown’. If such terms are recorded as the cause of death, the certifier must also specify the underlying cause, for example acute myocardial infarction.

The forthcoming Coroner’s Bill may revise the circumstances in which a death must be reported to the Coroners’ Office. At present all sudden unexplained deaths must be notified. Sudden death in the absence of known CHD, particularly in a younger person, warrants the performance of a post-mortem. The death certificate can then be definitively completed, recording the underlying disease processes. The post-mortem may find no evidence of structural heart disease and this should be recorded. Issues in relation to further post-mortem examination by a specialist cardiac pathologist are discussed in Section 3.4.2 of this report, including the recommendation that there should be at least two cardiac pathologists in Ireland.

The use of terms such as ‘cardiac arrest’ on death certificates and the identification of cases of sudden death on forms reporting the findings of inquests would support the CSO to more

accurately estimate and report on the frequency of SCD. During the consultation process there was a large measure of agreement that such developments were desirable. Further discussion involving the CSO, the Faculty of Pathology of the Royal College of Physicians of Ireland and The Coroners Association of Ireland will be required to agree the detail of the necessary changes. Communication with medical practitioners will be essential to ensure they comply with any new rules for death certification.

### 6.3 Risk Assessment Database

Chapter 3 described the medical assessment and care pathways of someone who may be at increased risk of SCD. Following initial assessment, the GP may refer the person to a regional cardiology centre. The person may subsequently be referred to a specialist centre for further investigations. Some people or families may undergo genetic testing, either in or coordinated by the NCMG at Our Lady's Hospital for Sick Children in Crumlin, Dublin. A register of people undergoing assessment for risk of SCD would provide valuable information for planning and evaluation of services, in addition to providing information on the epidemiology of conditions which increase risk of SCD in Ireland. Such a register could support follow-up of patients and would provide a valuable information base for research on these conditions.

A risk assessment database should be established, to include all patients assessed in specialist centres. The database should be maintained at the NCMG. This would allow the results of genetic tests to be entered into the register. Consideration should be given to extending this to include patients assessed in regional hospitals.

The Data Protection Acts assign responsibilities to data controllers who hold and control personal information. Informed consent is required to enter data about a person onto a register. This includes providing explanations about the purposes of the register, data security and confidentiality. Even in advance of risk assessment, patients may have concerns about the implications of the test results for life insurance and related products. Admitting that one is on an SCD risk assessment register will not alter access to life insurance, though the family history or medical condition which resulted in being referred for tests may do so. Even in the absence of a register, a person applying for life insurance would be required to disclose such a family history or assessment for risk of SCD, including disclosure of negative tests. At present, Huntington's Disease (not related to cardiac disease) is the only genetic test which the Irish Insurance Federation takes into account in the underwriting process (<http://www.iif.ie/infogene.htm>).

From a security perspective, there are advantages to maintaining an anonymised register. Disadvantages include that the register could have duplicate entries, giving false estimates of the prevalence of conditions. Without a method of linking the data files to individuals, the register could not support follow up, for example should new diagnostic tests become available. On balance, including a unique identifier in the register is desirable. Methods to follow up cardiac events or death occurring in those on the register should be explored with those developing the cardiac arrest databases, with the CSO and with specialist cardiac pathologists.

## 6.4 Data collection in the Pre-hospital Clinical Setting

### 6.4.1 Registration of cardiac arrests

There has been a cardiac arrest database in Donegal since 1992.<sup>1</sup> The purposes are to study outcome following cardiac arrest and to evaluate the impact of additional investment in the emergency services. An internationally accepted data set ('The Utstein Template') is used to record data on out-of-hospital cardiac arrest. Sixty-two living survivors have been identified - 2% of registered arrests. Cases are identified via the emergency ambulance service, with additional information being obtained on a monthly basis from Coroners and the CSO. Currently a Patient Care Report is being implemented. Nevertheless, the collection of data is time consuming.

There is no national system to collect data on cardiac arrests. The electronic Patient Care Report being evaluated by PHECC will be completed for all patients, including those who suffer cardiac arrest in the community, when attended by the EMS. While that system will not capture data on all cardiac arrests, it will provide information on trends in cardiac arrests in the community and on the outcome of such cases.

### 6.4.2 Registration of cardiac resuscitation in the community

The electronic Patient Care Report being implemented by PHECC provides a basis for registration of cardiac arrest and resuscitation in the community. Analysis and feedback from the register would support national, regional and local service quality improvement initiatives and audit of prevention, emergency and treatment services.

The location and demographic characteristics of cardiac arrests cases would be recorded, as well as the emergency response and the vital status of the person on arrival at the acute hospital. The Task Force proposes that the modified Utstein data set and definitions, as agreed by ILCOR, be adopted as a module in PHECC's electronic reporting system (Box 2).<sup>2</sup> Data should be returned by all first responders, in addition to the EMS.

## Box 2.

## Revised Utstein cardiac arrest data collection form

<b>Cardiac Arrest Data Collection Form</b>		
Date of arrest YYYY/MM/DD		
Patient identifier (first name, last name, or ID number)		
Sex		
Age	Years (estimated)	<b>OR</b> Date of birth YYYY/MM/DD
Cardiac arrest determined by		
Cause of arrest		
Treatment before EMS arrival		
<p><b>Bystander CPR</b></p> <p>Defibrillation by bystander <input type="checkbox"/> or implanted defibrillator <input type="checkbox"/></p>		
Resuscitation attempted by EMS		
Location of arrest	out of hospital	in hospital
Witnessed	If witnessed, time of arrest HH:MM	
Initial rhythm		
Chest compressions		
Defibrillation attempt		
Ventilation	Drugs	
Time of collapse HH:MM (estimated)		
Time of call receipt HH:MM		
Time vehicle stopped HH:MM		
Time of first rhythm analysis HH:MM		
Spontaneous circulation (on arrival in ED)		
Hospital admission		
Hospital Discharge		
Date of hospital discharge (or death) YYYY/MM/DD		
Neurologic status at discharge (CPC)		

The revised Utstein form includes data on the patient, the event and the outcome. When completed according to the standard definitions this enables comparison of processes and outcomes between areas or countries. The ILCOR Task Force recommended that all initial cardiac arrest rhythms be registered, including those not responsive to defibrillation.<sup>2</sup> To make valid comparisons of outcome, separate analysis should be done of those cases which are witnessed and have VF as the initial rhythm.

Though some of the items in the revised Utstein Template are specific to cardiac arrest, many are already included in PHECC's Patient Care Report. Liaison with the admitting hospital will be required to record vital status on discharge. There should be compatibility of coding of variables common to the modified Utstein data set and the planned National Cardiovascular Information System (NCIS).

The data collected by the EMS, including that on cardiac resuscitation, will be electronically transferred to PHECC. Returns by other first responders should also be supported, providing a national register of witnessed cardiac arrest and resuscitation in the community. The role of data controller for the register should be allocated to PHECC, including responsibility for data security and the maintenance of patient confidentiality. PHECC should also advise about data security and the maintenance of confidentiality of data held locally. When a person survives the resuscitation, informed consent will be required to maintain the record on the register. Responsibility for obtaining this consent could be assigned to the hospital staff member responsible for notifying vital status on discharge from hospital to the register.

When an AED is deployed, the ECG and shocks delivered are recorded. After the event, the ECG recording can be printed off, contributing to post-event audit. Data from the resuscitation register would support national, regional and local audit and provide a context for local case review sessions.

As described in Section 5.6.5, a report form was designed to collect information on resuscitation by lay responders using an AED in the U.K.<sup>3</sup> The forms are distributed through a number of channels, including the distributors of AEDs. The distributors inform all new customers about the database and include copies of the report form with each AED sold. Copies of the forms are also included with each set of defibrillator electrode pads.

It would be valuable if a system were put in place in Ireland to collect information on the deployment of AEDs, including the reporting of adverse events. The MDD of the IMB should be requested to liaise about this with the distributors of AEDs. The information could be returned to the IMB to support its role to assure the safe use of devices. The data could also be returned to PHECC, to complement the data collected from the EMS, general practitioners and first responders on response and outcome of witnessed cardiac arrest. Discussion and consultation will be required by PHECC and the IMB to agree data standards, to minimise the reporting burden on emergency responders and to ensure efficiency of the data collection processes.

### 6.4.3 Registration of cardiac arrest and resuscitation in hospitals

The Utstein data set is suitable for use in hospital as well as in the community. There is currently no national systematic data collection for audit of care of cardiac arrest and resuscitation in the hospital setting. The development of such a system could be supported by the Resuscitation Council of the Irish Heart Foundation. While PHECC's remit relates to care in the community, it would be most efficient if PHECC were to register response to all cardiac arrests, whether in the community or in hospital. HIQA when established will have responsibility to oversee health information and quality initiatives in the health services, including the proposed cardiac arrest and resuscitation register.

