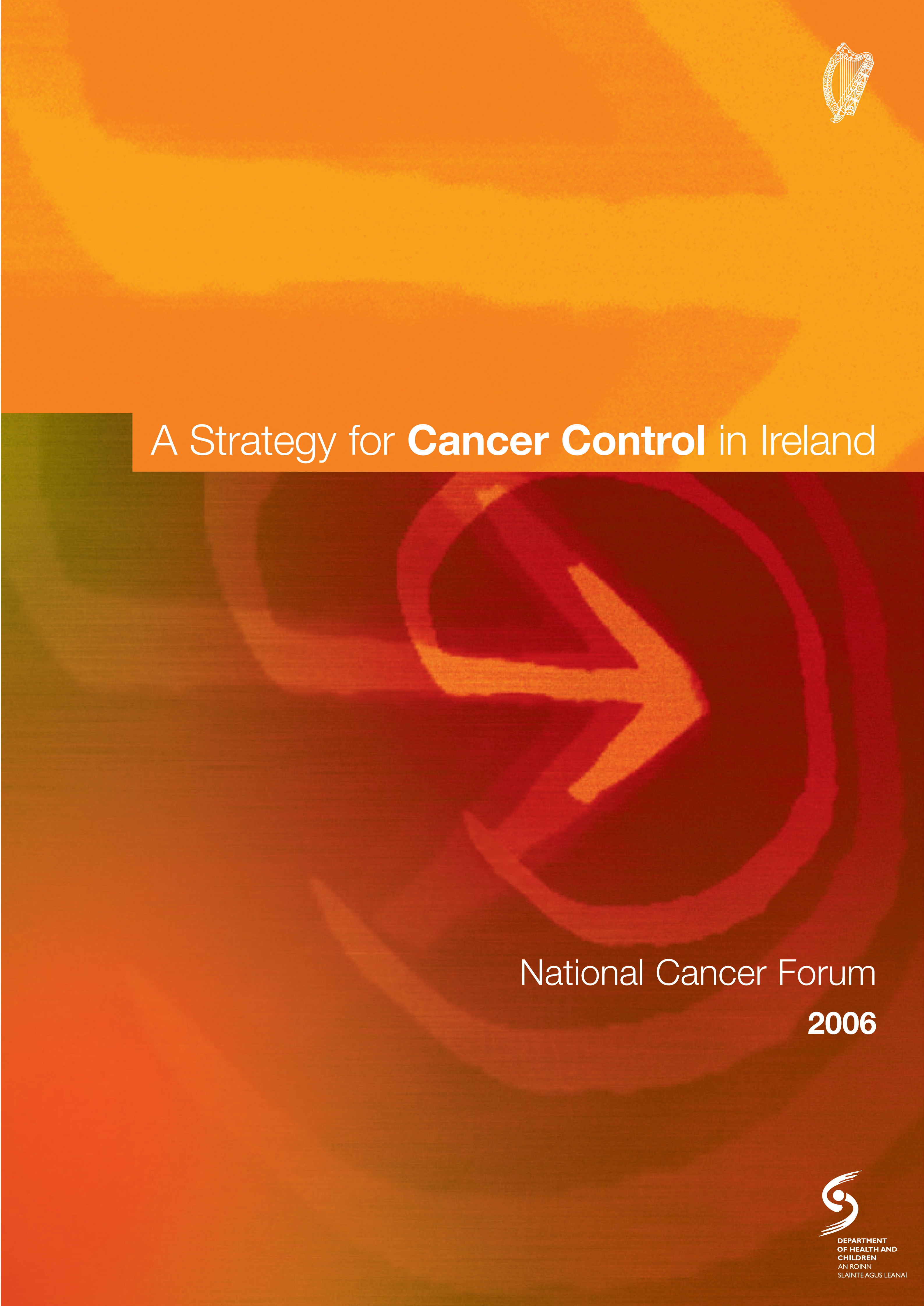

A Strategy for **Cancer Control** in Ireland

National Cancer Forum

2006

DEPARTMENT
OF HEALTH AND
CHILDREN
AN ROINN
SLÁINTE AGUS LEANAÍ

Chairman's Foreword

Cancer, its prevention, diagnosis and treatment are a major challenge for our society. Cancer is an illness that afflicts large numbers of people, from all backgrounds, and is feared by individuals and families alike. Yet there is much reason for optimism; research holds out the possibility of major strides forward in prevention and cure in the coming decades. We are witnessing major improvements in the treatment of many types of cancer, but these welcome improvements will also place substantial and diverse pressures on our health care system.

The ageing of our population will result in an approximate doubling in the number of people who will develop cancer in Ireland over the next 15 years. It is self-evident that the current services will not be in a position to meet the substantial demand for treatment, cure and care.

Keeping pace with these demands will require a major government commitment to cancer services in the coming years, which in turn will require the earliest possible decisions on investment, human resource planning and the organisation of services. Our aim is to deliver a universal, quality-based and timely service, in line with the best that is currently available internationally.

To address the rapidly rising burden of cancer, this second National Cancer Strategy *A Strategy for Cancer Control in Ireland 2006* advocates a comprehensive cancer control policy programme. Cancer control is a whole population, integrated and cohesive approach to cancer that involves prevention, screening, diagnosis, treatment, and supportive and palliative care. It places a major emphasis on measurement of need and on addressing inequalities and implies that we must focus on ensuring that all elements of cancer policy and service are delivered to the maximum possible extent.

This Strategy also focuses substantially on reform and reorganisation of the way we deliver cancer services, in order to ensure that future services are consistent and are associated with a high-quality experience for patients and their carers. There is evidence of considerable variation in cancer survival between regions and also significant fragmentation of services for cancer patients. These interrelated factors are of major concern to the National Cancer Forum.

This Strategy will ensure that the cancer experience in all parts of the country is comparable and is of the highest possible standard, an approach that underpins the recommendations concerning the creation of the Framework for Quality in Cancer Control. This framework will be vital to the development of cancer control as it will provide the means through which many of the recommendations can be implemented, monitored and quality-assured to the benefit – most importantly – of patients, but also to the benefit of those who provide and manage and those who fund the service.

This Strategy for Cancer Control aims to build on the major successes in cancer that have been delivered under the 1996 National Cancer Strategy. Cancer services have been transformed over its lifetime with manifold increases in infrastructure, services, clinicians and other health professionals. We see every reason to aspire to improve Ireland's international position in cancer so that we are towards the top of the international league table. This will require strong political, medical and executive leadership as well as significant investment programmes that are based on the principles and policies we have outlined. Cancer patients who access our health services should as a matter of right receive quality-assured treatment and care regardless of geography. To achieve this, we are recommending a major Framework for Quality in Cancer Control with an extensive role for the Health Information and Quality Authority. The much-needed expansion of services and its associated investment should be based on the quality and organisation model we have outlined. I wish to acknowledge the advice and support of the interim Health Information and Quality Authority and the Irish Health Services Accreditation Board in developing this framework.

At the later stages of the development of the Strategy, we held detailed discussions with the senior management team of the Health Service Executive, the Health Research Board and the Irish Cancer Society. We received significant endorsement and support for our work and the recommendations we have laid down in this document.

On a personal note, I wish to express my sincere thanks to the Forum members who have given of their time and effort to complete this important and demanding work. Their professional input and dedication was impressive and it was my privilege to have been appointed by Mícheál Martin T.D., Minister for Health and Children to chair such a Forum. I wish to express appreciation of the enormous support provided by Tracey Conroy, Assistant Principal Officer, Cancer Policy Unit in the Department of Health and Children. Her ability, energy and dedication as Secretary to the Forum were outstanding. The Forum relied considerably on the advice and direction presented to us by the general public, health care professionals and representative bodies; I am delighted to acknowledge their contribution and that of my fellow Regional Cancer Directors.

As Chairman and on behalf of the second National Cancer Forum, I am delighted to submit this Strategy for Cancer Control to the Tánaiste and Minister for Health and Children, Mary Harney, T.D. I do so with confidence that it will be implemented as a major element of health policy.

Professor H. Paul Redmond
Chairman

Acknowledgements

The National Cancer Forum would like to acknowledge the substantial contribution to the development of the National Cancer Control Strategy of the following:

- Members of the public, patients and their families who responded to the Forum's public consultation process

- Professional and voluntary organisations who made detailed submissions in relation to cancer control

- The Health Service Executive senior management team, professional staff of the former Health Boards, Regional Directors of Cancer Services, representatives of the interim Health Information and Quality Authority, BreastCheck, the Irish Cervical Screening Programme and the Irish Cancer Society

- Health professionals and cancer patients who made presentations to the Forum on particular areas of cancer care.

