Tackling Chronic Disease

A Policy Framework for the Management of Chronic Diseases

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MINISTER'S FOREWORD

I am pleased to introduce this policy on the prevention and management of chronic disease. Ireland is in transition. Our population is growing but, by European standards, is still relatively young. Within the next two decades, this will change and we will have a significant increase in the number of older people.

The health of Irish people has improved, especially over the past decade. Better treatment and prevention has reduced mortality from the major diseases. However, in Ireland, as in other countries, chronic health conditions such as diabetes and high blood pressure are on the rise. Our ageing population, together with adverse trends in diet, exercise, obesity and other risk factors, means that the level of chronic conditions will certainly increase. These conditions affect general wellbeing and quality of life; account for most of the healthcare resources used, and will represent a significant economic burden for Ireland in the future.

There is much which can be done because most of the chronic disease burden is caused by risk factors which can be prevented. This is everybody's business, from the level of Government policy to individual choices that are made regarding lifestyle habits. I welcome the cross departmental linkages set out in this policy which will ensure that health is reflected in the programmes and policies of other sectors. A number of lifestyle factors which contribute to chronic disease will be identified for action at Government level.

There are proven strategies to prevent and reduce the burden of chronic disease. For many individuals with a chronic condition, care is episodic, reactive and takes place within hospitals. It is generally now accepted that care should be structured and importantly that care is integrated with a greater emphasis on prevention. This new approach will put disease management programmes in a central position to treat and delay the onset of complications for those with a chronic condition. Much of this care can and should take place within the primary care setting. With the appropriate level of support, unnecessary hospital admissions can be avoided and quality of life improved for patients with chronic conditions. It will also involve the development of programmes to support self-care which is key to managing these conditions successfully.

This policy framework describes the burden of chronic conditions and the drivers which contribute to them. The health system will need to adapt to the challenges posed by chronic disease. I welcome the measures set out in the report and I would like to thank the Secretary General and the staff of the Department who contributed to this report.

Mary Harney, TD
Minister for Health and Children

INTRODUCTION

Chronic diseases are recognised as a major health challenge. In the healthcare system, they represent the major component of service activity and expenditure, as well as the major contributor to mortality and ill-health in this country. Given the population projections which predict a doubling of the elderly population over the next 30 years, this will give rise to a significant increase in chronic diseases with the consequent burden on society, the healthcare system and individuals.

The main causes of chronic disease are known. They are largely preventable. Lifestyle factors including tobacco and alcohol usage, together with physical inactivity, poor diet and obesity are key risk factors along with high blood pressure and cholesterol for chronic disease. These risk factors are also linked with ill-health in the general population where health improvement activities are not only directed against chronic diseases but aim to promote health across many groups in the population. Effective interventions are known and it is estimated that 80% of cardiovascular disease and type 2 diabetes as well as 40% of cancer could be avoided if major risk factors were eliminated. The burden of chronic diseases and the lifestyle factors that contribute to them rests more heavily in the lower socioeconomic groups.

Chronic diseases cluster in individuals. Approximately one third of men over 60 years of age have 2 or more chronic conditions and this trend increases with age. Chronic diseases occur more frequently among the poor and vulnerable. Chronic diseases have a lifelong course and place a significant burden on the patient, their families and carers. Chronic diseases represent one of the major health challenges in Europe today. Eighty six per cent of deaths and 77% of disease burden are now caused by chronic disease. They represent the significant majority of GP consultations and hospital admissions.

In response to these challenges, many countries are developing new policy frameworks for chronic disease. These are broadly based on **disease prevention programmes** to prevent the occurrence of disease and **disease management programmes** to treat and delay the onset of complications and reduce emergency hospital admissions. Many of these models have been successful. The European Union (EU) and World Health Organisation (WHO) are actively engaged in the development of policies and programmes to prevent and manage chronic disease.

This chronic disease policy framework addresses the challenges of chronic disease so as to reduce the burden for individuals, their carers and the health system. Broadly, the aims of this policy are (i) to promote and to improve the health of the population and reduce the risk factors that contribute to the development of chronic diseases and (ii) to promote structured and integrated care in the appropriate setting that improves outcomes and quality of life for patients with chronic conditions.

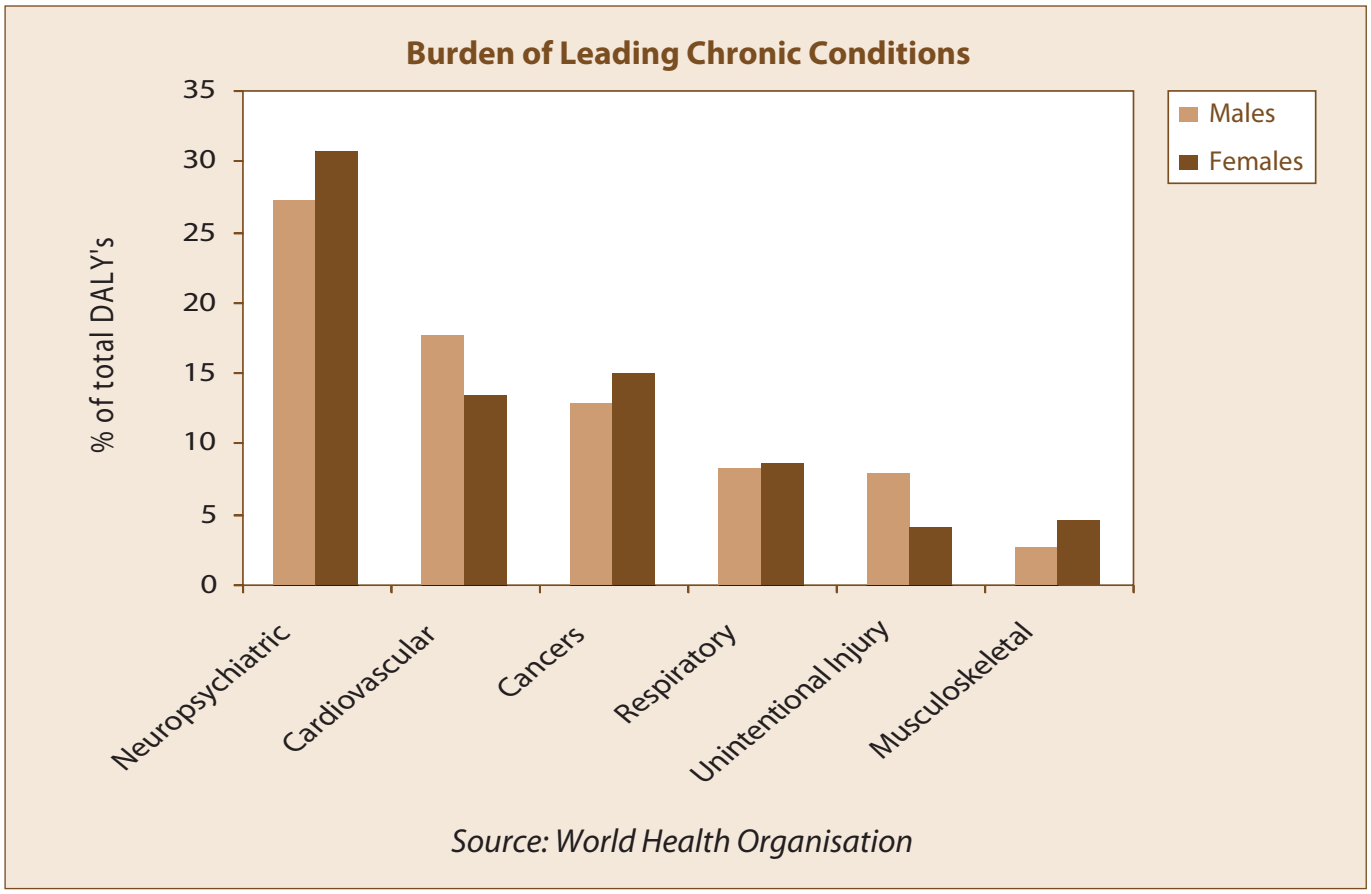
This framework for action underlines the importance of intersectoral activities for prevention of the emergence of adverse lifestyle factors that contribute to chronic disease It addresses the management of chronic disease at different levels through a reorientation towards primary care and the provision of integrated health services that are focused on prevention and returning individuals to health and a better quality of life.