## 6.5 Training Programmes

Priority groups for training in BLS and the use of AEDs were identified in Chapter 5. In order to monitor provision and to maintain standards it is recommended that responsibility for monitoring of training and the maintenance of training records be assigned to PHECC (Recommendation 5.10).

## 6.6 Register of AEDs

In order to meet the requirements of the State Claims Agency's CIS, structured records must be kept on the upkeep and maintenance of AEDs for use in first responder programmes (see Section 5.6.7, Recommendation 5.29). For indemnity and traceability purposes responsibility for the establishment and maintenance of a national register of AEDs should be assigned to the MDD of the IMB (Recommendation 5.30). Vendors should notify the sale of each AED to the national register (Recommendation 5.31). Current AED owners and purchasers should be encouraged to register ownership of the device (Recommendations 5.32).

Forms to report on the deployment of AEDs and on adverse events should be distributed with the devices. In order to monitor deployment and effectiveness, first responder programmes and all AED owners should be encouraged to return information to PHECC each time the device is used. (Recommendation 5.33). Data on adverse events with AEDs should be provided to the MDD of the IMB (Recommendation 5.30). As proposed in Section 6.4.2, PHECC and the IMB should discuss data standards and procedures so as to maximise the efficiency of reporting to the cardiac arrest register as well as to the register of AEDs.

**▶ The Task Force recommends that:**

- R 6.1: The use of terms such as 'sudden cardiac death' should be permitted when completing a death certificate, supported by information on the underlying cause. The CSO should discuss refinements to the data reported by pathologists and coroners with their professional organisations, to provide more accurate estimates of SCD.
- R 6.2: An information campaign will be required to inform medical practitioners about the modification of methods of completing death certificates.
- R 6.3: Pathologists performing autopsies in cases of SCD due to non-coronary causes should complete standard forms.
- R 6.4: A central national risk assessment register should be established and maintained at the NCMG to support follow-up of those assessed, to provide epidemiological information on conditions associated with increased risk of SCD, and to support the planning and evaluation of services.
- R 6.5: PHECC should build on work already under way to establish a register of witnessed cardiac arrest and attempted resuscitation. This should include collecting data, using the Utstein template, from the EMS, general practitioners, other health personnel and uniformed responders, and those participating in first responder programmes. Data on cardiac arrests and resuscitation in the hospital setting should also be returned to PHECC.
- R 6.6: PHECC and the IMB should discuss registration procedures so as to minimise the burden on emergency responders in reporting to the cardiac arrest register (Recommendation 6.5) and to the AED (and adverse events) register (Recommendation 5.30).
- R 6.7: Standards for response time by the ambulance service appropriate to urgency and seriousness of clinical condition should be established by PHECC.
- R 6.8: The Health Information and Quality Authority (HIQA) should report regularly on the adequacy of surveillance of SCD and of the information systems for risk assessment, resuscitation, training and use of AEDs.

## References

- <sup>1</sup> Dowling J, Doherty DT, Wright P. The need for an out-of-hospital cardiac arrest (OHCA) registry. Presented at the Irish Society for Immediate Care Seminar: Sudden Cardiac Death for Health Professionals; 25th June 2005. Dublin.
- <sup>2</sup> Jacobs I, Nadkarni V and the ILCOR Task Force. Cardiac arrest and cardiopulmonary resuscitation outcome reports. Update and simplification of the Utstein Templates for resuscitation registries. AHA Scientific Statement. *Circulation* 2004; 110: 3385-97. <http://www.circulationaha.org>
- <sup>3</sup> Colquhoun M, Davies CS, Harris S et al. Public access defibrillation – designing a universal report form and database for a national programme. *Resuscitation* 2004; 61: 49-54.



chapter 7

# Implementation

## 7.1 The Way Forward

The Report of the Task Force on SCD comes at an opportune time. The health service is undergoing a major reform process with the establishment of the HSE and the integration of old roles and responsibilities into a new structure to meet the demands placed on the system now and in the future. Central to this is the ability to deliver a timely and high quality service for people on a consistent national basis. Particularly relevant to this report is the imminent establishment of HIQA, whose functions, as outlined in Chapter 1, will include the establishment of service standards and the development of health information systems.

The empirical evidence on the incidence of SCD in Ireland is limited and there is no hard data on which to benchmark and measure outcomes. While it is not possible to provide full proof of efficacy, the Task Force believes that there is sufficient evidence to support the recommendations in this report. The recommendations were drawn up on the basis of international and local evidence. The knowledge gleaned from the consultation process and the practical experience of the organisations and individuals who made submissions were extremely valuable in framing the report's recommendations.

## 7.2 Framework for Implementation

The Task Force sought to provide a vision for the future, with thorough analysis of the issues and clear recommendations to quickly and effectively turn the vision into a reality. The framework for the report and its implementation is set out in Figure 9 and involves 3 levels:

### Level 1 - Overall aim

- to reduce the incidence of SCD in the Irish population

There is no definitive figure against which to benchmark progress in achieving this aim other than the estimated 5,000 deaths per year. The Task Force believes that the proposed changes to the death certificate will provide a more reliable estimate of the incidence of SCD in Ireland. The development of comprehensive surveillance systems will provide information on progress in particular groups and geographic areas, and highlight the groups for whom additional action is required.

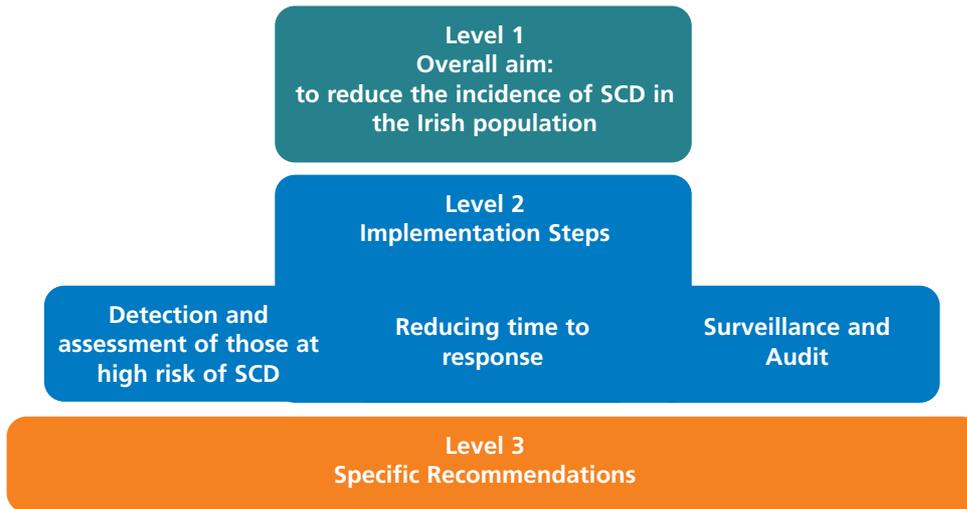
Three implementation steps have been identified to achieve the overall aim, which are in turn supported by 75 specific recommendations.

### Level 2 - Implementation steps

- the delivery of effective risk assessment measures for those at risk of SCD
- an improvement in early response to sudden collapse through multisectoral measures and coordinated first responder programmes, and
- the development of comprehensive surveillance systems to monitor and audit SCD.

### Level 3 - Specific recommendations

**Figure 9.**  
**Framework for Implementation**



The recommendations have been prioritised against implementation timeframes of immediate, medium and long term.

- immediate – to commence before the end of 2006 (48 recommendations)
- medium term – to be completed by end of 2008 (22 recommendations), and
- long term – achievable by the end of the year 2010 (5 recommendations).

While it is arguable that all the recommendations should be classified as immediate, the Task Force recognises it will take time for some of them to be implemented. All of the recommendations should be addressed as quickly as practicable.

It is the view of the Task Force that full implementation of the report is achievable by the year 2010.

### 7.3 Responsibilities for Implementation

The Task Force believes that everyone has a part to play in implementing the recommendations, from individuals to government agencies. The HSE, which has responsibility for the operational delivery of health services in Ireland, will have overall responsibility for the implementation and monitoring of the report's recommendations. The Task Force recognises that there are other organisations, both statutory and non-statutory, which will have an important role in the implementation process. It will be a matter for the HSE to identify and interface with all relevant organisations.