Terms of Reference of the Second National Cancer Forum

The National Cancer Forum is the national advisory body on cancer policy to the Minister for Health and Children. The Forum is multi-disciplinary and representative of professional, management, voluntary and patient advocacy groups in cancer. It was established in November 2000 with the following terms of reference:

To advise the Minister on:

- progress in the implementation of the National Cancer Strategy

- the co-ordination of cancer services at supra-regional and national level

- best practice in cancer prevention, treatment and care

- the development and implementation of protocols for the treatment and care of cancer patients

- the evaluation of the effectiveness and quality of cancer services

- the co-ordination of research into cancer, in conjunction with the Health Research Board.

Membership of the Second National Cancer Forum

Name	Position	Nominated by
Prof. Paul Redmond (Chair)	Professor of Surgery Cork University Hospital	Minister for Health and Children
Dr. Fin Breatnach	Consultant Paediatric Oncologist Our Lady's Hospital for Sick Children, Crumlin	Minister for Health and Children
Prof. Des Carney	Consultant Medical Oncologist Mater Misericordiae Hospital	Irish Cancer Society
Ms. Margaret Codd	Directorate Nurse Manager St. James's Hospital, Dublin	Minister for Health and Children
Mr. Gerry Coffey	Principal Officer Department of Health and Children	Minister for Health and Children[1]
Dr. Harry Comber	Director, National Cancer Registry	Minister for Health and Children
Ms. Barbara Cosgrave	Director, ARC Cancer Support	Minister for Health and Children
Dr. Michael Coughlan	General Practitioner, Galway	Irish College of General Practitioners
Dr. Pat Doorley	Director of Population Health Health Service Executive	former Health Board Chief Executive Officers[2]
Prof. James Fennelly	Consultant Medical Oncologist Chair, First National Cancer Forum	Minister for Health and Children
Dr. Michael Flynn	General Practitioner, Dublin	Irish College of General Practitioners
Ms. Eileen Furlong	Lecturer, School of Nursing, Midwifery & Health Systems, UCD	Irish Association for Nurses in Oncology[3]
Prof. Donal Hollywood	Professor of Clinical Oncology Trinity College Dublin	Faculty of Radiologists, Royal College of Surgeons in Ireland
Dr. Tony Holohan	Deputy Chief Medical Officer Department of Health and Children	Minister for Health and Children
Dr. Maccon Keane	Consultant Medical Oncologist University College Hospital Galway	Irish Society of Medical Oncology[4]
Prof. Liam Kirwan	Consultant Surgeon Cork University Hospital	Irish Society of Surgical Oncology
Mr. Michael Lyons	Chief Executive Officer Our Lady's Hospital for Sick Children, Crumlin	former Health Board Chief Executive Officers[2]
Prof. Shaun McCann	Consultant Haematologist St. James's Hospital, Dublin	Irish Haematology Association
Dr. Regina McQuillan	Consultant in Palliative Care St. Francis Hospice, Dublin	Irish Association for Palliative Care
Ms. Marie Moore	Reach to Recovery	Minister for Health and Children
Dr. Michael Moriarty	Consultant Radiation Oncologist St. Luke's Hospital, Dublin	Royal College of Physicians in Ireland
Dr. Conor O'Keane	Consultant Pathologist Mater Misericordiae Hospital	Faculty of Pathology, Royal College of Physicians of Ireland
Dr. Risteárd Ó Laoide	Consultant Radiologist St. Vincent's University Hospital	Faculty of Radiologists, Royal College of Surgeons in Ireland

Secretariat

Ms. Tracey Conroy	Assistant Principal Officer	Department of Health and Children

[1] Replaced Mr. Joseph Cregan, Principal Officer, Department of Health and Children in May 2002

[2] The Health Boards were replaced by the Health Service Executive on 1 January 2005

[3] Replaced Ms. Joan Kelly, Irish Association for Nurses in Oncology in March 2003

[4] Replaced Prof. Peter Daly, Irish Society of Medical Oncology in May 2002

Ms. Emily Logan, Association of Irish Nurse Managers resigned in January 2004 on appointment as Ombudsman for Children

The following people provided significant assistance to the Forum during the preparation of this Strategy: Dr. Catherine Conlon, Dr. Emer Feely, Dr. Orla Healy, Dr. Patricia MacDonald, Dr. Margaret O'Sullivan, Dr. Miriam Owens, Dr. Annette Rhatigan, Dr. Mary Ward.

Vision

‘Ireland will have a system of cancer control which will reduce our cancer incidence, morbidity and mortality rates relative to other EU15 countries by 2015. Irish people will know and practice health-promoting and cancer-preventing behaviours and will have increased awareness of and access to early cancer detection and screening. Ireland will have a network of equitably accessible state-of-the-art cancer treatment facilities and we will become an internationally recognised location for education and research into all aspects of cancer.’

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Executive summary

Cancer is a major cause of morbidity and mortality in Ireland. Each year about 20,000 Irish people develop cancer and 7,500 die of the disease. One in four people overall will die from cancer and 60% of cancer patients die within five years of diagnosis. Although cancer incidence appears to be falling, the actual number of people developing cancer is expected to increase because our population is ageing. The number of new cases the system can expect to deal with by 2020 will represent an increase of 107% on the number dealt with in 2000. We now have approximately 120,000 cancer survivors.

Vision and principles

The National Cancer Forum, responding to the continued priority that needs to be given to cancer policy, advances in this second National Cancer Strategy *A Strategy for Cancer Control in Ireland 2006* a vision of an Ireland that will have a system of cancer control to reduce cancer incidence, morbidity and mortality rates relative to other EU15 countries by 2015. Irish people will practice health-promoting and cancer-preventing behaviours and will have access to early cancer detection and screening. There will be a network of equitable, accessible cancer treatment facilities and Ireland will become a recognised location for cancer education and research.

The range and capacity of cancer services have been significantly enhanced since the first Cancer Strategy in 1996. These achievements need to be consolidated by focusing on the development of a culture of quality of care, process and outcome measurement, education and high-quality research. The concept of cancer control is at the heart of this Strategy in that it focuses on all aspects of cancer, including health promotion, prevention, diagnosis, treatment, and palliative and supportive care.

Promoting health and preventing cancer

Public health action by governments and the promotion of healthy lifestyles could prevent as many as one third of cancers worldwide. This Strategy supports the full implementation of the recommendations of the *Review of the National Health Promotion Strategy, the Strategic Task Force on Alcohol* and the *National Task Force on Obesity.* It makes additional recommendations in relation to tobacco, alcohol, nutrition and physical activity, and also in relation to risk reduction from ultraviolet radiation and radon.

Breast screening should be extended to include all women aged between 50 and 69. The national roll-out of the Irish Cervical Screening Programme should be completed as quickly as possible. The Strategy provides a set of criteria to guide decisions on the introduction of population-based screening. A colorectal cancer programme should be established and should encompass population screening, high risk screening and necessary developments in symptomatic services. However, prostate cancer screening should not be introduced as a population-based programme at present.

For many cancers, population-based screening is not an option. Detecting cancer early remains the best strategy for reducing cancer deaths. The Health Service Executive (HSE) should develop specific programmes to increase cancer awareness and to detect cancer early.

Managed Cancer Control Networks

All cancer care should be provided through a national system of four Managed Cancer Control Networks, each serving a population of about one million people and consisting of primary, hospital, palliative, psycho-oncology and supportive care. Patient care should be fully integrated between each of these elements within each network. Each network should have a formal structure of clinical leadership. The emphasis in the network should be on connection and partnership rather than on isolation and self-sufficiency, on distribution of resources rather than on centralisation, and on maximising the benefits for all patients.

Each network will be headed by a Director of Cancer Control, who should be a senior clinician. The Network Director should be responsible for the organisation of cancer care pathways connecting each element of the service within the network. He should lead a team made up of a lead clinician for each major cancer type and a lead clinician for each Cancer Centre within the network.

Primary care is pivotal in the coordination of the wide variety of services that patients may use. It is a key partner in the delivery of effective secondary care services. Care pathways for cancer should be developed to link primary care, hospital care, and other services. Care pathways should guide the process of cancer care delivery within each network.

Cancer Centres, each serving a minimum population of 500,000, should be designated by the HSE as soon as possible. Ireland will require about eight such centres. The Cancer Centres within each network should be seen as equal partners. In order to ensure adequate case-volume and expertise, some Cancer Centres should provide a higher level of care for those cancers that need larger volumes than would present in a single Cancer Centre.

Hospital-based cancer services need to expand to meet rising demands for cancer services. The HSE should conduct a needs assessment for cancer services with a particular emphasis on hospital based cancer treatment, that addresses the need for continued expansion in capacity and maximises the use of ambulatory care. Diagnosis and patient management should be planned and conducted by site-specific multidisciplinary teams.

Within each Cancer Network, access to comprehensive palliative care, psycho-oncology and supportive care services should be provided for cancer patients, their families and carers. A more structured partnership between the voluntary sector and the HSE will help to enhance supportive care services.