The target group of this report is decision makers and planners at all levels of the public health system who are involved in the prevention and care of chronic disease in Ireland. It sets out the policy requirements and the actions to give effect to these. It is intended to complement the broad range of health improvement activities aimed at promoting health across the population.

WHAT IS CHRONIC DISEASE?

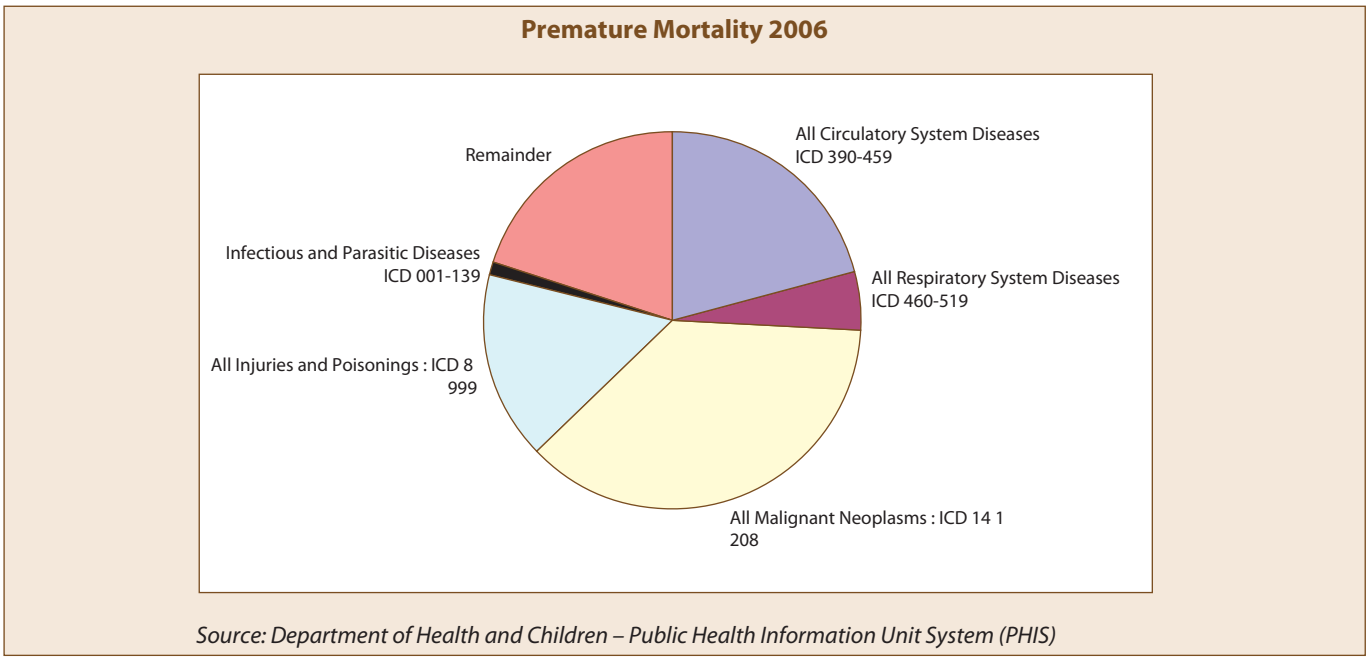
Chronic diseases are long-term conditions, lasting more than 6 months, are non-communicable and involve some functional impairment or disability and are usually incurable. Anyone can be affected, however, they usually occur in older people and are a significant contribution to the disease burden in society. They include conditions such as cardiovascular disease, diabetes, cancer, musculoskeletal conditions and osteoporosis, mental disorders, asthma and chronic bronchitis. Many of these are caused by lifestyle factors and other determinants of health including tobacco and alcohol consumption, diet, physical activity, obesity, accidents, the working environment, and finally other environmental factors. There are strong links between mental and physical health with both related through common determinants such as poor housing, poor nutrition, poor education and common risk factors such as alcohol. Approximately, 30% of individuals with cancer, cardiovascular disease or diabetes have major depression as a co-morbidity. Disability adjusted life years (DALY's) is an international quantitative measure commonly used in the description of morbidity in populations. Figure 1 demonstrates the burden of the leading chronic diseases in Ireland.

Figure 1. Burden of Chronic Disease



Chronic diseases are the leading cause of death and morbidity in developed countries. The World Health Organisation has attributed 86% of deaths and 77% of the overall disease burden in Europe to this broad group of diseases. The pattern in Ireland is similar. Cardiovascular disease and cancer are responsible for more than two thirds of all deaths and are the leading cause of premature mortality (Figure 2). Mental health conditions are one of the leading causes of morbidity in Ireland.