## 7.4 Critical Success Factors

The following critical success factors have been identified:

- **Strong and sustained commitment by Government**
- **Commitment by the HSE to implementing the operational recommendations** – the majority of the recommendations require the HSE as the lead agency to kick-start the process of implementation. Commitment from all pillars and levels in the organisation is essential because the recommendations will inform future planning and development of many services, particularly pre-hospital and cardiology services.
- **Enhancing partnerships between sectors, agencies and stakeholders** – tackling SCD is not the sole remit of any one sector or agency. In order for implementation of the report to succeed, a partnership approach must be adopted.
- **Coordination of early response systems** – the ongoing development of the ambulance services and the development of a national early defibrillation strategy will be crucial to the successful implementation of the recommendations in Chapter 5.
- **Provision of equipment, education and training** – accessible life support equipment, including defibrillators, will be fundamental to the implementation of early response strategies. Education and training are mentioned throughout this report. They are fundamental components for the change process and systems development necessary to reduce risk of SCD.
- **Development of information systems to support audit** – benchmarking progress in achieving the report's main objective cannot be realised without investing in ICT.
- **Successful communication and dissemination of the report** – this report evolved from extensive consultation and research into models of best practice nationally and internationally. Its recommendations need to be understood and adopted by all stakeholders both within and external to the health services. There has been considerable public expectation surrounding the report; its contents now need to be disseminated and clearly communicated to the public.

# Summary of recommendations and time frame for implementation

# Summary of Recommendations and Time Frame for Implementation

The 75 recommendations have been prioritised into immediate, medium and long term implementation time frames:

- immediate – to commence before the end of 2006 (48 recommendations)
- medium term – to be completed by end of 2008 (22 recommendations), and
- long term – achievable by the end of the year 2010 (5 recommendations).

## Chapter 3. Detection and Assessment of those at High Risk of Sudden Cardiac Death

No.	Recommendation	Time Frame
3.1	Primary prevention strategies to prevent CHD should continue to be developed and implemented.	Long
3.2	Secondary prevention programmes, including cardiac rehabilitation services and primary care based secondary prevention programmes, should continue to be developed in order to provide access for all patients.	Immediate
3.3	Family members of those who have suffered a cardiac event should be offered basic life support (BLS) and automated external defibrillator (AED) training.	Immediate
3.4	Information and continuing education on risk assessment for SCD should be made available to general practitioners.	Immediate
3.5	As outlined in the <i>Primary Care Strategy</i> , GPs should have improved access to diagnostic facilities and other secondary care services for their patients.	Medium
3.6	A national education campaign to raise awareness of the symptoms which indicate increased risk of SCD should be developed and implemented.	Immediate
3.7	An education programme for all personnel involved in the immediate and post-event management of SCD should be developed and implemented.	Medium
3.8	Training of personnel in the management of SCD should include a module on appropriate psychological support.	Medium
3.9	Following certification of SCD in individuals less than 40 years of age, the Coroner should notify the next of kin and the patient's GP of a potential increased risk of SCD in first degree relatives.	Immediate

3.10	The Coroner and all medical professionals involved should encourage the next of kin to communicate this information to other first degree relatives as appropriate, and risk assessment of each relatives should ensue.	Immediate
3.11	Protocols should be formalised for informing GPs and families of the results of post-mortems and the implications for families in terms of risk assessment.	Immediate
3.12	In cases of SCD, pathology reports should be forwarded to the GP as soon as possible in order to avoid delays in notifying family members who may be at risk.	Immediate
3.13	Guidelines for the conduct of a post-mortem in SADS cases should be developed as has already been done for Sudden Infant Death Syndrome (SIDS).	Medium
3.14	When a post-mortem examination fails to determine the cause of SCD in a person under the age of 40 years, a further examination of the heart should be undertaken by a pathologist with cardiac sub-speciality training, in a specialist referral centre. This will necessitate the appointment of at least two cardiac pathologists in Ireland.	Long
3.15	There is insufficient evidence to support the implementation of a mass population screening programme for SCD. The first degree relative of those who died of SCD under 40 years of age are the priority group for risk assessment.	Immediate
3.16	In cases of SCD under the age of 40, initial assessment of first degree family members should be by the GP with referral to a regional cardiology centre for investigation when indicated.	Immediate
3.17	All cases of possible cardiomyopathy or channelopathy identified in a regional centre should be assessed by a cardiologist with expertise in these conditions. Supra-regional centres should be identified for assessment and treatment of children with a family history of SCD.	Immediate
3.18	As access to a geneticist is an integral part of the service, each regional and supra-regional cardiac referral centre should have a link with the National Centre for Medical Genetics at Our Lady's Hospital, Crumlin for testing for known cardiomyopathy and channelopathy genes.	Medium

## Chapter 4. Systematic Assessment of those Engaged in Sports and Exercise

No.	Recommendation	Time Frame
4.1	Those with a history of heart problems or other major illness are advised to speak to their doctor before starting an exercise programme. Otherwise leisure activities such as walking, swimming or tennis do not require any formal pre-participation assessment (See R 4.2). Anyone feeling any pain or discomfort during exercise is advised to seek advice about exercising safely from their doctor or exercise specialist.	Immediate
4.2	Those aged 14 years or older who engage in recreational activity without joining a club or organisation should be encouraged to self-administer a risk assessment questionnaire (see R 4.5) and to seek advice from the GP if the questionnaire is positive.	Immediate
4.3	Individuals aged 14 years or older who wish to join a sports club, gym or other sports facility but not involved in national, provincial or county level sports, should be offered a pre-participation questionnaire. Informed consent to risk assessment should be sought. Those with a positive questionnaire should be advised to contact their GP.	Immediate
4.4	Following assessment by the GP, those with family histories of SCD, cardiac symptoms or abnormal cardiac examination should be referred to a cardiologist for further assessment.	Immediate
4.5	A protocol for risk assessment should be agreed by the major sports and sports medicine organisations, and the Irish Cardiac Society and Irish College of General Practitioners under the aegis of the Irish Sports Council, for those who wish to join a sports club, gym or other sports facility but are not involved in national, provincial or county level sports. The protocol should include methods for obtaining informed consent, a model questionnaire and procedures for its administration and referral for medical assessment if indicated, as well as guidelines on physical examination and diagnostic tests, including referral to cardiac and specialist centres if required.	Medium
4.6	A protocol for risk assessment should be agreed by the major sports and sports medicine organisations, and the Irish Cardiac Society and Irish College of General Practitioners under the aegis of the Irish Sports Council, for those involved in moderate or vigorous intensity sports at national, provincial or county level. (The protocol in R 4.5 should apply to those engaged in low intensity sports at this level.) The protocol should include methods for obtaining informed consent, a model questionnaire and procedures for its administration, and guidelines on physical examination for all athletes at this level and on further tests and referral to cardiac and specialist centres if required.	Medium

4.7	The Irish Sports Council should support the development and delivery of training courses for sports and medical personnel, including general practitioners, on the implementation of protocols for risk assessment of athletes.	Medium
4.8	Multisectoral strategies are required to achieve safe participation in sports and exercise. Education programmes should emphasise the dangers of using performance enhancing, recreational and other drugs.	Long
4.9	Pre-participation assessment should explore the use of performance enhancing and illicit drugs.	Immediate
4.10	If sudden cardiac death occurs in an athlete, risk assessment should be offered to training colleagues and team members.	Immediate

## Chapter 5. Reducing Time to Response

No.	Recommendation	Time Frame
5.1	The Task Force welcomes the establishment of the Health Service Executive National Ambulance Service and recommends that it should lead a national education programme on contacting the EMS.	Immediate
5.2	Signage on all emergency vehicles should include "In an emergency phone 999 or 112" analogous to the Garda Síochána confidential telephone number on Garda Síochána vehicles.	Medium
5.3	Regardless of their purpose, all ambulances should carry an AED. The drivers of all such vehicles should be trained in BLS and AED use.	Immediate
5.4	The recommendations in the <i>Ambulance Service Communications Review (2005)</i> concerning the function and role of communication centres should be implemented expeditiously.	Immediate
5.5	All providers of pre-hospital emergency care who are contacted by the public should provide pre-arrival advice including telephone-assisted CPR according to a national standard.	Medium
5.6	The early administration of aspirin should be encouraged if chest pain, not collapse, is the problem and acute coronary syndrome is thought to be the cause.	Immediate
5.7	The respective roles of the statutory and voluntary organisations in BLS / AED training should be agreed and operationalised to maximise benefit to the public.	Medium
5.8	Irish standards for BLS and AED courses and trainers should be published by PHECC. Statutory, voluntary and private training providers should be accredited according to these standards.	Medium