National Framework for Quality in Cancer Control

A ‘Framework for Quality in Cancer Control’ should be put in place, made up of four elements:

- quality in cancer control groups – the Health Information and Quality Authority (HIQA) should establish site-specific groups at national level to develop guidelines for quality in major site-specific cancers
- a statutory system of licensing and accreditation that should apply to both public and private sector services
- an information model and infrastructure to address the information needs of patients, professionals, managers and policymakers – HIQA should develop a cancer surveillance system
- health technology assessment (HTA) – HIQA should establish a Cancer HTA Panel. This Panel will develop a model of assessment that allows the speedy introduction of proven technologies.

Thinking ahead

Planning must address education, human resource needs, technology trends and developments, evolution of workplace roles and changes in service-delivery models. The HSE should develop a national cancer workforce plan to support the operational planning needs for the cancer control system. This would include the creation of a register of trained cancer control personnel and enhancement of coordination between bodies responsible for training and research on service delivery models and personnel issues.

There is a need to establish a strategic process to identify cancer research themes, to facilitate and oversee cancer research, and to support the evaluation of programmes, treatments and outcomes. There is also a need to improve clinical trial access for patients. Ireland should establish a national tissue bio bank to support research and service delivery. The third National Cancer Forum, in partnership with the Health Research Board, should advise on the development of a specific plan for cancer research.

Policy Indicators

The HSE should present a report on policy indicators each year to the National Cancer Forum. The first report on policy indicators from the HSE will allow targets to be set for each policy indicator. These targets should then be reviewed annually by the National Cancer Forum.

Section A

Setting the scene

Key messages

- Cancer is a generic term used to describe a group of over a hundred diseases that occur when malignant forms of abnormal cell growth develop in one or more body organs
- A sustained increase in cancer funding in recent years has enabled services to expand substantially
- Recent decades have witnessed sustained year-on-year improvements in overall cancer survival. Cancer can increasingly be viewed as a condition that people can expect to survive
- More than 30% of all cancers are preventable. Prevention must remain a central focus of cancer policy
- Effectively tackling the problem of cancer means achieving specialist services of a consistently high quality with sufficient capacity as well as appropriate support services for patients, their carers and their families
- With this second National Cancer Strategy, the National Cancer Forum has embraced the concept of cancer control that has emerged internationally in cancer policy and has been promoted and supported by the World Health Organisation
- The focus of this Strategy is on the development of a culture of quality, measurement, outcomes, education and research, and increased service capacity
- A third National Cancer Forum should be appointed by the Minister with terms of reference and composition reflecting the changed health system.

A.1 Introduction

A.1.1 What is cancer?

Cancer is a generic term used to describe a group of over a hundred diseases that occur when malignant forms of abnormal cell growth develop in one or more body organs. These cancer cells continue to divide and grow to produce tumours.

There are several main types of cancer. Carcinoma is cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukaemia is cancer that starts in blood-forming tissue such as the bone marrow. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system. Some of the biological mechanisms that change a normal cell into a cancer cell are known; others are not.

Cancer differs from most other diseases in that it can develop at any stage in life and in any body organ. No two cancers behave exactly alike. Some may follow an aggressive course, with the cancer growing rapidly, while others grow slowly or may remain dormant for years.

A.1.2 Why is cancer important?

Recent decades have witnessed striking changes in the patterns and treatments of cancer. There have been sustained year-on-year improvements in overall cancer survival and mortality. In childhood leukaemia there has been a dramatic improvement in survival. Similar improvements have occurred in Hodgkin's disease, testicular cancer and melanoma. In many other cancers, less dramatic improvements have been taking place. This has greatly changed the experience of cancer.

Cancer is increasingly viewed as a condition from which people can expect to survive. Very high cure rates can be achieved for some types of cancers, but for others the cure rates are disappointingly low and await improved methods of detection and treatment. However, in excess of 30% of all cancers are preventable. It is for this reason, that prevention must remain a central focus of cancer policy.

Effectively tackling the problem of cancer means providing specialist services of a consistently high quality with sufficient capacity, as well as appropriate support services for patients, their carers and their families. Our focus has to be on ensuring that there is access to services that deliver this experience for each and every person who is diagnosed with cancer.

Achieving this will pose significant challenges as a substantial rise is expected in cancer cases in the population over the next fifteen years. The number of cases is expected to increase largely as a result of population changes from under 14,000 in 2000 to over 28,000 in 2020.

There is rapidly expanding knowledge of the pathogenesis of a variety of cancers at the molecular level, allowing a new focus for drug discovery and development –already expressed in the development of targeted therapies in various cancers including breast cancer and soft-tissue cancer. This promises significant potential benefits for patients, in that traditional chemotherapy agents are toxic to healthy cells as well as cancer cells, while targeted treatments can be less toxic to normal cells and can improve tolerability.

Recent advances in oncology diagnosis and therapy, based on targeted therapies, have significant financial implications – the cost of such therapies is very high. While opening up exciting new possibilities, this will create significant challenges for cancer policy and cancer services in the coming years.

A.1.3 Origin and vision of the second National Cancer Strategy

The Health Strategy *Quality and Fairness: A Health System for You (2001)* provided a highly ambitious and challenging agenda for the delivery of major improvements in health services throughout the country and signified the clear and high priority that the Government attaches to cancer and cancer control as part of the overall health system.

The first national goal of better health for everyone encompasses a number of critical objectives in relation to cancer care. In response, the National Cancer Forum has developed the second National Cancer Strategy.

In this context, the Forum agreed a clear vision and associated aims that would underpin a policy blueprint that would take Ireland to the top of the international league table in terms of cancer control. This vision, which embodies an approach based on maximising health gain for the whole population, is stated as follows:

> 'Ireland will have a system of cancer control which will reduce our cancer incidence, morbidity and mortality rates relative to other EU15 countries by 2015. Irish people will know and practice health-promoting and cancer-preventing behaviours and will have increased awareness of and access to early cancer detection and screening. Ireland will have a network of equitably accessible state-of-the-art cancer treatment facilities and we will become an internationally recognised location for education and research into all aspects of cancer.'

The National Cancer Forum also identified high-level aims that are consistent with this vision. The achievement of these aims will reduce the burden of cancer in Ireland through the consistent and effective application of knowledge aimed at:

- reducing the age-standardised and – where appropriate – age-specific, incidence of cancer in Ireland relative to other EU25 countries through health promotion and preventive activities
- enabling detection of cancer at the earliest possible time, through education of the public, patients and professionals and the application of evidence based screening technologies
- ensuring that patients, families and carers understand fully all aspects of their care and of their treatment options
- providing equitable access to care for those who develop cancer by ensuring that the services people receive are appropriate to their needs and clinical circumstances
- providing cancer control services that reduce the severity of the illness and enhance quality of life throughout the disease process
- ensuring that cancer control services are of a high quality and ensure best outcomes in keeping with international standards of best practice and that this can be demonstrated for both those who use and fund cancer services
- ensuring that appropriate services are in place to minimise the psychosocial impact of cancer
- optimising the management and administration of cancer control services at all levels in the system to ensure that a given level of resourcing is having the greatest possible impact on the burden of cancer
- providing undergraduate and postgraduate education and training appropriate to the needs of a modern and evolving cancer control system
- stimulating high-quality research on all aspects of cancer control
- developing and maintaining international alliances in support of cancer control.

A.1.4 Cancer control – a population health approach to cancer

In developing the approach to the achievement of the vision and aims of this second National Cancer Strategy *A Strategy for Cancer Control in Ireland 2006*, the National Cancer Forum has advanced a series of recommendations that aim to produce maximum health gain for a given level of investment.

This is conceptually and practically different to the approach taken in the first National Cancer Strategy, which was about increasing capacity from a low baseline and about ensuring availability of services, and was particularly focused on hospital services. Cancer services have been transformed over its lifetime, with increases in services and in numbers of clinicians and other health professionals. The rapidly changing technology and demographic context has meant that there is still some way to go, particularly with certain services such as radiation oncology. However, the focus of this National Strategy for Cancer Control, while continuing to increase capacity should be on consolidating this rapid growth with the development of a culture of quality, measurement, outcomes, education and research.

It is now time to benchmark ourselves against the best performing countries in terms of cancer control. Strategic international alliances will open up opportunities to benefit from the best that is available. We must focus now on ensuring that our policy is capable of enabling us to not only follow, but to lead international standards in cancer control.

The National Cancer Forum has embraced the concept of cancer control that has emerged internationally in cancer policy and is promoted and supported by the World Health Organisation (WHO). A cancer control approach to delivering the vision outlined earlier should, in the context of the Irish health system, be interpreted as consisting of:

- a whole population approach to cancer care with a strong emphasis on integration and holistic care including survivorship, support services and palliative care
- a greater emphasis on health promotion and prevention
- an emphasis on addressing inequalities
- a strong focus on quality and the development of a culture of measurement and quality assurance
- a system of planning and evaluating policy and service delivery on the basis of scientific needs assessment, evidence and health technology assessment
- a greater emphasis on partnership with community and voluntary sectors
- a strong focus on rights and entitlements of patients, their families and carers.