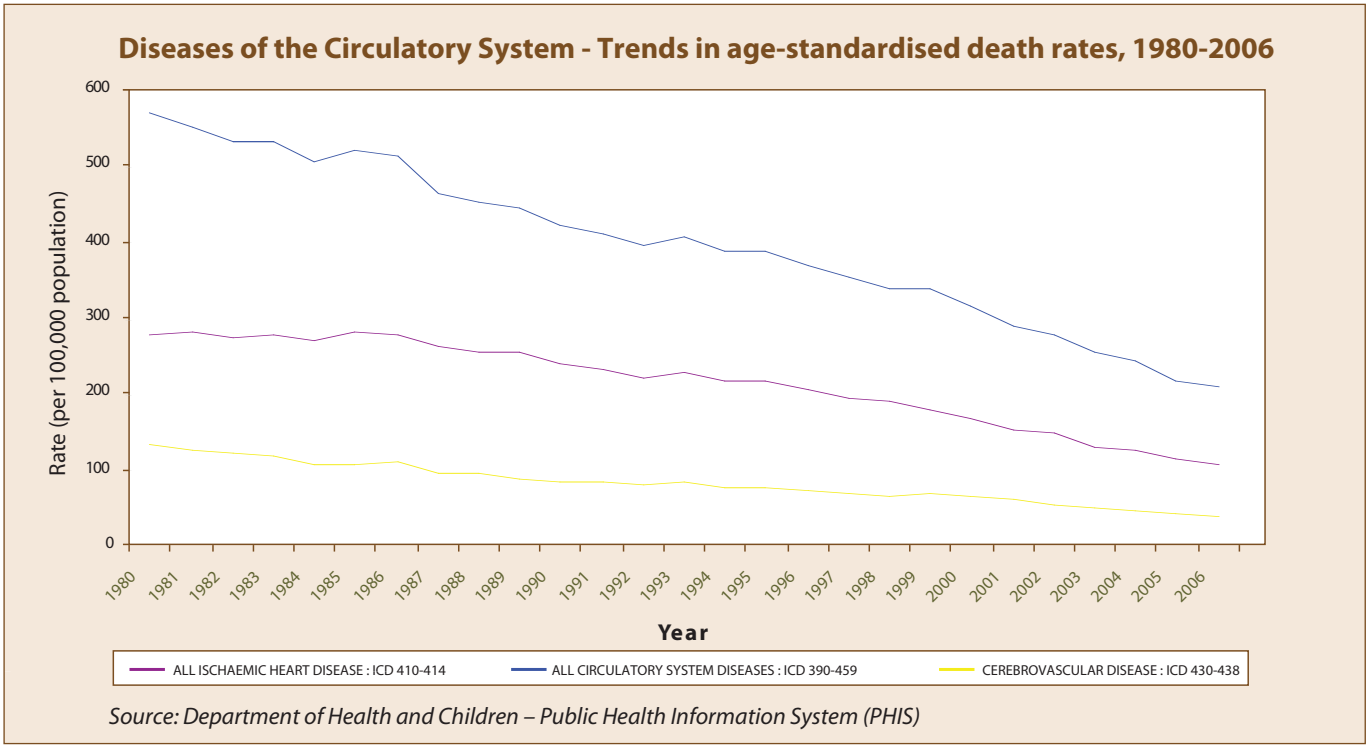
Figure 2: Premature mortality



Source: Department of Health and Children – Public Health Information Unit System (PHIS)

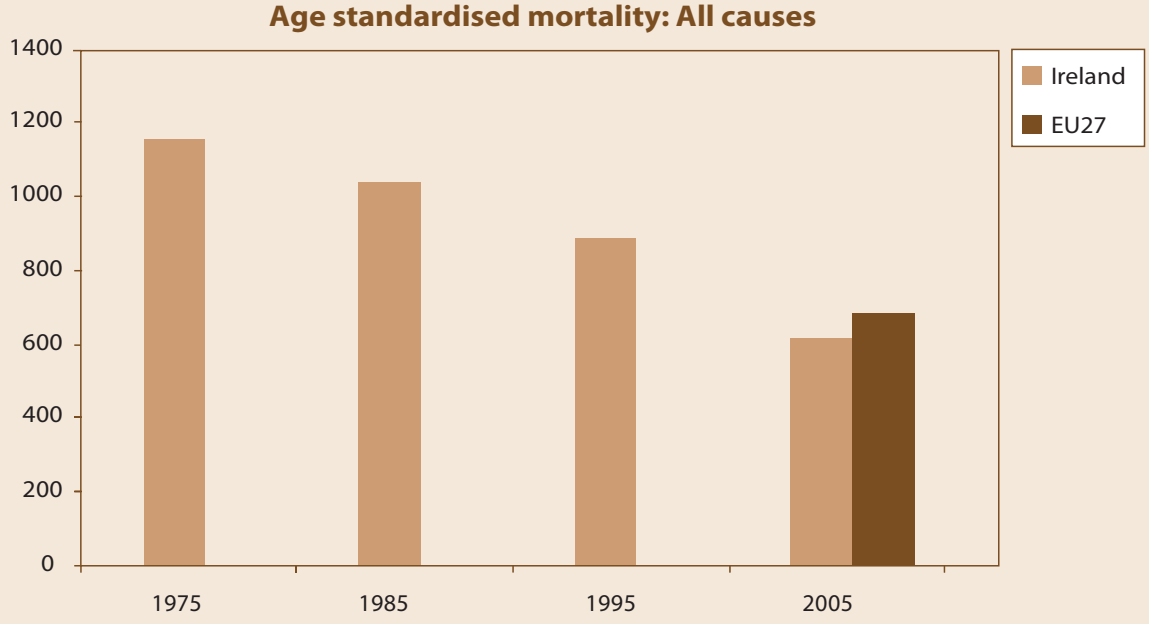
Mortality from certain major conditions such as heart disease and stroke has reduced significantly in recent years (Figure 3. Between 1980 and 2003, there have been approximately 6,000 fewer deaths due to better prevention and treatment. Despite improvements in mortality from chronic diseases in recent years, Irish rates are high (Fig 4) with corresponding lower life expectancies than EU 15 countries (Fig 5). The welcome mortality reduction as illustrated in Figure 3 means that more people are surviving the acute phase of the illness such as heart attack, and are now living with a long-term chronic illness. Chronic diseases usually occur in older people and many of these diseases cluster in individuals. Three quarters of people over 75 have at least one chronic condition and over a third of men over 60 years of age have two or more chronic diseases. Some European countries with older populations now estimate that 40% of society is living with a long-term, chronic condition.