<p>5.9 The following training initiatives should be prioritised:</p> <ul style="list-style-type: none"> <li>– BLS / AED training is essential for all health care professionals</li> <li>– BLS / AED for family members of those who have suffered a non-fatal cardiac event or are at high risk of SCD</li> <li>– AED training should be a requirement for occupational first aid certification</li> <li>– first responders linked to the EMS</li> <li>– BLS / AED training should be included in the curriculum for primary and secondary schools.</li> </ul>	<p>Immediate</p>
<p>5.10 Responsibility for accreditation and monitoring of all BLS / AED training and the maintenance of training records should be assigned to PHECC.</p>	<p>Medium</p>
<p>5.11 Access to defibrillation should be optimised to meet European recommendations. The challenges in meeting the ESC targets should be identified and addressed, recognising that it will take some years to achieve this.</p>	<p>Long</p>
<p>5.12 Closer integration should be encouraged between the statutory and the voluntary ambulance and emergency services</p>	<p>Medium</p>
<p>5.13 In establishing first responder programmes, priority should be given to programmes, geographic locations and facilities identified as having the greatest need. All such programmes should be coordinated by the HSE Ambulance Service, with best practice guidance from PHECC.</p>	<p>Immediate - Long</p>
<p>5.14 First responder programmes must include standardised quality assurance / quality improvement structures (see Section 5.6.8).</p>	<p>Immediate</p>
<p>5.15 All AEDs and trained personnel available to voluntary aid organisations should be immediately integrated within first responder programmes associated with the statutory ambulance services.</p>	<p>Immediate</p>
<p>5.16 First responder programmes outside the voluntary aid organisations should be integrated where appropriate with the statutory ambulance service.</p>	<p>Medium</p>
<p>5.17 Community first responder coordinators should be appointed in each ambulance service region to coordinate all programmes. A standard specification should be agreed for such posts.</p>	<p>Immediate</p>
<p>5.18 All community-based health personnel, particularly health professionals, should be trained to manage a cardiac event. All community health facilities, including general practice premises should be equipped to deal with such an emergency. This includes the provision and maintenance of an AED.</p>	<p>Immediate - Medium</p>

<p>5.19 A tiered response system should prioritise the training and equipping of rapidly deployable ‘uniformed responders’ such as:</p> <ul style="list-style-type: none"> <li>– full time fire services in urban communities</li> <li>– retained fire services in rural communities</li> <li>– the evaluation of the pilot programme of Garda patrol car-based AEDs should be concluded prior to such programmes being implemented nationally</li> <li>– auxiliary and voluntary providers</li> <li>– security personnel at large shopping centres / sports grounds / public amenities, and</li> <li>– local first responder programmes should facilitate participation by off-duty trained health services and uniformed personnel.</li> </ul>	<p>Immediate - Medium</p>
<p>5.20 All priority facilities should be encouraged to provide first responder programmes and consideration should be given to requiring this on a statutory basis.</p>	<p>Immediate - Medium</p>
<p>5.21 Management of other site specific locations should be advised of the potential benefits of implementing programmes e.g. leisure centres, sports clubs (GAA, golf courses, etc).</p>	<p>Immediate</p>
<p>5.22 A template should be developed urgently for the provision of local information and advice to communities, councils, organisations, etc. who wish to establish first responder programmes in their area.</p>	<p>Immediate</p>
<p>5.23 Appropriate support should be available for responders to receive ‘critical incident stress debriefing’ following a resuscitation attempt.</p>	<p>Medium</p>
<p>5.24 The HSE ambulance service should be required to establish structural links to first responder programmes.</p>	<p>Immediate</p>
<p>5.25 A technology assessment should be conducted of devices currently in place and those proposed, to ensure the most appropriate device is in place for the specific setting.</p>	<p>Immediate - Medium</p>
<p>5.26 AEDs should be placed in facilities where the incidence of cardiac arrest is high, including:</p> <ul style="list-style-type: none"> <li>– inpatient health facilities</li> <li>– GP surgeries and primary care facilities</li> <li>– airports, shopping centres, major sports venues and golf courses, bus/rail terminals, ferries/ferry terminals, concert and conference venues</li> <li>– universities and colleges</li> <li>– gyms and fitness clubs, and</li> <li>– other venues for major public events.</li> </ul>	<p>Immediate - Medium</p>

5.27	National signage for AEDs should be agreed and used in all locations.	Medium
5.28	Individuals and organisations who purchase an AED should be informed by the vendor about procedures to ensure that the AED is maintained in a state of operational readiness.	Immediate
5.29	A designated person in each location where an AED is housed should ensure that clear roles and lines of responsibility are identified, maintenance schedules are observed and recorded, and regular checks / refurbishment of consumables are performed.	Immediate
5.30	Responsibility for the establishment and maintenance of a devices / customer register should be assigned to the IMB. This should include a system for recording adverse events associated with the use of AEDs.	Immediate - Medium
5.31	Vendors should notify the sale of each AED to a national register. Manufacturers and vendors must notify the IMB in the event of a product recall or requirement to provide technical information to AED owners.	Immediate - Medium
5.32	An AED purchaser should be required to provide the following information at the time of purchase: <ul style="list-style-type: none"> <li>– a registration form with all contact details for submission to a central register</li> <li>– a training form stating that the purchaser understands the responsibility that owning an AED brings and a recommendation that they complete a BLS / AED training course, and</li> <li>– a community response form notifying their local EMS station that they have an AED and specifying whether they wish to become part of an integrated community response programme, have a limited role in such a response programme or have no role in such a programme.</li> </ul>	Medium
5.33	The standardised form developed by PHECC should be used to report sudden cardiac events, including data on AED use. Those involved in first responder programmes should record this information as an integral part of each programme's procedures.	Immediate
5.34	The legal situation should be reviewed to protect rescuers from any possible litigation. The HSE should review other aspects of insurance requirements for first responders.	Immediate
5.35	PHECC in consultation with HIQA should develop and implement a national programme of audit of emergency cardiac response.	Medium - Long
5.36	Advanced cardiac life support training should be readily accessible to health professionals as appropriate, including those who work in a community setting.	Immediate

<p>5.37 After contacting the healthcare system (ambulance service, GP services or Emergency Department) patients with suspected AMI should:</p> <ul style="list-style-type: none"> <li>– have access to a defibrillation within ten minutes</li> <li>– be offered aspirin within 20 minutes (if appropriate)</li> <li>– have a completed assessment of suitability for reperfusion therapy within 30 minutes, and</li> <li>– have access to thrombolysis (if appropriate) within 60 minutes.</li> </ul>	<p>Immediate</p>
<p>5.38 Timely reperfusion therapy for patients with AMI should involve:</p> <ul style="list-style-type: none"> <li>– pre-hospital thrombolysis via GP services or advanced paramedic units of the ambulance service where hospital assessment for reperfusion is unlikely within 30 minutes or hospital provision of reperfusion is unlikely within 90 minutes of the patient contacting the health services; the medium term target is for patients to receive reperfusion therapy within 60 minutes of making contact, and</li> <li>– fast-tracking within Emergency Departments where patients are brought by ambulance or self-present, and</li> <li>– if possible primary angioplasty.</li> </ul>	<p>Immediate - Medium</p>
<p>5.39 Best practice guidelines for the management of cardiac arrest survivors during the post-resuscitation phase should be developed and implemented.</p>	<p>Medium</p>

## Chapter 6. Surveillance and Audit

No.	Recommendation	Time Frame
6.1	The use of terms such as 'sudden cardiac death' should be permitted when completing a death certificate, supported by information on the underlying cause. The CSO should discuss refinements to the data reported by pathologists and coroners with their professional organisations, to provide more accurate estimates of SCD.	Immediate
6.2	An information campaign will be required to inform medical practitioners about the modification of methods of completing death certificates.	Immediate - Long
6.3	Pathologists performing autopsies in cases of SCD due to non-coronary causes should complete standard forms.	Immediate
6.4	A central national risk assessment register should be established and maintained at the NCMG to support follow-up of those assessed, to provide epidemiological information on conditions associated with increased risk of SCD, and to support the planning and evaluation of services.	Medium
6.5	PHECC should build on work already under way to establish a register of witnessed cardiac arrest and attempted resuscitation. This should include collecting data, using the Utstein template, from the EMS, general practitioners, other health personnel and uniformed responders, and those participating in first responder programmes. Data on cardiac arrests and resuscitation in the hospital setting should also be returned to PHECC.	Immediate - Medium
6.6	PHECC and the IMB should discuss registration procedures so as to minimise the burden on emergency responders in reporting to the cardiac arrest register (Recommendation 6.5) and to the AED (and adverse events) register (Recommendation 5.30).	Medium
6.7	Standards for response time by the ambulance service appropriate to urgency and seriousness of clinical condition should be established by PHECC.	Immediate - Medium
6.8	The Health Information and Quality Authority (HIQA) should report regularly on the adequacy of surveillance of SCD and of the information systems for risk assessment, resuscitation, training and use of AEDs.	Long

# Appendices

# Appendix 1

## INVITATION FOR SUBMISSIONS TO THE **NATIONAL TASKFORCE ON SUDDEN CARDIAC DEATH**

A national Task Force on Sudden Cardiac Death has been established and will report to the Tánaiste and Minister for Health and Children, Mary Harney T.D.