A.2 Strategic context

The Health Strategy was guided by the four principles of equity, people-centredness, quality and accountability. Based on these principles, the Health Strategy sets out four national goals: better health for everyone, fair access, responsive and appropriate care delivery, and high performance. These principles and goals are readily applicable to cancer control and have informed the major recommendations contained within this Strategy. Recommendation 12 of the Health Strategy led to the production and publication of this Strategy.

A.2.1 Health system reform and reorganisation

The Health Act, 2004 set out revised roles for the Minister and the Department of Health and Children and provided for the establishment of the Health Service Executive on 1 January 2005. It also provided for stronger accountability requirements, governance structures and quality measurement. An additional element of planned reforms is the establishment of the Health Information and Quality Authority (HIQA). The respective roles are set out as follows:

The Minister and the Department of Health and Children

The role of the Minister and the Department of Health and Children in relation to cancer in the reorganised health system is more focused on strategic policy formulation and evaluation. The role also encompasses responsibility for legislation, negotiation of the annual estimates, performance measurement, and setting and ensuring adherence to governance and accountability standards.

Health Service Executive

The Health Service Executive (HSE) is responsible for the management and delivery of health and personal social services. It directly manages the funding of the health system and is required under the Health Act, 2004 to integrate the delivery of health and personal social services, to have regard to the policies and objectives of the Government and relevant Ministers and to secure the most beneficial, effective and efficient use of resources.

The HSE is required to prepare and submit to the Minister for approval a corporate plan that sets service objectives and performance measures and a code of governance that includes integration and quality of services to be provided. The Executive is further required to submit an Annual National Service Plan to the Minister for approval, encompassing the type and volume of services to be provided.

Health Information and Quality Authority

HIQA was first proposed in the Health Strategy and forms an integral component of the health reform programme. HIQA will take the lead in the development of health information, quality and health technology assessment in Ireland. Once established, HIQA will provide an independent review of quality and performance in the health service and its analysis will inform policy development by the Department of Health and Children. The interim Authority was established and its Board appointed in January 2005.

A.2.2 National Cancer Forum

1 **A third National Cancer Forum should be appointed by the Minister with terms of reference and composition reflecting the changed health system.**

The National Cancer Forum was established by the Minister on foot of a recommendation in the 1996 National Cancer Strategy. Its primary role is to provide ongoing and independent policy advice on cancer to the Minister and the Department of Health and Children. The evaluation of the first National Cancer Strategy concluded that the Forum played a pivotal role in the development and improvement of cancer services. It has also played an important role in the creation of national consensus around many aspects of cancer policy.

This Strategy has identified the ongoing need for policy guidance to be provided on many aspects of cancer control, particularly on screening, management of cancer patients, genetics, quality assurance, and research. The Minister and the Department will continue to require expert guidance from the National Cancer Forum to support their policy roles in respect of cancer. There is a need to examine the Forum's terms of reference and its membership in the context of the reformed health system. In particular, it should now focus more on policy and its impact. Cancer care is changing more rapidly now than at any time in the past and this generates a particular need to have a consistent high-quality source of credible leadership capable of creating a policy consensus in respect of priorities, necessary developments and deficiencies in service performance.

The National Cancer Forum will be an essential source of this leadership and direction in supporting the ongoing formulation of cancer policy in a developing environment that holds the prospect of exciting new means of detecting and managing cancer. This leadership role should be multi-professional and involve service providers, professional groups, and the community and voluntary sectors which can effectively champion evidence-based cancer policy.

A.2.3 International cooperation and partnership

International cooperation through the European Union (EU) and WHO has recently provided very substantial assistance and leadership to Ireland as a small country in the planning and development of its cancer services. At EU level there has been substantial activity in the development of information systems, some directly related to cancer, others more global in their focus. These systems provide a vital source of information and offer an ongoing ability to measure a wide variety of cancer data in a manner that can easily be compared between countries and over time. They are therefore an invaluable asset at all levels of our cancer control system. In particular, information from this channel supported much of the background work undertaken in the preparation of this Strategy. WHO leadership in the development of cancer control systems is also reflected substantially in this Strategy.

We are fortunate that we have on the island a unique collaboration involving the health systems, North and South, and the internationally prestigious National Cancer Institute (NCI) in Washington. This trilateral partnership involves political and health system collaboration in cancer control and progresses key cancer themes such as prevention, education and training, cancer clinical trials, information and information technology. The substantial support offered by the NCI is widely recognised and appreciated. The Forum sees significant opportunities to develop this partnership and to further support the development of cancer control on the island.

Section B
Analysis

Key messages

- One Irish person in three will develop invasive cancer, while one in four will die from it
- At present about 20,000 Irish people develop cancer and 7,500 die of the disease each year. There are approximately 120,000 cancer survivors. A substantial proportion of these cases are preventable
- About 60% of cancer patients die of the disease within five years of diagnosis
- Although cancer incidence is falling, the ageing of the population will lead to large increases in the number of people who develop cancer. The number of new cases which the system can expect to deal with by 2020 will represent an increase of 107% on the number dealt with in 2000
- There has been a transformation in the range and capacity of cancer services as a result of the 1996 National Cancer Strategy and the work of the first National Cancer Forum
- There continues to be a need for significant expansion in all aspects of cancer service capacity in order to meet the cancer needs of the population
- With some exceptions, such as paediatric cancer, Ireland performs poorly by international standards in relation to cancer risks, incidence and survival
- The current fragmented arrangements for the delivery of cancer services are not in accordance with best practice and their continuation cannot be recommended
- There is inequity in the provision, availability and performance of cancer services when examined by region, social class, age and sex
- Our cancer control system should have the potential to achieve population and individual outcomes that are on a par with the highest international standards
- This Strategy must focus on quality and accountability requirements which support the implementation and monitoring of its recommendations
- Addressing the significant issues outlined in this Strategy will require strong leadership at professional, managerial and political levels as well as meaningful accountability systems for the overall performance of the services.

B.1 Epidemiology

Cancer is a major cause of mortality and morbidity in Ireland – it accounts for approximately 7,500 deaths each year, a quarter of all deaths, and gives rise to approximately 20,000 new cases, including non-melanoma skin cancer (NMSC). There were almost 81,000 hospital discharges and over 48,000 day cases with a diagnosis of cancer in 2002.

In spite of the scale of the cancer burden in Ireland, there have been improvements both in curtailing the risk of developing cancer and in increasing cancer survival in recent years. The true risk of developing cancer is increasing by 0.5% a year for women and 0.8% for men. A significant part of this increase may be due to increased cancer detection from screening.

Allowing for the effects of population change and ageing, the overall true risk of dying from cancer is decreasing by about 1% per year. Between 1995–1997 and 1998–2000, overall relative survival from cancer (excluding NMSC) increased from 48% to 50% for women and from 38% to 44% for men. For women, there were increases in survival rates for cancers of the breast, colon or rectum, cervix, uterus and melanoma. For men, survival rates improved for many cancers, notably for prostate, colorectal and bladder cancer and for lymphoma.

B.1.1 Cancer incidence

Almost 20,000 cases of cancer (including NMSC) were diagnosed in Ireland each year between 1994 and 2001 (Table B.1). The commonest cancer was NMSC, which made up 25% of all cancers diagnosed. The next commonest cancer was colorectal, comprising 9% of the total, followed by breast (8%) and lung (8%) and prostate (7%) cancers. These five cancers were considerably more frequent than any others, and account for 57% of all cancers, including NMSC (Figure B.1).

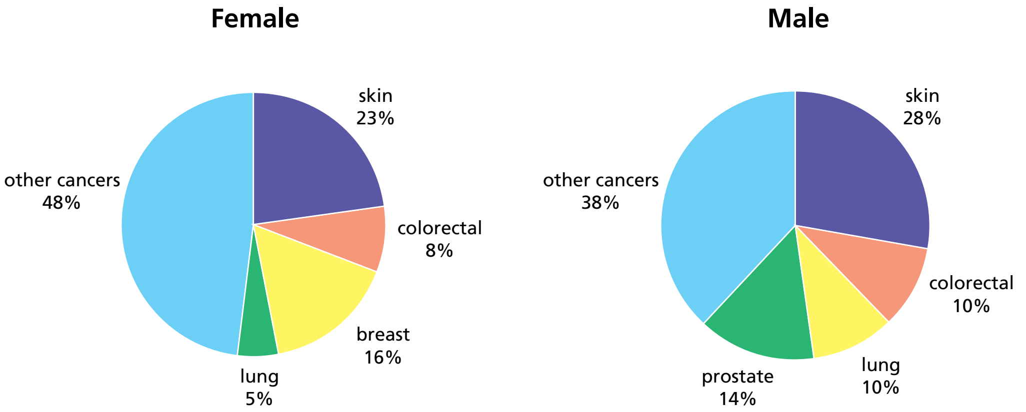
Table B.1: Number of new cancer cases per year (1994 to 2001)