Figure 3: Diseases of the circulatory system



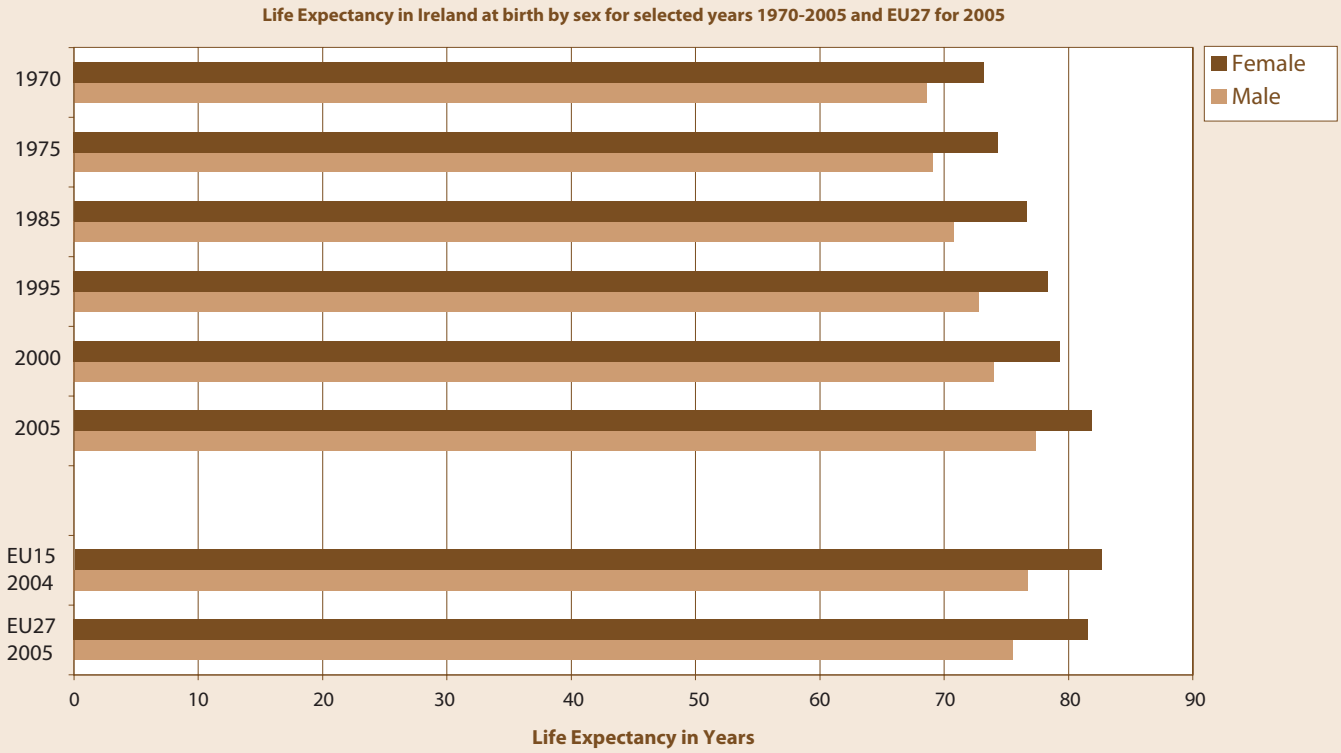
Source: Department of Health and Children – Public Health Information System (PHIS)

Figure 4: Age standardised mortality: all causes



Source: European Health for All database, WHO Regional Office for Europe

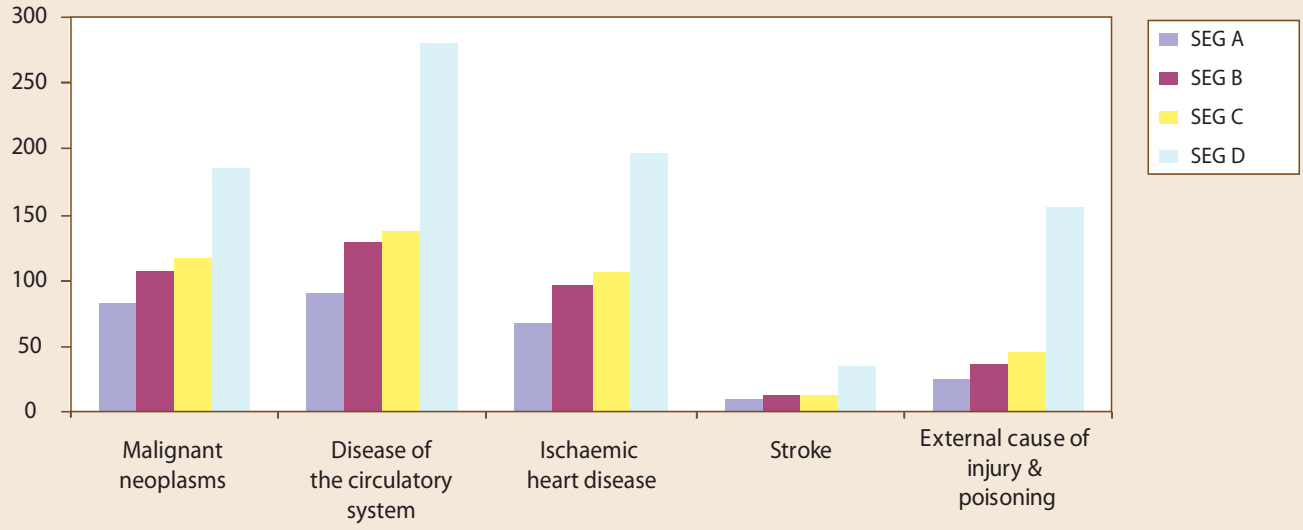
Figure 5: Life expectancy at birth



Source: European Health for All database, WHO Regional Office for Europe

These conditions and their underlying health determinants are distributed unevenly within society. Gaps are widening and the differences in life expectancy between the highest and lowest socioeconomic groups are increasing. This is particularly true for chronic diseases such as cancer and cardiovascular disease (Figure 6). For chronic disease mortality, overall there is three-fold difference between the highest and lowest occupational classes. The lifestyle factors that lead to these conditions are also distributed unevenly across society, in particular smoking, alcohol consumption, diet and physical activity.

Figure 6: Occupational class gradients in health



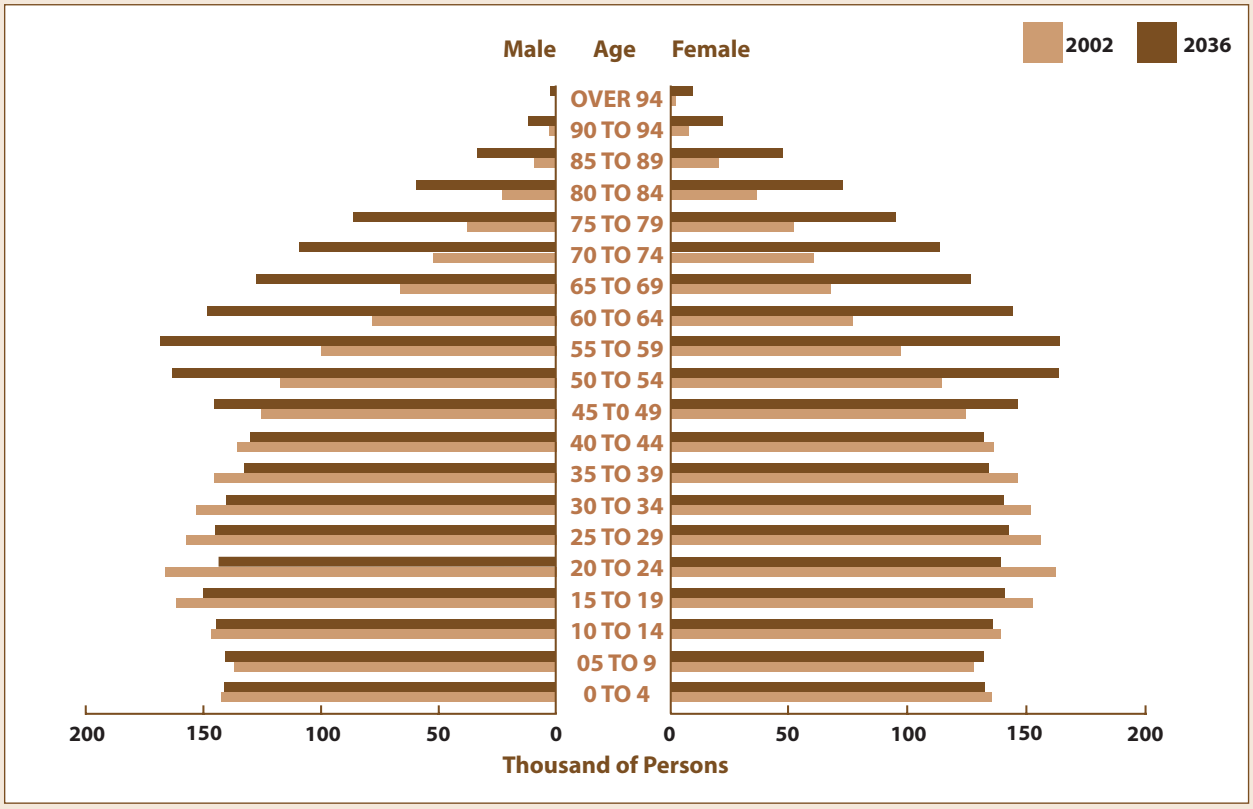
Source: Health Statistics, Department of Health and Children – Public Health Information System (PHIS)