The Task Force will make recommendations on the prevention of sudden cardiac death and on the detection of those at high risk, including risk assessment of those engaged in sports and exercise. The Task Force will also advise on equipment and training programmes to improve the outcome in those suffering from sudden cardiac collapse and on the establishment of appropriate surveillance systems.

The Chairman of the Task Force, Dr Brian Maurer, consultant cardiologist and Vice-President of the Irish Heart Foundation, invites submissions from members of the public and from professional, voluntary and private organisations. These should be 3 A4 sized pages or less, to arrive not later than 5.00 p.m. on Friday 4th March 2005.

Submissions may be sent by a-mail to:

suddencardiacdeath@health.irg.gov.ie or by post to:

The Task Force on Sudden Cardiac Death  
Room 11:11  
Department of Health and Children  
Hawkins House  
Dublin 2

Further information is available at:

<http://www.healthpromotion.ie/topics/suddencardiacdeath/>  
or by telephone from Marie Kinsella at 01 6354526.

## Appendix 2

### Consultation

Organisations, health professionals, industry representatives and members of the public involved in the consultation process:

Ms. Fiona Barton  
 Ms. Regina Black  
 Ms. Carmel Brennan  
 Ms. Mary Brosnan  
 Cardiac Risk in the Young  
 Cardiac Services Ltd., Services (Irl) Ltd.  
 Carlow Institute of Technology  
 Ms. Bernadette Casey  
 Mr. Brendan Cavanagh  
 Central Statistics Office  
 Civil Defence  
 Ms. Bronagh Connolly  
 Córas Iompair Éireann  
 Mr. Nick Corish  
 Coroners Association of Ireland  
 Mr. Michael J. Corry  
 Croí  
 Ms. Maeve Cusack  
 Department of Environment, Heritage and Local Government  
 Department of Physical Education and Sports Sciences, University of Limerick  
 Dr. John Dowling  
 Dublin Fire Brigade  
 Dublin and Wicklow Mountain Rescue Team  
 Dundalk Institute of Technology  
 Mr. Paul Dunne  
 Emergency First Response Limited  
 Equestrian Federation of Ireland  
 H. Evans and Sons  
 Faculty of Pathology  
 Faculty of Sports and Exercise Medicine  
 Mr. Joe Fahy  
 Ms. Siobhan Fitzpatrick  
 Ms. Orlagh Fleming  
 Fleming Medical Limited  
 Football Association of Ireland  
 Ms. Maura Foran  
 Mr. Pádraig Foy  
 Gaelic Athletic Association  
 Garda Síochána  
 Ms. Roslyn Garrett  
 Ms. Mairead Gleeson  
 Prof. Ian M. Graham  
 Prof. Andrew Greene  
 Mr. John Hammond  
 Ms. Helen Harney  
 Health and Safety Authority of Ireland

Ms. Shirley Ingram  
Irish Cardiac Society  
Irish Coast Guard  
Irish College of General Practitioners  
Irish Heart Foundation  
Irish Medicines Board  
Irish Nurses Cardiac Society  
Irish Nurses Cardiovascular Association  
Irish Nurses Organisation  
Irish Prison Service  
Irish Red Cross  
Irish Rugby Football Union  
Irish Society for Immediate Care  
Irish Sports Council  
Ms. Mary Ivory  
Ms. Wendy Keena  
Dr. Con Kelleher  
Mr. Denis Kelly  
Mr. Mike Keohane  
Ms. Marian Kiernan  
Ms. Regina Kiernan  
Ms. Fionnuala Killalea  
Ms. Brid Manning  
The Mater Pilot Family Screening Clinic  
Medtronic  
MDI Ltd.  
Mr. Shane Mooney  
Ms. Margaret Moran  
Ms. Karen Murphy  
Mr. Pat McCreanor  
National Retained Firefighters Association  
Ms. Grainne NicGabhann  
Ms. Fionnuala O'Brien  
Ocean Divers  
Ms. Catherine O'Connell  
Ms. Kate O'Flaherty  
Dr. Siobhan O'Halloran  
Ms. Kay O'Neill  
Order of Malta Ambulance Corps  
Ms. Eileen O'Toole  
Pre-Hospital Emergency Care Council  
Ms. Geraldine Quinn  
Ms. Prannie Rhatigan  
Ms. Claire Robinson  
Mr. John Ryan  
Ms. Monica Schaefer  
South Infirmary Victoria Hospital  
St. John Ambulance Brigade of Ireland  
Tallaght Institute of Technology  
The Turf Club  
Ms. Rosemary Walsh  
Waterford Institute of Technology  
Ms. Rosemary Walsh  
Dr. Peter Wright

## Appendix 3

### Codes for Cardiac Conditions in the International Classification of Diseases

Codes for cardiac arrest, sudden cardiac death and conditions which may give rise to sudden cardiac death, in ICD Ninth Revision (Table A3.1) and in the 10th Revision (Table A3.2).

Table A3.1 International Classification of Diseases, Ninth Revision (ICD-9-CM)	
390-392	Acute rheumatic fever
393-398	Chronic rheumatic heart disease
402	Hypertensive heart disease
404	Hypertensive heart and kidney disease
410	Acute myocardial infarction
411	Other acute and sub-acute forms of ischaemic heart disease
412	Old myocardial infarction
413	Angina pectoris
414	Other forms of chronic ischaemic heart disease
415-417	Diseases of pulmonary circulation
420-429	Other forms of heart disease, including:
420-24	Carditis, diseases of the pericardium and diseases of the endocardium including valvular heart disease
425	Cardiomyopathy
426	Conduction disorders
427	Cardiac dysrhythmias
427.5	Cardiac arrest
428	Heart Failure
429	Ill-defined descriptions and complications of heart disease
745	Bulbus cordis anomalies and anomalies of cardiac septal closure
746	Other congenital anomalies of heart
798.1	Instantaneous death
798.2	Death occurring in less than 24 hours from onset of symptoms, not otherwise explained
798.9	Unattended death
799	Other ill-defined and unknown causes of morbidity and mortality

Table A3.2 International Classification of Diseases, Tenth Revision	
I00-I02	Acute rheumatic fever
I05-I09	Chronic rheumatic heart diseases
I11	Hypertensive heart disease
I13	Hypertensive heart and renal disease
I20	Angina pectoris
I21	Acute myocardial infarction
I22	Subsequent myocardial infarction
I23	Certain current complications following acute myocardial infarction
I24	Other acute ischaemic heart diseases
I25	Chronic ischaemic heart disease
I26-I28	Pulmonary heart disease and diseases of pulmonary circulation
I30	Acute pericarditis
I31	Other diseases of pericardium
I32	Pericarditis in diseases classified elsewhere
I33	Acute and subacute endocarditis
I34	Nonrheumatic mitral valve disorders
I35	Nonrheumatic aortic valve disorders
I36	Nonrheumatic tricuspid valve disorders
I37	Pulmonary valve disorders
I38	Endocarditis, valve unspecified
I39	Endocarditis and heart valve disorders in diseases classified elsewhere
I40	Acute myocarditis
I41	Myocarditis in diseases classified elsewhere
I42	Cardiomyopathy
I43	Cardiomyopathy in diseases classified elsewhere
I44	Atrioventricular and left bundle-branch block
I45	Other conduction disorders
I46	Cardiac arrest
I46.1	Sudden cardiac death, so described
I47	Paroxysmal tachycardia
I48	Atrial fibrillation and flutter
I49	Other cardiac arrhythmias
I50	Heart failure
I51	Complications and ill-defined descriptions of heart disease
I52	Other heart disorders in diseases classified elsewhere
Q20	Congenital malformations of cardiac chambers and connections
Q21	Congenital malformations of cardiac septa
Q22	Congenital malformations of pulmonary and tricuspid valves
Q23	Congenital malformations of aortic and mitral valves
Q24	Other congenital malformations of heart
R96.0	Instantaneous death
R96.1	Death occurring less than 24 hours from onset of symptoms, not otherwise explained
R98	Unattended death
R99	Other ill-defined and unspecified causes of mortality