	Both sexes		Females		Males	
Cancer	Annual average number of cases	% of total	Annual average number of cases	% of total	Annual average number of cases	% of total
All cancers	20,523		10,509		10,014	
Skin*	5,195	25%	2,404	23%	2,790	28%
Colorectal	1,821	9%	792	8%	1,029	10%
Breast	1,740	8%	1,726	16%	14	<1%
Lung	1,576	8%	563	5%	1,014	10%
Prostate	1,371	7%	–	–	1,371	14%
Other cancers	8,819	43%	5,025	48%	3,795	38%

**Excluding melanoma*

Source: National Cancer Registry

Figure B.1: Sites of common cancers in males and females, showing percentage of all cancers (1994 to 2001)



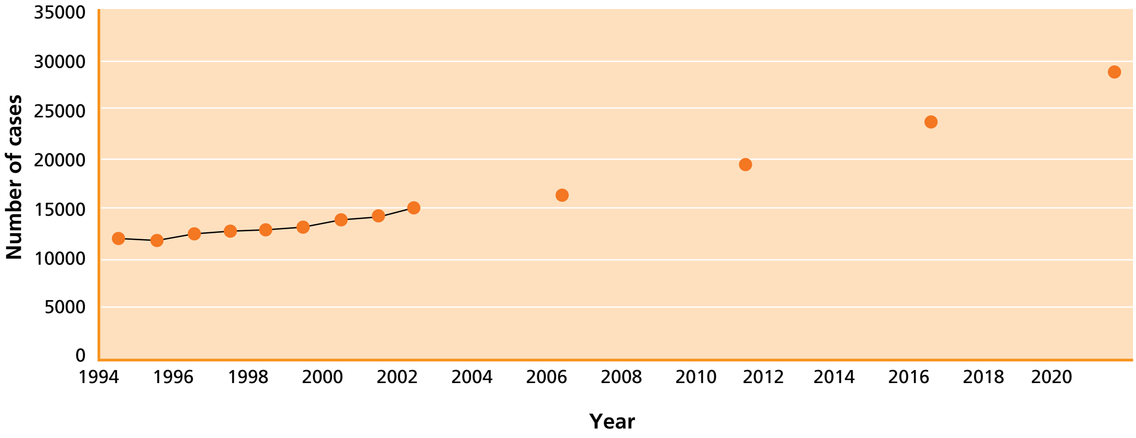
Source: National Cancer Registry

During the same period the lifetime risk of developing any cancer was 36% for women and 39% for men. Excluding NMSC, the overall risk of developing an invasive cancer was about 23% for women and 28% for men. For women, the lifetime risk of developing breast cancer was 8% (one in 13); for men the lifetime risk of prostate cancer was 6% (one in 16). The lifetime risk for women of developing colorectal cancer was 3% (one in 30) and for men 5% (one in 20), while the risk of lung cancer was 2% (one in 50) for women and 5% (one in 20) for men.

B.1.2 Cancer projections to 2020

Figure B.2 shows the increase in new cancer cases from 1994 to 2002 together with selected single-year projections up to 2020. It can be seen that the number of cases of cancer that are diagnosed will rise substantially in the next 15 years. The number of new cancer cases that the system can expect to deal with by 2020 (28,785) will represent an increase of 107% on the number dealt with in 2000 (13,888).

Figure B.2 Number of new cancer cases (1994–2002) [solid line] with projected numbers to 2020



Source: National Cancer Registry

B.1.3 Cancer mortality

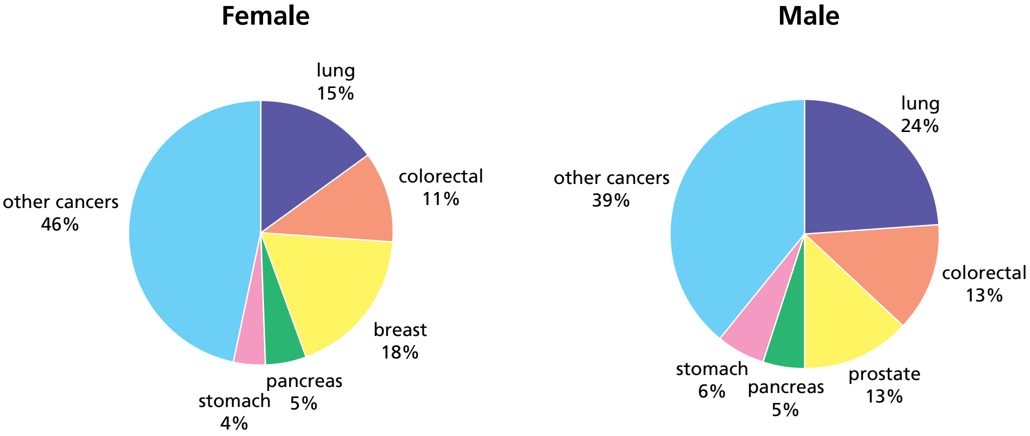
More than 7,500 deaths each year are due to cancer, accounting for about a quarter of all deaths. Between 1994 and 2001 lung cancer was the commonest cause of cancer death overall (20%). It was also the commonest cause of cancer death among men (24%). Breast cancer was the commonest cause of cancer death for women (18%) (Table B.2). Lung, colorectal, breast and prostate cancer accounted for almost half of all cancer deaths over this period (Figure B.3).

Table B.2: Number of cancer deaths per year (1994–2001)

	Both sexes		Females		Males	
Cancer	Annual average number of deaths	% of total	Annual average number of deaths	% of total	Annual average number of deaths	% of total
All cancers	7,584		3522		4,062	
Lung	1,499	20%	534	15%	963	24%
Colorectal	930	12%	404	11%	526	13%
Breast	649	9%	644	18%	5	<1%
Prostate	519	7%	–	–	519	13%
Pancreas	360	5%	176	5%	184	5%
Stomach	375	5%	152	4%	224	6%
All other	3,251	43%	1,612	46%	1,639	40%

Source: National Cancer Registry, Central Statistics Office

Figure B.3: Deaths from common cancers in males and females, by site (1994–2001)



Source: National Cancer Registry

B.1.4 Cancer morbidity

Cancer places a considerable and increasing burden on the health service. The number of discharges from public hospital with a diagnosis of cancer rose from 58,507 in 1998 to 92,508 in 2004. The number of day cases increased by 106% between 1998 and 2004. The number of hospital bed-days used by patients with cancer increased by 16% over the same period (Table B.3).

Table B.3 Hospital in-patient activity for cancer: discharges, day cases and bed-days (1998–2004)

Year	1998	1999	2000	2001	2002	2003	2004
Discharges	58,507	62,509	64,252	70,609	80,789	88,141	92,508
Day cases	28,789	32,554	33,708	39,467	48,260	56,037	59,353
Bed-days	346,737	342,778	357,560	366,875	387,437	385,637	401,442

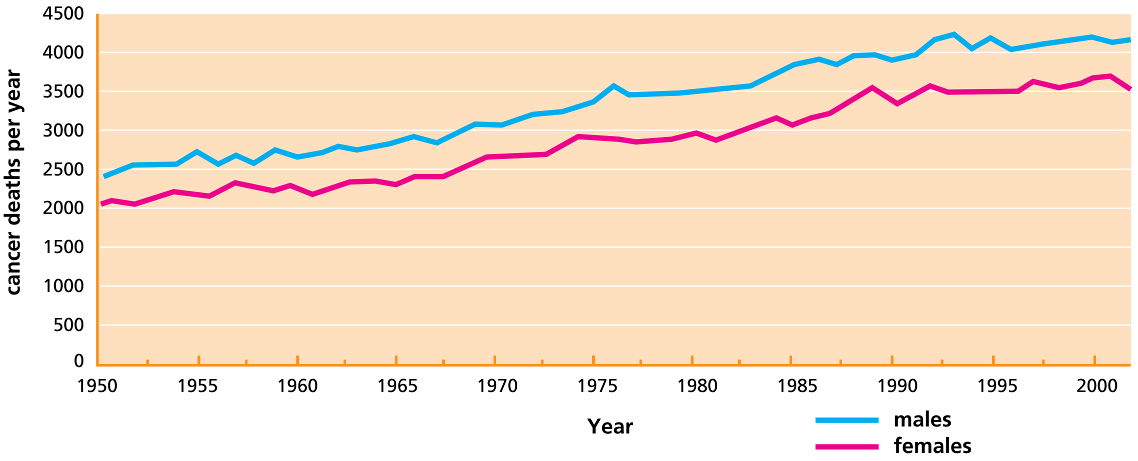
Source: Public Health Information System, version 8

B.1.5 Time trends

Long-term trends: Mortality

Information on the annual number of deaths in Ireland from cancer is available for at least the past century. The figures show deaths from cancer have increased from 4,300 in 1951 to 7,726 in 2001 (Figure B.4). Much of this increase may be explained by population growth and, to a lesser extent, the ageing of the population. As cancer registration in Ireland only began in 1994, comparable long-term trends in cancer incidence are not available.