Patients with chronic conditions are heavy users of the health services. It is estimated that three quarters of the healthcare expenditure is allocated to the management of chronic diseases. Healthcare costs and the risk of avoidable inpatient admission increases dramatically with the number of co-morbidities. Approximately 80% of GP consultations and 60% of hospital bed days are related to chronic diseases and their complications. Chronic diseases account for two thirds of emergency medical admissions to hospitals. The UK have estimated that 8 of the top 11 causes of hospital admissions are due to chronic diseases and that 5% of inpatients with a long-term condition account for 42% of all acute bed days.

There are also economic consequences for those with disease and their families. In some circumstances, treatment may not be affordable and the burden of cost can push families further into poverty. Long-term illness or disability has economic consequences for society. Families and society carry a burden of healthcare costs with reduced income, early retirement and an increased reliance on social care and welfare support. Employers and society also carry a burden related to diminished productivity and absenteeism. The World Health Organisation has recently estimated that in developed countries, chronic diseases are predicted to increase by 10-15% over the next decade and that this will reduce GDP by an order of 1%.

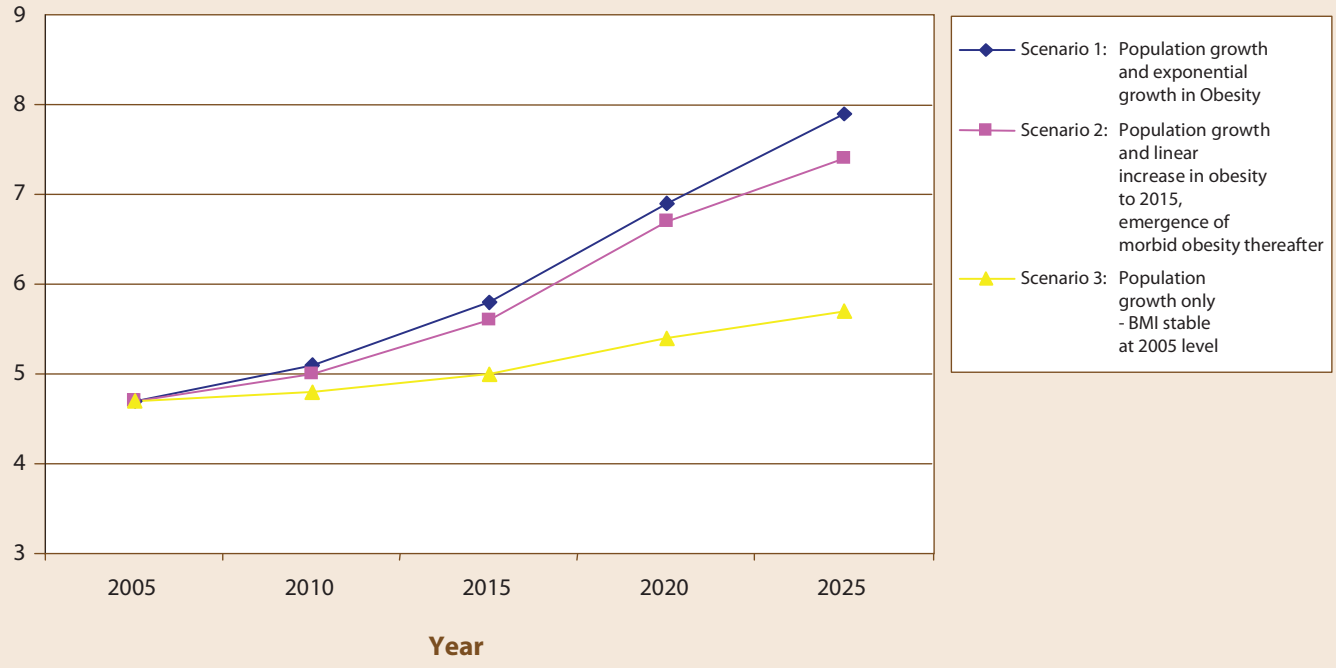
The demographic profile in Ireland is set to change with an ageing population and a corresponding increase in the burden of chronic diseases (Figure 7). Disease modelling from the Institute of Public Health shows the size of the increase for diabetes (Figure 8). This has implications for the health system, if the current trends continue, bed requirements will increase by 50%-60% over the next 15 years.

Figure 7: CSO Irish Population Projections



Source : Central Statistics Office - Population and Labour Force Projections 2006 to 2036

Figure 8: Forecasts of population prevalence of diabetes (adults only) from 2005 to 2025 under three scenarios

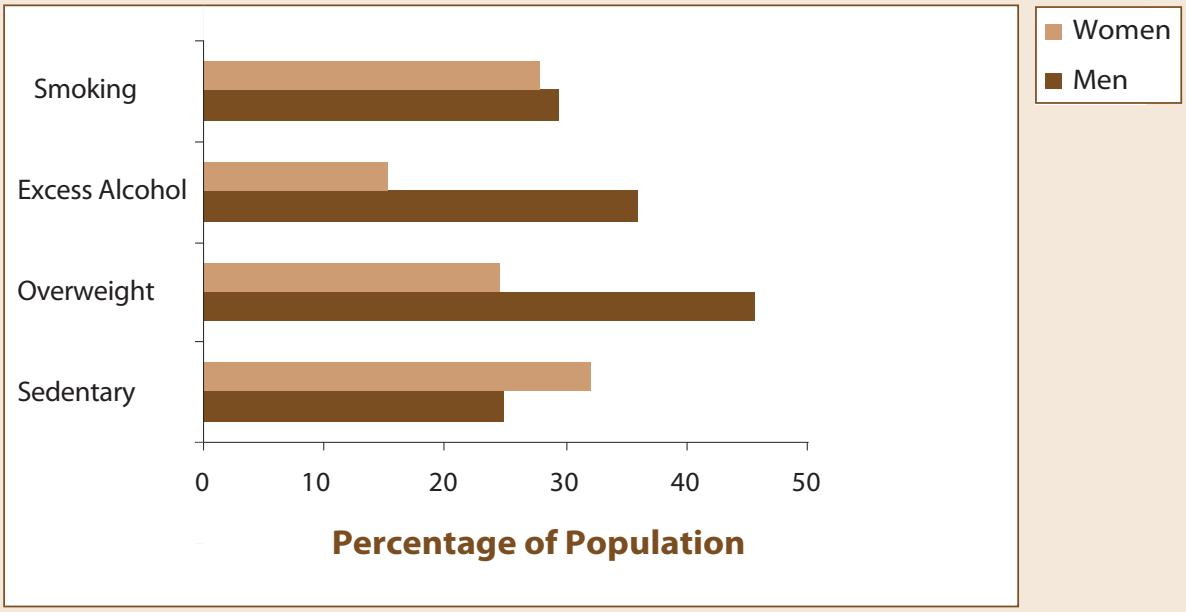


Source: Institute of Public Health

WHAT CAUSES CHRONIC DISEASES?