# Appendix 4

## Causes of SCD and associated risk factors

Cause of Death	Risk Factors
<b>Coronary heart disease</b>	<ul style="list-style-type: none"> <li>- prior cardiac arrest</li> <li>- severely depressed left ventricular function (LVF)</li> <li>- spontaneous or provoked ventricular tachycardia (VT) particularly when associated with syncope or pre-syncope (fainting/blackouts)</li> </ul>
<b>Hypertrophic cardiomyopathy(HCM)<sup>1</sup></b>	<ul style="list-style-type: none"> <li>- syncope</li> <li>- a family history of SCD in a first degree relative</li> <li>- VT</li> <li>- an increased thickness of heart wall to &gt;3mm</li> <li>- hypotension (low blood pressure) developing with exercise</li> </ul>
<b>Dilated cardiomyopathy (DCM)<sup>2</sup></b>	<ul style="list-style-type: none"> <li>- prior cardiac arrest</li> <li>- ejection fraction (EF) &lt; 35% indicating severely depressed LVF</li> <li>- syncope</li> <li>- VT</li> </ul>
<b>Right ventricular cardiomyopathy (RVCM)<sup>3</sup></b>	<ul style="list-style-type: none"> <li>- prior cardiac arrest</li> <li>- syncope</li> <li>- VT</li> </ul>
<b>Channelopathies</b>	<ul style="list-style-type: none"> <li>- prior cardiac arrest</li> <li>- syncope</li> <li>- VT</li> </ul>
<b>Myocarditis</b>	<ul style="list-style-type: none"> <li>- prior cardiac arrest</li> <li>- syncope</li> <li>- VT</li> </ul>
<b>Anomalous coronary arteries</b>	<ul style="list-style-type: none"> <li>- prior cardiac arrest</li> <li>- syncope</li> <li>- VT</li> </ul>
<b>Drugs (illicit and prescription)</b>	Consumption at relevant time
<b>Commotio Cordis</b>	

<sup>1</sup> Spirito P, Seidman CE, McKenna WJ, Maron BJ et al. The management of hypertrophic cardiomyopathy. N Eng J Med 1997; 336: 775-85.

<sup>2</sup> Galvin JM, Ruskin JN. Ventricular tachycardia in patients with dilated cardiomyopathy. Cardiac Electrophysiology: From Cell to Bedside 4th Edition; Saunders, Philadelphia, USA

<sup>3</sup> Fontaine G, Fontailran F, Hebert JL et al. Arrhythmogenic Right Ventricular Dysplasia. Ann Rev Med 1999; 50: 17-35.

# Appendix 5

## Management of Coronary Heart Disease

All individuals with CHD should be advised on aggressive risk factor modification. Those with angina or evidence of induced ischemia during stress testing should be considered for coronary angiography. Those with demonstrable CHD warrant treatment with aspirin, a beta blocker and, when appropriate, revascularisation in addition to aggressive risk factor modification. These individuals should be treated with a statin irrespective of their cholesterol level.<sup>1,2</sup>

Individuals with an acute coronary syndrome (unstable angina or myocardial infarction) should be treated with aspirin, clopidogrel, a beta blocker, low molecular weight heparin, a statin, urgent angiography and when appropriate percutaneous coronary intervention (PCI) or coronary bypass grafting (CABG).

Individuals with a STEMI should be treated with primary angioplasty or when and where appropriate, with thrombolysis.<sup>3,4</sup>

ACE inhibitors have also been associated with reduced death rates.

Those adults with CHD who have:

- had a prior cardiac arrest
- severely depressed left ventricular function (left ventricular ejection fraction <35%)
- syncope with inducible ventricular tachycardia or
- haemodynamically unstable ventricular tachycardia

should be treated with an implantable cardiac defibrillator (ICD) if not contra-indicated. Robust data from a number of trials (AVID<sup>5</sup>, MADIT I<sup>6</sup> and MADIT II<sup>7</sup>, COMPANION<sup>8</sup>, SCDHeFT<sup>9</sup>, MUSTT<sup>10</sup>, CIDS<sup>11</sup>) have improved survival using this approach.

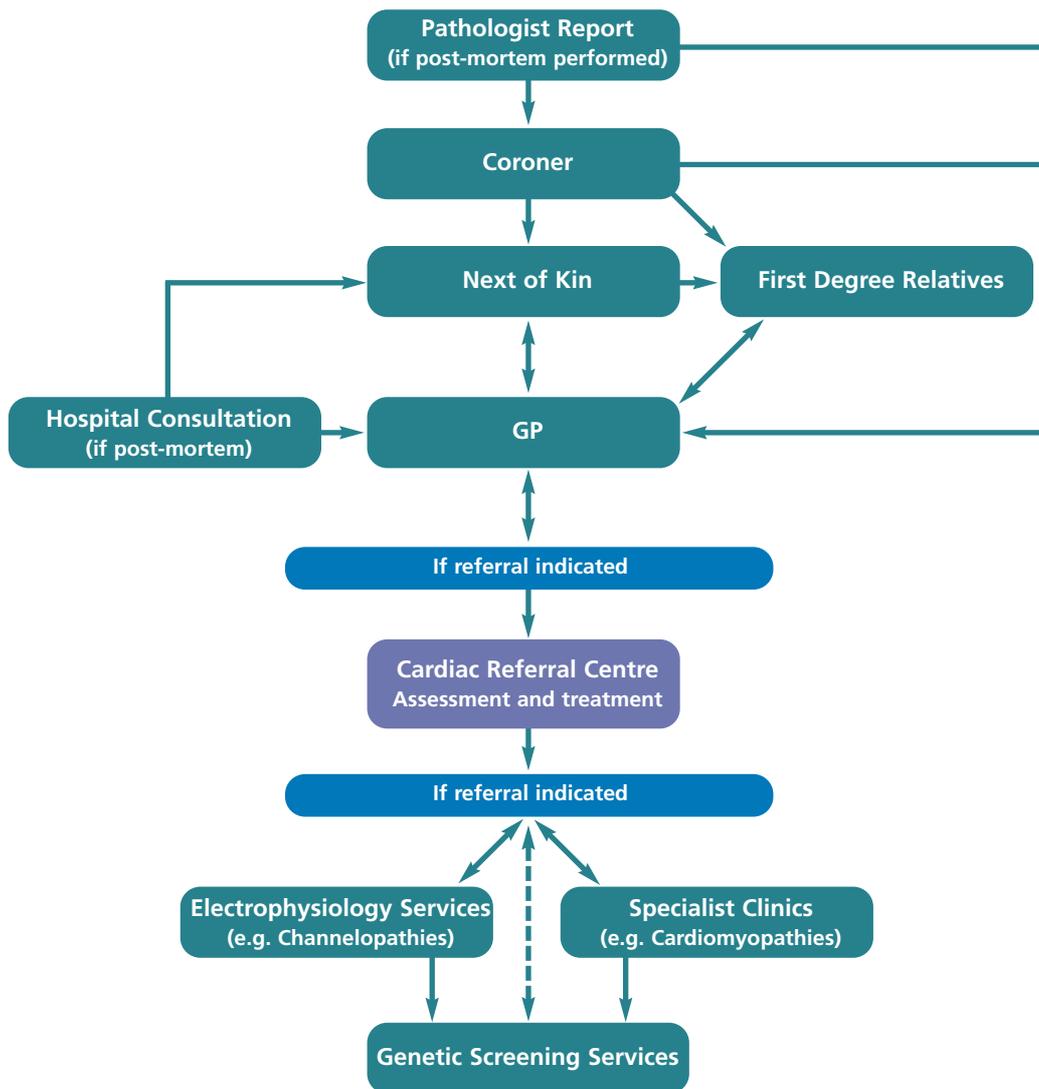
In summary, appropriate and timely intervention in patients with CHD combined with secondary prevention measures and the use of drugs such as aspirin<sup>12</sup>, statins<sup>13</sup> and beta-blockers<sup>14</sup> reduces the incidence of SCD in patients with significant degree of left ventricular impairment.