Figure B.4: Number of cancer deaths in males and females, 1950 to 2002



Source: Central Statistics Office

Recent trends: Incidence and mortality

Most common cancers increased in number between 1994 and 2001. The largest increase in cancer numbers was in cancer of the prostate, which increased by an average of 7.6% per year from 1,089 cases in 1994 to 1,824 cases in 2001. The total number of cancer cases increased at an annual rate of 2.6% for women and 2.0% for men between 1994 and 2001 (Table B.4). However, as with the long-term trends, much of the increase noted was due to population growth and ageing. Between 1994 and 2001 age-standardised incidence rates for many cancers including cancers of the gastrointestinal tract, head and neck, bladder and cervix decreased.

Table B.4: Numbers, cancer cases and deaths, including the lifetime risk of developing cancer by age 75 (1994–2001)*

	Cases				Deaths			
	Number		Risk to age 75		Number		Risk to age 75	
Year	Males	Females	Males	Females	Males	Females	Males	Females
1994	9,505	9,785	35.2%	38.8%	3,980	3,453	13.1%	17.7%
1995	9,427	9,605	34.0%	38.1%	4,109	3,435	12.8%	17.4%
1996	9,727	10,212	35.5%	38.7%	4,006	3,425	12.4%	17.2%
1997	9,942	10,501	35.8%	38.4%	4,023	3,541	13.0%	17.2%
1998	9,888	10,426	35.0%	38.5%	4,059	3,490	12.6%	17.1%
1999	10,101	10,642	35.4%	38.4%	4,111	3,534	12.2%	17.2%
2000	10,678	11,268	36.3%	39.7%	4,132	3,647	13.4%	17.3%
2001	10,841	11,632	36.7%	40.0%	4,074	3,652	12.6%	16.5%
Annual rate of change	2.0%	2.6%	0.7%	0.5%	0.3%	0.9%	-0.1%	-0.6%

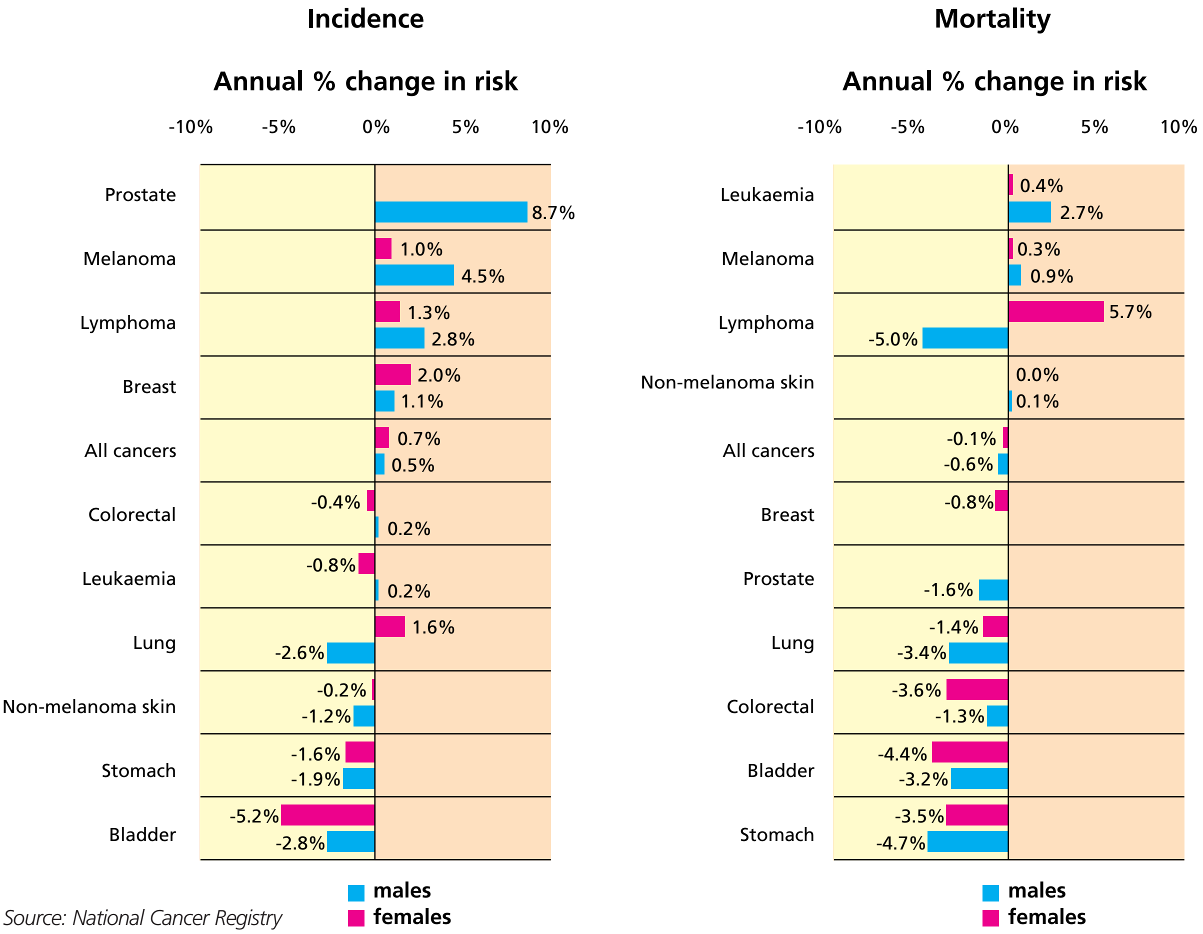
** Not all trends are statistically significant*

Source: National Cancer Registry

There was little change in the number of cancer deaths between 1994 and 2001. The true risk of dying from cancer before age 75 (allowing for the effects of population change and ageing) is decreasing by about 0.1% per year for men and 0.6% for women.

Lung cancer remains the leading cause of cancer death overall, although the risk seems to be decreasing for men. Breast cancer remains the most important cause of cancer death for women, but is also decreasing in frequency (Figure B.5).

Figure B.5: Trends in risk of developing or dying of cancer before age 75, 1994 - 2001



Source: National Cancer Registry

The true risk of developing cancer before the age of 75 (allowing for the effects of population change and ageing) is increasing by 0.7% per year for women and by 0.5% per year for men (Table B.5).

Table B.5: Trends in risk of developing or dying of cancer before age 75 (1994–2001)*

	% annual change			
	New cases		Deaths	
Cancer	Female	Male	Female	Male
All cancers	0.7%	0.5%	-0.1%	-0.6%
Non-melanoma skin	-0.2%	-1.2%	0.03%	0.08%
Colorectal	-0.4%	0.2%	-3.6%	-1.3%
Breast	2.0%	1.1%	-0.8%	–
Lung	1.6%	-2.6%	-1.4%	-3.4%
Prostate	–	8.7%	–	-1.6%
Lymphoma	1.3%	2.8%	5.7%	-5.0%
Stomach	-1.6%	-1.9%	-3.5%	-4.7%
Bladder	-5.2%	-2.8%	-4.4%	-3.2%
Melanoma	1.0%	4.5%	0.3%	0.9%
Leukaemia	-0.8%	0.2%	0.4%	2.7%

* *Not all trends are statistically significant*

Source: National Cancer Registry

B.1.6 Cancer survival

Overall cause-specific survival from cancer (excluding NMSC) increased from 48% for women diagnosed 1994–1996 to 50% for those diagnosed 1998–1999, and from 38% to 44% for men. For women, the greatest increases in survival were observed in cancers of breast, colorectum, cervix and uterus. For men, survival improved for many cancers, notably for prostate, colorectal and bladder cancer and for lymphoma.

Table B.6 shows the percentage of cancer patients diagnosed 1994–1996 who have survived their cancer for at least five years after diagnosis, excluding patients who have died from other causes. Overall, 38% of male cancer patients and 48% of female cancer patients have survived for five years. For men, this is almost identical to the European average, but for women, it is poorer than the average.

Table B.6: Five-year relative survival for Ireland (1994-1996) and European population (1991-1994)

		Ireland		European average	
Cancer	Sex	Five-year survival	95% C.I.**	Five-year survival	95% C.I. **
All cancers excluding NMSC*	Male	38.4	37.4–39.4	39.6	39.3–39.8
	Female	47.7	46.8–48.6	51.9	51.6–52.1
Colorectal	Male	47.4	44.6–50.2	48.6	47.8–49.4
	Female	50.8	48.0–53.5	51.2	50.5–51.9
Lung	Male	8.5	7.3–9.7	11.3	10.8–11.8
	Female	10.0	8.2–11.7	10.6	9.8–11.6
Breast	Female	72.8	71.1–74.5	77.4	76.8–78.1
Prostate	Male	64.1	61.2–67.0	67.0	65.1–67.0

**non-melanoma skin cancer*

*** 95% confidence intervals of the survival estimate*

Source: National Cancer Registry

By far the best survival for the common cancers was for female breast cancer (73%), although survival in Ireland was well below the European average (Table B.6). The poorest survival rate was for lung cancer (8% in men and 10% in women). Survival for colorectal and prostate cancer was close to the European average. Survival for all cancers, other than breast, was better for women than for men.