Approximately 60% of the disease burden in Europe is accounted for by 7 leading risk factors comprising high blood pressure, tobacco, alcohol, cholesterol, overweight, poor diet and physical inactivity. In addition, there are strong interrelationships between physical and mental health which in turn can be linked to common determinants such as poor housing, poor education, diet or alcohol abuse. Tobacco is well known as a major contributor to chronic disease. Harmful use of alcohol is now emerging as a key contributor, particularly amongst younger people where our pattern of binge drinking and overall per capita consumption is amongst the highest in Europe. The current lifestyle pattern in adults and children in Ireland, interacting with the demographic changes, will give rise to significant increases in chronic diseases (Figure 9).

Figure 9: Lifestyle Patterns



Source: Department of Health and Children - Public Health Information System

These risk factors above are common to many of the leading conditions. Risk factors are often associated with two or more conditions and each chronic disease is also associated with two or more risk factors. Risk factors cluster, especially in the socially disadvantaged. Risk factors interact, often in a multiplicative fashion. The foundations of adult health are laid in early childhood. Individuals face different incentive structures with respect to their lifestyle choices and responsibility for achieving and maintaining good health is multilayered involving the individual, the health sector, other sectors and broader society.

HOW CHRONIC DISEASE GETS MANAGED

There is good international evidence that many patients with chronic diseases have sub-optimal care and that there are quality issues with how this care is provided including:

- Approximately half of patients with chronic diseases are adequately identified
- A minority of patients receive the proper care in the appropriate setting
- Insufficient attention to the prevention of these conditions
- Diagnostic registries are incomplete
- Evidence-based guidelines are not followed
- High readmission rates to hospital
- Inadequate patient self-management support
- Discontinuity in care between the primary care and hospital settings
- Poor compliance with clinical management.

While this reflects the international experience, there is no reason to suspect that a different picture applies in Ireland. The Cancer Register is the only national register for chronic disease. Clinical guidelines and protocols for chronic conditions are under development but generally unavailable for use in the primary care and hospital settings. There are good examples of shared care approaches for certain conditions such as diabetes and chronic obstructive pulmonary disease in some locations. In general, however there is an over reliance on episodic acute hospital care that is not well equipped to meet the requirements of effective chronic disease care. Current models of health service delivery are unlikely to cope with future demand. Inadequate and fragmented services for chronic illness contribute to unnecessary and costly hospital admissions and inconvenience for patients.

1. Prevention

The issues facing Ireland are similar to those in other developed countries, many of whom are in the process of introducing integrated chronic disease action plans to reduce the impact of these conditions. A general challenge relates to how best to enhance prevention and health promotion opportunities and increasing the coverage of effective interventions so that more people can benefit. The recent WHO Strategy for Chronic Disease recommends that countries adopt an integrated strategy that promotes population level health promotion and prevention and tailors this with a targeted chronic disease management approach focusing on individuals at high risk. This approach views chronic disease as a continuum where upstream action focuses on the avoidable cause of disease, disability and premature death in addition to the downstream action to improve the health and quality of life of those already suffering from the condition. Leading EU countries are now following this approach and Ireland is collaborating with the WHO to set out the action programmes in support of this policy. Eighty per cent of heart disease, stroke and type 2 diabetes could be avoided if major risk factors were eliminated. Forty per cent of cancer could be avoided if major risk factors were eliminated. Despite this, the OECD has estimated that only 3% of total healthcare expenditure goes towards population wide prevention and public health programmes. It follows that there should be greater emphasis on prevention and a greater reorientation towards primary care and more health promoting services to achieve this.

Cardiovascular mortality has reduced significantly for the past two decades. In Ireland, almost half of this is due to prevention of adverse risk factors including smoking, cholesterol and blood pressure. More than 40% of this is due to treatment and this has been relatively cheap to implement including the detection and treatment of hypertension, management of acute myocardial infarction and heart failure.

2. Care of Chronic Disease

The organisation of healthcare with particular reference to how chronic disease is managed has now become a key issue for developed countries. Chronic disease management programmes are initiatives which are designed to address the systemic barriers to effective care and establish evidence based standards of care for particular conditions. They include strategies and elements relating to how care is provided for patients with chronic diseases so that outcomes can be improved. American models of chronic disease management have been under development for several decades and adapted for use in several European countries. There is a growing body of evidence that they deliver better care, reduce hospital admission rates and healthcare costs. A recent evaluation by the US Agency for Healthcare Research and Quality has shown significant clinical improvements for processes of care relating to screening and disease prevention as well as enhanced disease monitoring and treatment.

Further data from the US has shown that chronic disease management programmes can achieve a 50% reduction in unplanned hospital admissions as well as a 50% reduction in bed day rates for these conditions. This has been achieved with greater than 95% family and carer satisfaction rates with the chronic disease management programme. While chronic disease programmes have improved processes of care for these conditions, it is probably too early to demonstrate improved longer term clinical outcomes and some programmes have not delivered the expected reductions in hospital admissions. Some of this may also be due to the early generation programmes which were less focused than recent programmes which are more effective and efficient. The UK is currently sponsoring a number of approaches to chronic disease with similar outcomes. While some have reduced hospital admissions for older people, others have not and despite improvements in the processes of care, clinical outcomes remained largely unchanged. Experience from the Nordic countries shows that chronic disease management can be effective in halting the progression of these conditions with the ensuing health benefits seen for patients and the health system.

Emerging lessons from the development of chronic disease programmes in other countries are summarised as follows:

- Health systems should shift away from a medical curative model of healthcare that is reactive towards a more structured, planned approach for patients with long-term conditions
- The chronic care model requires better integrated care across institutional boundaries between primary care and the acute setting
- The chronic care model should emphasise prevention and operate in an environment that promotes health opportunities
- Chronic disease programmes require standards, clear objectives and quality assurance mechanisms
- Chronic disease programmes should be supported by networks and clinical pathways that cut across the traditional boundaries of healthcare delivery.

BEST PRACTICE

In recognition of the emerging evidence from other countries and the best practice developments that are advocated by the World Health Organisation, there are a number of principles which should be applied for effective and efficient care for the management of chronic conditions. These include:

- The national focus on population directed disease prevention and health promotion
- The need to develop structured, planned care for patients with long-term chronic conditions
- The use of information systems and registers to plan and evaluate care for individuals with chronic disease
- The requirement to support and strengthen self-care
- The need to develop a model of shared care that is integrated across organisational boundaries
- Provision of supportive clinical decision systems such as guidelines for the management of chronic disease
- Planning care that is delivered in the appropriate setting
- Using multidisciplinary teams in the provision of care
- Providing a monitoring and evaluation framework for chronic disease programmes.