## References

- <sup>1</sup> AHA / ACC Guidelines for treatment of stable exertional angina.
- <sup>2</sup> ESC Guidelines for treatment of stable exertional angina.
- <sup>3</sup> AHA / ACC Guidelines for treatment of acute coronary syndromes.
- <sup>4</sup> ESC Guidelines for treatment of acute coronary syndromes.
- <sup>5</sup> The antiarrhythmics versus Implantable Defibrillators (AVID) Investigators: A comparison of antiarrhythmic drug therapy with implantable defibrillators in patients resuscitated from near-fatal ventricular arrhythmias. *N Engl J Med* 1997;337: 1576-83.
- <sup>6</sup> Moss AJ, Hall WJ, Cannom DS, et al. Improved survival with an implanted defibrillator in patients with prior coronary artery disease at high risk for ventricular arrhythmia. Multicenter Automatic Defibrillator Implantation Trial. *N Engl J Med* 1996; 335: 1933-40.
- <sup>7</sup> Moss AJ, Zareba W, Hall WJ, et al. Prophylactic implantation of a defibrillator in patients with myocardial infarction and reduced ejection fraction. *N Engl J Med* 2002; 346(12): 877-83.
- <sup>8</sup> Insert Cleland JG, Coletta AP, Nikitin N, Louis A, Clark A. Update of clinical trials from the American College of Cardiology 2003. EPHEBUS, SPORTIF-III, ASCOT, COMPANION, UK-PACE and T-wave alternans. *Eur J Heart Fail* 2003; 5: 391-8.
- <sup>9</sup> Bardy GH, Lee KL, Mark DB et al. Amiodarone or an implantable cardioverter-defibrillator for congestive heart failure (SCDHeFT). *N Eng J Med* 2005; 352: 225-37.
- <sup>10</sup> Buxton AE, Lee KL, Fisher JD, et al. A randomized study of the prevention of sudden death in patients with coronary artery disease. Multicenter Unsustained Tachycardia Trial Investigators. *N Eng J Med* 1999; 341: 1882-90.
- <sup>11</sup> Connolly S, Gent M, Roberts R, et al. Canadian Implantable Defibrillator Study (CIDS): A randomized trial of the defibrillator against amiodarone. *Circulation* 2000; 101:1297-1302.
- <sup>12</sup> Driess DL, Domanski MJ, Waclawiw MA, et al. Effect of antithrombotic therapy on risk of sudden coronary death in patients with congestive heart failure. *Am J Cardiol* 1997;79: 909-13.
- <sup>13</sup> Long-term intervention with pravastatin in ischaemic disease (LIPID) study group. Prevention of cardiovascular events and death with pravastatin in patients with coronary disease and a broad range of initial cholesterol levels. *N Engl J Med* 1998; 339: 1349-57.
- <sup>14</sup> Kennedy HL, et al. Beta-blocker therapy in the Cardiac Arrhythmia Suppression Trial. *Am J Cardiol* 1994; 74: 674-80.

# Appendix 6

## Communication and Referral Pathways for First Degree Relatives after SCD



## Appendix 7



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

### **Information and Practical Advice for Developing Community First Responder Programmes and the use of Automated External Defibrillators (AEDs)**

## Foreword

This information pack has been developed by the First Responder Steering Group, Health Services Executive, Southern Area in conjunction with the Pre-Hospital Emergency Care Council (PHECC).

PHECC is an independent statutory agency charged with responsibility for standards, education and training in the field of pre-hospital emergency care in Ireland.

The Council was established as a body corporate by the Minister for Health and Children in April 2000 by Statutory Instrument Number 109 of 2000. This order was made under the Health (Corporate Bodies) Act, 1961 as amended.



## 1. Introduction

It is widely recognised that Ireland has a high rate of death from coronary heart disease (CHD), with one in five of all deaths being attributed to this cause. However the incidence of sudden cardiac death (SCD) in Ireland is more difficult to determine. Using internationally comparable data, it has been estimated that SCD could account for approximately 5,000 deaths annually in Ireland.

Sudden death can be caused by a number of conditions, but the majority of deaths occur from late middle age onwards and are as a result of CHD. Other causes of SCD include viral infections of the heart muscle, inherited genetic conditions including enlarged heart muscles and faulty wiring of the electrical system of the heart muscle (cardiomyopathies and channelopathies).

In the majority of cases, SCD occurs due to the sudden disturbance of the heart's electrical conduction system, resulting in a chaotic heart rhythm, called ventricular fibrillation (VF). If ventricular fibrillation is not treated, death ensues within minutes.

The treatment for VF is the delivery of an electrical shock to stabilise the hearts rhythm, this is known as defibrillation. The chances of successful defibrillation decline at a rate of 7 to 10% with each minute. If defibrillated within 5 minutes, survival rates are approximately 50%, potentially higher with younger people. If time to defibrillation is 10 minutes, survival rates approach zero percent without cardiopulmonary resuscitation (CPR) and 10 to 20% if CPR has been used.

**This underlines the need for more defibrillators to be readily available, more timely in their use and for more people to be trained in using them.**

## 2. The Role of a First Responder

A 'first responder' is:

*'A person trained as a minimum in basic life support and the use of an automated external defibrillator (AED), who attends a potentially life threatening emergency. This response may be by the statutory ambulance service or complementary to it. If complementary, first responders can be linked with the statutory emergency services or they can be independent and stand alone. In any single event the first responder may be an individual who happens to be present or part of a first response service. Many trained first responders may or may not participate in a first responder programme'.*

When a community is considering developing a First Responder Programme including defibrillation, it should be remembered that even in a well targeted, structured programme, the defibrillator may never be used. Furthermore, on the rare occasion that it is used the life may not be saved, not due to shortcomings of the programme or the individual but due to an underlying medical condition. This may be a difficult situation for the 'responder' and the community to come to terms with.

This information pack has been designed to provide practical advice and information on all aspects of developing a First Responder Programme, in order that your community can make an informed decision.

### 3. Link to Emergency Services

When an emergency collapse or cardiac arrest occurs, a speedy and effective response is required if the chances of the person's survival are to be maximised. This is the basis of a concept known as the "chain of survival"<sup>1</sup>

The components in the chain of survival are:

- Early access to emergency medical services (EMS)
- Early cardiopulmonary resuscitation (CPR)
- Early defibrillation
- Early advanced cardiac life support (ACLS)

It is essential that 'first responders' are in a position to recognise that there is an emergency and to call the emergency services **immediately**, either themselves or by instructing another person to do so. This phone call ensures that professional medical help is on the way, as every minute that there is a delay in calling for help can make a significant difference to the outcome.

**Remember!**  
**When an emergency occurs the first step is always to:**  
**Dial 999 or 112**

If you are a part of a First Responder Programme that is **linked or integrated** with the emergency services, the ambulance service will be relying on you to respond by way of an on-call system.

If you are operating a **stand alone or independent programme** we would request that you would inform the First Responder Coordinator, Health Service Executive (HSE), Southern Area as to the defibrillators location and that you are trained in its use.

Irrespective, it is essential to contact the ambulance service by dialling 999 or 112 in an emergency.

### 4. Types of First Responder Programmes

There is no one type of recommended First Responder Programme to suit all communities. The type of programme you should develop will depend on the specific needs of your community.

There is good evidence to suggest training to the level of CPR and AED use is effective in First Responder Programmes. The evidence for more comprehensive training in other medical and trauma situations is less clear and requires a greater investment of time and resources in training. It seems sensible at this time to concentrate efforts on cardiac events and this will build a good foundation for expansion at a later time if needs be.

<sup>1</sup> Cummins RO, Omato JP, Thies WH, Pepe PE. Improving survival from sudden cardiac arrest: the 'Chain of survival' concept. A statement for health professionals from the Advanced Cardiac Life Support Sub-committee and the Emergency Cardiac Care Committee. American Heart Association. Circulation 1991; 83:1832-47.

Other than the statutory ambulance service, the most common First Responder Programmes are:

- General Practitioner (GP) led
- Uniformed
- Community
- Site specific
- Public Access Defibrillation (PAD)
- Home/individual

### GP First Responder

A GP First Responder Programme is one whereby the local GP practice is equipped and trained to use an AED in responding to an acute cardiac event. In the Cork / Kerry region this programme is linked with the EMS and has been established in the following areas;

- Dingle Peninsula
- Kinsale
- North Cork West

It is planned to establish four further sites in the near future;

- Cobh
- Castletownbere / Beara Island
- Skibbereen / Sherkin/ Cape Clear
- Macroom / Ballingearry / Ballyvourney

### Uniformed First Responders

There are two types of uniformed programmes that can be developed.

- **On-duty** – these would include the gardaí, fire brigade, etc acting as a first responder during the course of their work.
- **Off-duty** – off-duty health professionals including emergency medical technicians (EMT), voluntary and auxiliary organisations who are used to responding to emergencies are an ideal group of people to organise and deliver a uniformed programme that is linked with the EMS on a voluntary basis.

### Community First Responders

A community First Responder Programme can be stand alone / independent or linked / integrated with the EMS.

- **Stand alone / independent**

A stand alone model would consist of defibrillators that are easily accessed by trained people in the community. In an event, after contacting 999 or 112, the local response would be according to your locally agreed protocols, (this may involve setting up an on-call rota, carrying a mobile phone, designated contact points, etc.)