B.1.7 Cancer survivors

The term 'cancer survivors' refers to the total number of people alive at any time who have ever had cancer. It is not possible to measure this directly. The figures given here are estimates and are provided as a general guide only. They exclude NMSC.

In 2002, it is estimated that there were approximately 120,000 cancer survivors in Ireland, 3.3% of the population (Table B.7). The largest number of survivors was for breast cancer (more than 24,000 women or 1.3% of the female population). On average, there were about nine cancer survivors in the population for each new cancer case. This figure was highest for breast cancer (13 to1) and lowest for lung cancer (1.3 to 1), as few patients survived for more than a year.

Table B.7: Cancer survivors in Ireland (2002)

Cancer	Estimated number of cancer survivors	Survivors/ incidence ratio	Survivors %
All cancers excluding NMSC*	118,000	9.1	3.3%
Colorectal	13,000	7.2	0.4%
Lung	2,100	1.3	0.1%
Female breast	24,000	13.5	**1.3%
Male prostate	11,000	7.5	***0.6%
All other cancers	67,900	8.9	1.9%

** non-melanoma skin cancer*

***females only*

**** males only*

Source: National Cancer Registry

B.2 Cancer service provision in Ireland

In developing this Strategy to reflect best international practice in cancer control, the National Cancer Forum's considerations were informed by the following:

- A review of the current status of cancer care, including an evaluation of the 1996 National Cancer Strategy involving a broadly based consultation process; an analysis of Hospital In-Patient Enquiry (HIPE) data; the report *Patterns of Care and Survival in Ireland 1994 to 1998*
- A review of international approaches to cancer strategies and policies.

While the elements of the analysis were quite separate, key themes and issues emerged which suggest clear ways in which cancer control could be strengthened in order to build upon the successes of the first National Cancer Strategy.

B.2.1 Review of the current status of cancer care

Evaluation of 1996 National Cancer Strategy

An evaluation of the 1996 Strategy, including a broadly based consultation process, was commissioned by the Department of Health and Children on behalf of the National Cancer Forum. The evaluation found that the target of the 1996 National Cancer Strategy to reduce the death rate from cancer in the under-65 age group by 15% in the ten-year period from 1994 was achieved by 2001. The key achievement of the 1996 National Cancer Strategy most commonly attributed by those consulted was that it provided a framework for the development and funding of cancer services in Ireland.

In summary, the review concluded that the 1996 National Cancer Cancer Strategy has delivered:

- a major reduction in premature cancer mortality ahead of target
- significant year-on-year increasing spend on cancer services
- increasing activity in chemotherapy, radiotherapy and surgery
- a more coordinated and structured approach to the delivery of cancer care
- a significant increase in the number of cancer care professionals.

In relation to the organisation of cancer services, the review of the 1996 National Cancer Strategy concluded that:

- there is a lack of clarity concerning the scope and complexity of acute services that should be provided at different levels in the acute sector

- there should be a broad understanding within the health system – among providers, general practitioners and patients – of the services that are available and their locations
- to provide the essential requirement of assured quality in line with international norms, evidence should be the deciding principle and should not be compromised for geographic reasons
- international research has consistently demonstrated that better outcomes are achieved in larger centres through the centralisation of resources, skills and expertise, facilitated by a critical mass of patients.

HIPE Analysis of Surgical Activity

The National Cancer Forum examined data relating to four indicators for a range of ten common site-specific cancers in Ireland between 1997 and 2004 using data from the HIPE system. The analysis was carried out in respect of specific procedures performed on people whose primary diagnosis was a specific cancer. The indicators were chosen to provide a regional perspective on workload at unit level and a national perspective on workload at surgeon level. They also provide a view of cross-boundary flow of cancer-related surgical workload between former health board areas.

The Forum's conclusions based on its consideration of this data are as follows:

- international experience in oncology surgery, especially in relation to complex procedures, is that it should be limited to the hospitals that have adequate case volume and the appropriate skill mix and support services in the various modalities of care
- there is insufficient case volume to support the number of consultants and hospitals engaged in oncology surgery
- the current arrangements for the delivery of cancer services are not generally in accordance with best practice and cannot be recommended to deliver best-quality cancer care.

The Forum and the Department of Health and Children also sought the views of bodies such as the Royal College of Surgeons in Ireland, Comhairle na nOspidéal and the Irish Society of Medical Oncology in relation to this data.

Their responses emphasised the need to organise services on a basis that clearly recognises that for many cancer types there is a relationship between the volume of activity in cancer care and the outcomes that patients experience from that care. They believe that cancer care should be delivered through more specialised services provided by multidisciplinary teams of clinicians in fewer locations.

Patterns of Care and Survival from Cancer in Ireland: 1994 to 1998

The National Cancer Registry published a report in 2003 entitled *Patterns of Care and Survival from Cancer in Ireland, 1994-1998*, which found many significant differences in treatment patterns for all kinds of cancer between former health board areas. It established that there are clear differences in treatment and survival depending on area of residence. The report explored the many possible reasons why survival may vary between geographical areas. An important additional finding was the lack of consistency in treating the same cancer at the same stage.

B.3 International trends in cancer control

Cancer services have developed along broadly similar lines internationally. In recent years, the development of a strategic, planned approach to the delivery of health services has been seen in most developed parts of the world. Key to the success of these strategies is the existence of a high-level policy-oriented body, comprising medical professionals and other stakeholders. The purpose of such national bodies is largely to provide clear and evidence-based policy direction for all aspects of cancer services.

B.3.1 Prevention

Most countries recognise that cancer prevention depends on research, lifestyle, and environment. The majority have implemented or are planning anti-smoking campaigns. Some countries are backing public-awareness initiatives with legislation to regulate tobacco prices, limit or prevent tobacco advertising and restrict the availability of tobacco for certain age groups. Partnerships often develop between non-governmental organisations and government bodies to implement health promotion initiatives in smoking, diet and sun exposure.

B.3.2 Screening

National breast and cervical cancer screening initiatives occur in the majority of developed countries, although target populations may vary. Pilot screening programmes have been established in many countries for cancers such as colorectal cancer, melanoma and prostate cancer. In most countries, screening programmes face common difficulties that include ensuring lower socio-economic groups get equitable geographical access and equal screening and treatment options and ensuring there is appropriate uptake in the target population.

B.3.3 Diagnosis and treatment

There are some consistent trends in evidence that show that most countries are now seeking to develop cancer control programmes that enable care to take place in centres characterised by high caseload, earlier access to care, multidisciplinary care, integration of care delivery, availability of sub-specialty expertise, availability of support services (e.g. intensive care, specialist nurses, specialist therapy services, support services), availability and quality of technology, and the existence of training and research facilities.

Most national cancer control programmes are founded on the acceptance that these requirements can best be captured in a model of cancer control that locates multi-modal, multidisciplinary, integrated and quality-assured care in large and appropriately staffed and equipped centres. These initiatives are often underpinned by arrangements for the development and implementation of best-practice guidance and quality assurance.

B.3.4 Palliative care

Palliative care is seldom addressed in national cancer-specific strategies. Internationally, there are no standards available that could be applied to regional or nationwide services for palliative care. The guidelines that do exist generally relate to individual clinical services rather than high-level strategic standards.

B.3.5 Supportive care

Many countries recognise the importance of cancer support services that include self-care, caregiver support, psychological support, physiotherapy, occupational therapy, dietetics, speech therapy, patient education and health promotion, appliance fitting, nursing services, and community liaison. However, in most countries, this has not translated into a specific national strategy to develop and support such services. In the main, countries support non-governmental organisations in their efforts to directly provide such services. Very often, many of these services are not directly provided by government bodies.

B.4 Conclusion of analysis

There have been major strides forward in cancer care following the first National Cancer Strategy. The range of services and their performance have continued to improve in recent years. Cancer care is undergoing a major and positive transformation. That success must, however, be consolidated and built on. Major developments which are being planned, such as the extension of screening for breast and cervical cancer, various policies in health promotion, symptomatic breast cancer services and palliative care, as well as the much-needed expansion of radiation oncology services, must be implemented without delay.

This Strategy is faced with some new priorities. It is clear from the analysis undertaken that a comprehensive cancer control strategy that addresses all aspects of cancer care is required, through health promotion and prevention as well as diagnosis and management. The ageing of the population will lead to a substantial increase in the number of people who will develop cancer. There needs to be significant expansion in all aspects of cancer service capacity in order to meet this need.

There is inequity in the availability of, access to, and performance of cancer services throughout the country. This must be addressed as part of the expansion and development of services. It should not, however, lead to small-scale developments that do not meet the requirements of evidence and best international practice and, as a result, cannot be sustainable.