The principles will underpin the new approach to chronic disease prevention and care that is set out in this report.

POLICY REQUIREMENTS

The description of the current disease burden, set against adverse lifestyle factors and an ageing population, clearly illustrates the challenges for the health sector. Current models of health service delivery are unlikely to cope with future demand.

What follows is an integrated strategy to tackle chronic disease and its determinants. The responsibility for implementing this strategy rests primarily with the Health Service Executive (HSE), however, other organisations including the Health Infromation and Quailty Authority (HIQA), other government departments, the Institute of Public Health, health professional training bodies, health professionals themselves, the academic sector and non-governmental organisations will also have important roles to play in reducing the burden of chronic disease. This document sets out the policy requirements for the future prevention and care of chronic disease in Ireland. In its future work on chronic diseases, the Department of Health and Children (DOHC) will follow up on the stated recommendations through service planning and other accountability mechanisms. The Department of Health and Children will continue to monitor progress and review policy requirements within three years.

1. Chronic disease programmes and initiatives should operate within the overall policy requirements established by the Minister and the Department of Health and Children.

Context

The DOHC has developed policies on cancer, cardiovascular disease and diabetes. A new cardiovascular strategy including stroke is under consideration. The HSE is developing initiatives on chronic disease including cardiovascular disease and diabetes. Chronic diseases are also of relevance in the context of the development of new contracts, in particular those relating to the General Medical Services (GMS) contract. They are also relevant to the consultant contract where the development of shared care models and integrated services is an important requirement.

Action

Quality and Fairness and *Primary Care – A New Direction* set out a policy framework within which strategies and programmes should be implemented. Further policies include the Task Force Reports on Alcohol and Obesity as well as the National Health Promotion policy. Current and future initiatives on chronic disease should be patient centred and operate within the overall DOHC policy framework on chronic diseases established in **this** document as well as the existing disease policies and those which are under consideration.

2. Department of Health and Children will support the development of intersectoral working to deal with the preventative aspects of chronic disease

Context

It is acknowledged that chronic diseases and the lifestyle factors which contributed to these, are distributed unevenly across the population. The Programme for Government has set out policy measures to prevent illness and promote health across the population. These will complement the existing initiatives currently being taken on lifestyle factors including tobacco, alcohol and obesity. Structures are currently being put in place to give affect to these actions. The legislative measures on tobacco control have been a success and need to be complemented with further work to reduce smoking in younger adults, especially females. Alcohol and obesity have been the subject of task force reports, where recommendations have identified actions to be taken in other sectors. The HSE is committed to intersectoral action and is involved in a broad range of projects on creating environments that support health and contribute to building health public policy. Many government departments

already contribute to the development of measures and actions around individual health and lifestyle issues. Sometimes, this is fragmented and it is important to maximise opportunities for health improvement. A whole of government approach is essential in promoting health and reducing the burden of chronic disease in the population.

Action

The Government has recently agreed to interdepartmental and inter-sectoral collaboration on the prevention of chronic diseases which will address the wider determinants of, and risk factors to health, such as lifestyle (tobacco, alcohol, high blood cholesterol, overweight, low fruit and vegetable intake, and physical inactivity) and social, economic and environmental factors such as poor housing, poor nutrition or poor education. This single interdepartmental structure through which **all** health improvement actions will be channelled, will build on the work of the senior officials group on social inclusion and will report to Government through the Cabinet Committee on Social Inclusion. A cross divisional group in the Department of Health and Children will support the interdepartmental work relating to the prevention of chronic diseases.

The work programme will be focused and include the collation of existing intersectoral health improvement actions, the identification of priority future actions and the development of screening tools to evaluate the health impact of relevant policy proposals being submitted to government. The working group will report to government on a six-monthly basis.

3. Health service delivery should provide structured and integrated care for patients with long-term chronic conditions.

Context

Management of patients with chronic disease is complex involving self-care, primary care, acute care and rehabilitation. Complex problems often require a variety of health professional competencies underlining the need for an interdisciplinary effort. At present, there are a small number of specific initiatives which are intended to integrate care across the various settings. Many of these HSE initiatives have been successful including the provision of structured care for diabetes and the management of individuals with chronic obstructive airways disease outside of the hospital setting. However, for most patients with chronic disease, care is fragmented and does not include all of the elements to reduce the burden from the disease for the individual.

Action

The HSE has identified chronic diseases as a transformation priority and is developing a model for preventing and managing chronic illness. This positive development should be elaborated further through the service planning process in future years. An implementation plan should indicate the resource requirements, the manner in which services are to be integrated as well as how the objectives will be achieved.

4. Programmes should be developed for the major disease groups in the form of *disease management programmes*. Disease management programmes should be evidence based, recognise the nature of the interdisciplinary work concerned and comprise the total course of the disease.

Context

A considerable body of international knowledge has developed around the issue of disease management programmes and their role in improving care and reducing hospital admissions. These programmes set out the organisation and resource requirements and how they should be structured with reference to specific diseases. They set out the roles and responsibilities of different healthcare providers in primary and acute care settings, indicate the interdisciplinary nature of management and

operate to disease management protocols for each condition. The HSE is developing this work, starting with Diabetes through its Expert Advisory Group. A further Expert Advisory Group is being established for cardiovascular disease.

Action

The HSE should develop and implement disease management programmes for the major chronic diseases. This will be an iterative process and build on the various initiatives already in existence. It will require research and the development, implementation and quality assurance of disease management programmes which should be supported. Disease management programmes should be quality assured via performance indicators and reflected in the service planning process. It will require the support of the professional training bodies, HIQA, the Institute of Public Health and other providers who have a role to play in the management of chronic disease.

5. Criteria should be established for the definition, diagnosis and stratification of the major chronic diseases.

Context

Disease management programmes generally operate on the basis of the pyramid of care. Individuals with chronic disease can be categorised into three levels. The low risk category, compromising 75% of people living with a chronic condition are amenable to self-management with some health professionals' support. The medium risk category, compromising 20%, require a higher level of primary care support, either provided by doctors or nurses. The high risk category is often termed case management, involves 5% of people and who are at greatest risk of hospitalisation. These three levels of disease represent a spectrum and people in each level can improve or dis-improve and move between the levels. This depends on exacerbations of the disease and the degree to which complications can be prevented and general care and rehabilitation is provided. Registration of the diagnosis as well as the stage of the disease is therefore, important for implementing an individual disease management plan as well as for the overall monitoring of the quality and efficiency of the programme.

Action

Diagnostic criteria, including the stage of the disease, should be developed for each of the major conditions. This should be agreed by the HSE and the healthcare professionals who provide services. It should form the basis of epidemiological monitoring including monitoring contract service provisions of the various healthcare providers.