- **Linked / integrated**

In a linked / integrated model the ambulance service, on receiving the 999 or 112 call would dispatch a rostered on-call community based first responder.

In either model there is evidence to suggest that you should target and include those members of the community who are used to responding to emergencies in their working environment, e.g. uniformed workers.

#### Site specific

Similar to a community programme, as lay people are the first responders, however the programme is site specific, in a defined area / facility e.g. those sites listed under priority locations. (See Section 8)

#### Public Access Defibrillation (PAD)

Public access defibrillation is AEDs made overtly accessible for use by members of the public. In reality, there are very few true public access defibrillator programmes as the evidence for the introduction of PAD is not conclusive at this moment in time. However there may be certain venues or locations where it may be of benefit.

#### Home/Individual

Some individuals at high risk may establish their own programme within their home.

## 5. Management of the Programme

We would recommend that a small group within your community is established to manage this programme which would include or develop strong links with the local GP and ambulance service. This group should take responsibility for ensuring that the programme has well documented procedures. These procedures should cover areas such as communication and activation, access to and use of AED, maintenance of AEDs, debriefing after an event, etc.

An area that needs careful consideration by the group will be how to manage long term motivation, especially if there are no incidents to respond to over a long period of time.

To help this and also for the longer term benefit of the community, we recommend that your group adopt a broader approach to heart health, rather than focussing solely on the management of an acute cardiac event or sudden death. A community approach to heart health promotion will complement the focus on managing cardiac events and will help maintain long term motivation.

## 6. Insurance

One of the main stumbling blocks to communities purchasing AEDs and developing programmes has been concern over legal indemnity.

The State Claims Agency (Clinical Indemnity Scheme [CIS]) has agreed that members of the public/volunteer first responders participating in a **formalised (linked)** programme, who have

been trained in the use of AEDs and CPR in a formal, structured way and post-training remain under the supervision and control of the HSE Ambulance Service, will be indemnified.

This indemnity does not apply however to those members of the public (including uniformed personnel e.g. fire fighters, gardaí) who receive **CPR training only**. This includes those members of the public who may attend mass training days provided by the ambulance services or HSE Resuscitation Training Officers and are not enrolled on any formal, structured training programme and do not report thereafter to the ambulance services.

The CIS has agreed that health professionals employed by the HSE will also be indemnified for Good Samaritan acts when in an off-duty capacity.

The CIS has also advised GPs to seek their own cover under their own medical malpractice policies.

Site specific e.g. golf clubs, GAA clubs, etc. will be able to obtain insurance cover as part of their broader public liability policies.

Credible legal opinion supports that the likelihood of successful litigation arising from a "Good Samaritan" act is remote.

Further advice on insurance issues can be obtained from the First Responder Coordinator whose contact information is at the end of this advice guide.

## 7. Training

A variety of first aid courses of varying duration and content are provided by various statutory, voluntary and private providers. The cost of this training will depend upon which course you wish to do and who provides the training.

The Irish Heart Foundation (IHF) is the franchise holder for American Heart Association (AHA) training and trainer courses in Ireland, which is the training standard that Ireland currently works to. The IHF web site ([www.irishheart.ie](http://www.irishheart.ie)) contains helpful information on the courses they offer as well as the location of approved training sites and approved trainers.

Training in CPR and AED can generally be delivered between 4 and 6 hours.

Before embarking on a training course it is important to understand that ongoing recertification will be required if you are to remain proficient in CPR and AED use. The training provider you choose will also advise on keeping your skills up to date with renewal training and how often this should be undertaken.

Presently the IHF recommend that CPR and AED revalidation is obtained every 90 days especially for those who would not be using the skills on a regular basis, i.e. out in the community. Recertification on CPR and AED training should be every two years.

It is therefore important to build this ongoing cost into your budget.

Not only can CPR and AED training potentially reduce the incidence of pre-hospital cardiac deaths, it can also be used to educate the public in the symptoms of heart attack, stroke, choking and cardiac arrest. Training will also put greater emphasis on the importance of a quick response to an incident and is an ideal opportunity to promote heart health and general well being in the community.

## 8. Placement of AEDs

There is no restriction on where AEDs can be placed or who can purchase them. There is however good evidence to suggest that some locations are more appropriate than others.

**Priority** locations would include:

- Inpatient health facilities
- GP surgeries and primary care facilities
- Airports, shopping centres, major sports venues and golf courses, bus / rail terminals, ferries / ferry terminals, concert and conference venues
- Universities and colleges
- Gyms and fitness clubs, and
- Other venues for major public events

Certain people who have suffered from heart disease and are identified at high risk may be advised to purchase an AED for use in their household.

Certain localities, distant from emergency medical services are also a priority.

You should carefully consider the optimal location within your community, bearing in mind possible distances of travel, access to users and security issues. Wherever you choose to site an AED, ensuring that it is readily available is essential.

The numbers of AEDs that would be required to cover any given area or site depends on the number of potential cardiac events and would also be determined by a response time of 'collapse to use' within 5 minutes.

## 9. AED Selection and Maintenance

There are many models of AEDs available and they are relatively inexpensive. However the ongoing costs of consumables need to be taken into consideration when purchasing your model. In considering its specification, an AED must be totally reliable, low weight, require little maintenance, have a long battery life, a lengthy warranty and most importantly is easy to use.

A model with recording facilities would be helpful to facilitate evaluation and audit.

**It is particularly important that the model you choose is compatible with your local ambulance service.**  
 Prior to purchasing your chosen model we suggest that you contact the First Responder Coordinator to discuss the specifications to ensure compatibility.

When you purchase your AED, the manufacturer or supplier should always provide you with training on the technical aspects of the model. They should also advise you on maintenance requirements. It is highly advisable, (and is usually an insurance requirement) that you keep an accurate record of maintenance of your AED, that maintenance schedules are observed and recorded, regular checks / refurbishment of consumables are performed, and clear roles and lines of responsibility are identified. A designated person in each location should ensure that these objectives are achieved.

It is essential that AED owners / users inform the local EMS of the location of the AED.

## 10. Information Collection and Audit

It is important to keep a record of times and interventions when an AED is used. It is especially important to know if the collapse was witnessed, what time it occurred, when help arrived, when CPR commenced, when defibrillation was attempted and how many times. Ideally a system for recording this information should be developed as part of your procedures. The First Responder Coordinator or local EMS will provide you with special forms to capture this information.

## 11. Follow Up after an Event

If and when you have to use a defibrillator it will obviously be a traumatic event for all concerned. This is particularly so if the person dies. It is essential that support is given to those members in the community who were involved. This may involve access to formal services such as counselling. Again this should be included when you are developing your procedures.

After an event, it is also an important opportunity to reflect and learn from the experience in order to further refine and develop the programme for the community. It is therefore essential that when setting up a programme, consideration should be given as to how this can be achieved.

## 12. Conclusion

After considering the information and advice in this pack, you are now aware that a considerable amount of thought and planning is needed before embarking on a First Responder programme in your community. The purchase of an AED, whilst an essential component in the chain of survival, must be considered in context with the development and management of the **whole programme**. Careful consideration will need to be given to not only the initial cost of setting up your programme, but also to the ongoing costs.

The HSE Southern Area First Responder Steering Group are committed to developing a range of First Responder Programmes, across all levels. Where and when these programmes are developed is dictated by evidence based best practice and priority areas of greatest need. In addition, the critical resources required to support and to implement these programmes is dependent upon our yearly financial allocation from the HSE.

Due to the above, we are not in a position to include all requests from all communities for immediate inclusion in our linked programmes. If we are not in a position to include your community programme immediately, we do hope that after consultation with us you will consider developing a stand alone / independent First Responder Programme that can in the future be integrated with our official programme.

Please note that these guidelines will be subject to amendments and will need to be updated as and when additional information and advice becomes available to us. We will endeavour to keep you informed of these updates.

Good luck with your programme and we ask that you would keep us informed of your developments.

### Further information can be obtained from:

First Responder Coordinator  
HSE Southern Area  
Ambulance Headquarters  
Unit 5  
South Ring Business Park  
Kinsale Road  
Cork

Tel. No.: 021/4927393  
Email: [first.responder@mailp.hse.ie](mailto:first.responder@mailp.hse.ie)

### For further information on Health Promotion initiatives in your community contact

Health Promotion Department  
HSE Southern Area  
Eye, Ear & Throat Hospital  
Western Road  
Cork

Tel. No.: 021 4921641  
Email: [hpdi@mailp.hse.ie](mailto:hpdi@mailp.hse.ie)