6. Clinical decision systems such as guidelines for the management of the major chronic diseases should be developed.

Context

The development of a shared care model will require the support of clinical guidelines for the management of each of the major conditions. Some of these have been developed previously for the management of cardiovascular disease. Clinical guidelines are close to completion for diabetes and describe how primary care and specialist services should provide quality care for people with disabilities.

Action

Disease management programmes should incorporate clinical guidelines for the major conditions. These should be developed and updated on an incremental basis starting with cardiovascular disease, stroke, diabetes and cancer. Other diseases may include asthma, chronic bronchitis and musculoskeletal conditions. This work should be supported by DOHC, HSE, HIQA and the professional training bodies.

7. Models of shared care should be developed within disease management programmes and that describe the nature of tasks between primary care and specialist services.

Background

Shared care describes clinical care which is shared between primary care and specialist services. It is developed jointly in advance, sets out roles and responsibilities, is evidence based and delivers care at the most appropriate level. Much of the care of patients with chronic disease can and should take place in the primary care setting, however, some will require a specialised level of care for diagnosis, establishment of treatment plans or the management of complications. Each condition will require criteria and protocols to determine the pathways of care and the most appropriate setting where patients should be managed.

Action

Disease management programmes should incorporate the existing clinical guidelines, where available such as diabetes and incorporate these into shared care models for each condition. This will require the agreement of medical practitioners, nurses and other healthcare staff in setting out the roles and responsibilities of all concerned. It should acknowledge the partnership role of community groups who make an important contribution in enhancing the health of local communities. It should also include the training and educational requirements, the task requirements and the necessary areas of competence to fulfil these tasks. It will involve the establishment of clinical networks in the primary and acute care settings with the aim of providing integrated and appropriate care for patients with chronic diseases.

8. The primary healthcare sector should play a central role in the care of patients with chronic disease. Primary healthcare should be strengthened to meet the needs of patients with chronic conditions.

Background

Most of the care of patients with chronic conditions takes place within the primary healthcare sector. This includes the diagnosis, treatment and even the rehabilitation of patients with chronic conditions. It includes early detection, assessment and follow-up, comprehensive medical treatment as well as preventive activities including smoking cessation, dietary advice, and support of patients' self-care. Many patients have more than one chronic disease, attend different acute care providers, all of which underlines the complexity involved and the central role that primary care should play in managing and co-ordinating care for patients with chronic conditions. There have been a variety of primary care initiatives for chronic disease such as HeartWatch and structured diabetes care initiatives in recent years. It is important to learn from these initiatives and build on these where primary care has been successful in delivering high quality, effective and efficient care for patients with chronic conditions.

Action

The overall planning for primary care services in chronic disease should take place within a general framework for the management of chronic disease. This relates to the implementation of the primary care strategy, the rollout of the primary care teams and the development of multidisciplinary team working and integration with hospital services. Future primary care contracts should include enabling provisions with respect to the management of chronic conditions. The roles and responsibilities of general practitioners, nurses and other professional staff within primary care teams should be agreed. This work will need to be supported by clinical protocols and guidelines for the management of the major chronic conditions.

9. There should be an agreed management plan for each patient; whether care is provided in primary care or by a specialist unit.

Background

Patients with chronic conditions should have access to treatment which is appropriate to their needs and access to differing levels of services should be equitable. Under the shared care model, patients should expect to receive high quality care through a management plan which is followed throughout the course of the illness.

Action

Services should be patient centred and individual disease management plans should be prepared for each patient and include the treatment goals. The plan should reflect the stage of the condition, the interventions that are necessary and how these will be provided. The plan should also include the patients' commitments to comply with the achievement of treatment goals. All this should be central to the model of shared care that is described earlier.

10. Patients should actively participate in the management of their condition.

Context

Patient participation in managing their condition has been demonstrated to improve health outcomes. Examples include self-management strategies in people with diabetes which have been shown to improve blood glucose levels. The patients' understanding of symptoms and knowledge of the disease and its treatment is a requirement for suitable self-care. Knowledge of the disease and its treatment not only improves quality of life but also can reduce the dependency on healthcare services. There are a number of aspects to self-care including general patient education and awareness, self-monitoring and self-treatment. The HSE is developing a model of self-care for patients with chronic diseases.

Action

The HSE should continue the development of a self-care programme for patients with chronic conditions. This should include disease specific patient education including the skills required for self-monitoring and self-treatment and psychological support as appropriate. Healthcare professionals involved in the care of patients with chronic disease should participate in the development of these programmes. Self-care programmes should comply with the general requirements of chronic disease programmes and, in particular, to fit with the shared care model for chronic disease.

11. Clinical information systems should be further developed to support chronic disease management programmes.

Context

Patient registration systems are usually condition specific and include registers on diabetes, cardiovascular disease, cancer, asthma and chronic lung conditions, arthritis and renal disease. At present, cancer is the only condition with national registration. There are some local registers on cardiovascular disease and diabetes. The use of these information systems allows access to key data on individuals and populations. They can be used to schedule individuals for clinical care and record information on co-morbidities. They are a key requirement for the effective implementation of chronic disease management in the primary care and specialist settings.

Action

The development of patient registration systems for the major chronic conditions should continue to be supported. It is recommended that these be developed on an incremental basis starting with diabetes and cardiovascular disease.

Development should begin at local level using primary and specialist data where available. These should be subsequently developed into regional and national registration systems. Registration systems should comply with the general ICT policy requirements and the governance arrangements as determined by HIQA.

12. Quality assurance should be established as part of the disease management programmes for chronic diseases.

Context

There is international evidence that quality monitoring frameworks are a prerequisite for the achievement of good clinical outcomes for patients with chronic diseases. Quality monitoring can also achieve efficiency gains and facilitates the efficient targeting of resources towards interventions that are effective in reducing the burden of these conditions.

Action

It is recommended that quality assurance be an integral part of the disease management programme. It is envisaged that HIQA will provide the overall framework within which this will operate. This should include incidence data, hospital utilisation data, clinical outcomes and other quality data including patient satisfaction. These should be followed up systematically at local, regional and national levels.

13. Evidence-based methods and research on chronic disease programmes should be supported.

Context

Much of the research on chronic disease and the development of evidence based methodologies have taken place in an international context in countries with several years of experience in chronic disease management programmes. It is generally accepted that better use could be made of existing knowledge on evidence based interventions and how research could be put into practice more quickly and effectively.

Action

Health service research on chronic disease in Ireland should be strengthened. The Health Research Board should consider how it might support such research. This should include research on health determinants and prevention, health inequalities and clinical interventions to reduce chronic diseases and its complications.

14. Chronic disease programmes should be monitored and evaluated on an ongoing basis.

Context

The international experience shows that some chronic disease programmes have been more successful than others and it is important to learn from these experiences and adapt programmes as necessary. The HSE is committed to identifying key indicator measures relevant to chronic disease so as to enhance performance.

Action

The service planning mechanism provides an accountability framework with respect to the delivery of health services. Chronic disease management programmes should be specified within the HSE service plan mechanism. Each programme should include targets and performance indicators so that progress in achieving the objectives of the programme can be monitored.

NOTES

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