The first requirement of a cancer control system is that it should have the potential to achieve population and individual outcomes that are on a par with the highest international standards. One of the most significant strategic issues facing cancer services is the variation in survival rates within Ireland and our relatively poor survival rates for many common cancers (with notable exceptions such as paediatric oncology) when compared to other European countries. In part, this can be attributed to the fragmentation of cancer services, which leads to too many hospitals and too many consultants being involved in the provision of treatment for cancer sufferers. This is not in accordance with best practice. In terms of the delivery and future development of cancer services, the continuation of current arrangements cannot be recommended.

The Forum's view is that addressing these significant issues will require strong leadership at professional, managerial and political levels as well as meaningful accountability systems for the overall performance of the services.

Section C

Promoting health and preventing cancer

Key messages

- The World Cancer Report (WHO, 2003) provides clear evidence that public health action by governments and the promotion of healthy lifestyles could prevent as many as a third of cancers worldwide
- Tobacco use accounts for almost a third of all cancer deaths. The single most effective measure against smoking is sharp price increases
- High consumption of alcoholic beverages increases the risk of cancers of the oral cavity, pharynx, larynx, oesophagus, liver and breast. In the last decade, Ireland has had the largest increase in alcohol consumption among EU15 countries
- Poor diet and obesity are cancer risks. Specific measures are required to improve nutrition and to control obesity. Regular physical activity is a significant element in cancer prevention and control
- Regulation of sunbed use, including restriction of use to adults only, should be put in place
- Inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes are evident and must be monitored and addressed
- Population-based screening programmes for cancer should only be considered where clear evidence exists of the benefit to the health of the whole population to be screened outweighing harm at reasonable cost
- Breast screening should be extended to include all women aged between 50 and 69
- The national roll-out of the Irish Cervical Screening Programme should be completed as a matter of priority
- A colorectal screening programme should be established following resolution of a range of implementation issues
- Population-based prostate screening should not be introduced in Ireland at present
- Opportunistic testing of asymptomatic individuals for cancer is not recommended
- For many cancers, population-based screening is not supported by evidence. Early detection of cancer through other means, therefore, must be a key element of an overall National Cancer Strategy.

C.1 Health promotion

Health promotion is a component of population health aimed at tackling the major determinants of health to achieve health and social changes that can improve the health of the whole population. Health research provides evidence for the value of health promotion in terms of cancer prevention.

It is well documented that lifestyle issues, particularly smoking, can increase the risk of cancer while others, including physical activity and exercise, can have a protective effect. The World Cancer Report (WHO, 2003) provides clear evidence that public health action by governments and the promotion of healthy lifestyles could prevent as many as a third of cancers worldwide.

C.1.1 The Health Promotion Strategy

2 **The recommendations of the Review of the National Health Promotion Strategy, 2004 should be implemented across all sectors.**

The developments in health promotion in Ireland since the launch of the first National Cancer Strategy reflect the global trend to integrate health promotion in relevant health policies. These developments are underpinned by the strategic direction set out in the second National Health Promotion Strategy, *National Health Promotion Strategy 2000-2005,* and in many other related strategies. The purpose of the second National Health Promotion Strategy is to set out a broad policy framework within which actions can be carried out at an appropriate level to advance the key strategic aims and objectives of health promotion policy.

The Department of Health and Children conducted a review of the impact of the Health Promotion Strategy (*Review of the National Health Promotion Strategy 2004*). It found high levels of implementation at both national and regional level in relation to tobacco control, physical activity and nutrition. The review focused in its recommendations on a number of components of the National Health Promotion Strategy. For example, it advocated more effective intersectoral action, strengthening partnerships, building health promotion capacity, and strengthening the performance measurement, research and evidence base underpinning health promotion.

The recommendations of the *Review of the National Health Promotion Strategy, 2004* should be implemented. Given the particular risks that lifestyle-related factors among the young pose for cancer in later life, there should be a particular emphasis on reaching young people in the implementation of the National Health Promotion Strategy.

C.1.2 Smoking

3 **Compliance with all provisions of the Public Health (Tobacco) Acts, 2002 and 2004 should be monitored.**

Tobacco use is the single largest causative factor for cancer, accounting for 30% of all cancer deaths in developed countries. Environmental tobacco smoke (passive smoking) is also carcinogenic to humans. Many advances have been made with regard to smoking and smoking control in Ireland in recent years.

Towards a Tobacco Free Society, produced by the Department of Health and Children in 2000, proposes an integrated strategy for tackling tobacco consumption and promoting a tobacco-free society. The Office of Tobacco Control (OTC) was established as a statutory structure in May 2002 to increase the capacity of the health services to tackle the problem of smoking.

The national smoking prevalence declined from 31% in 1998 to 27% in 2003 (Survey of Lifestyle, Attitudes and Nutrition (SLÁN), 1999 and 2003). The most recent survey by the OTC in October 2005 shows smoking prevalence is now down to 23.93%. This is most probably because of the strong policy measures introduced in recent years and further strengthened through the Public Health (Tobacco) Acts, 2002 and 2004. This legislation *inter alia* places significant restrictions and conditions on the advertising, sale and consumption of tobacco and includes the ban on smoking in indoor workplaces. Compliance with all its provisions should be monitored and all necessary enforcement action should be taken.

The ban on smoking in indoor public places, which was implemented in Ireland in 2004, is a very significant success. It is an example of how Ireland can play a leadership role in cancer control internationally.

4 **Excise duty on cigarettes should be substantially increased each year above the rate of inflation. To this end the National Cancer Forum should produce a pre-Budget submission to the Minister for Finance each year in order to continue advocating for price increases on tobacco.**

Evidence shows that the most effective measure against smoking in the short term consists of sharp price increases. There is a strong social gradient evident in smoking patterns in both adults and teenagers in Ireland with the highest rates among lower socio-economic groups. Children and those in the lower socio-economic groups are most sensitive to price increases.

5 **Nicotine replacement therapy should be made available free of charge to all medical card holders.**

Smoking cessation support has increased significantly in Ireland in recent years. There is strong evidence to show that helping smokers quit is cost-effective in terms of years of life gained, reduction in cost of treatment and potential savings on drugs. The evidence shows that pharmacological aid in the form of nicotine replacement doubles a person's chance of successfully quitting. The provision free of charge of nicotine replacement therapy will particularly benefit medical card holders.

C.1.3 Alcohol

6 **The Report of the Strategic Task Force on Alcohol, 2002 should be implemented in full.**

A high consumption of alcoholic beverages increases the risk of cancers of the oral cavity, pharynx, larynx, oesophagus, liver and breast. In the last decade, Ireland has had the largest increase in alcohol consumption among EU15 countries. Between 1989 and 2001, per capita alcohol consumption in Ireland increased by 49% while ten of the EU member states showed a decrease and three other countries showed a modest increase during the same period.

The Report of the Strategic Task Force on Alcohol, 2002 sets out the way forward in terms of what is effective to reduce alcohol-related harm. The policy measures that have been shown to be most effective in reducing the consumption of alcohol involve regulating the market availability of alcohol beverages and drink-driving counter-measures.

C.1.4 Nutrition

7 **The recommendations of the Report of the National Task Force on Obesity, 2005 should be implemented in full. In particular, there is a need for measures that raise awareness of the links between diet and cancer.**

It is estimated that around a third of all cancers are related to diet. Diet has been recognised as contributing to the development of cancers of the colon, rectum, stomach, lung, and prostate. Overweight and obesity, which are increasing throughout the western world, are risk factors for developing certain forms of cancer. In Western Europe, it has been estimated that being overweight or obese accounts for approximately 11% of all colon cancers, 9% of breast cancers, 39% of endometrial cancers, 37% of oesophageal adenocarcinomas, 25% of renal cell cancers and 24% of gall bladder cancers.

8 **The health services should work with the food industry in order to encourage it to produce, market and improve access to attractive and healthy options.**

There is an increasing body of evidence indicating that health promotion in nutrition leads to health gains at a much lower cost than medical treatment of either high-risk groups or patients. But improving knowledge alone is ineffective in improving people's diets; affordability and lack of accessibility to foods such as fruit and vegetables have been identified as key barriers to eating a healthier diet.

C.1.5 Physical activity

9 **The recommendations of the Report of the National Task Force on Obesity, 2005 in relation to physical activity should be implemented in full.**

The WHO states that regular physical activity is a significant element in cancer prevention and control. There is consistent evidence that some form of regular physical activity is associated with a reduction in the risk of colon cancer. There is also a suggestion of a risk reduction in relation to cancer of the breast, endometrium and prostate. The protective effect of physical activity on cancer risk improves with increasing levels of activity. According to the 2002 SLÁN Survey, only 51% of the population reported engaging in some form of regular physical activity.

C.1.6 Ultraviolet radiation

10 **In conjunction with campaigns to promote safe sun practices and to reduce exposure to ultraviolet radiation, regulation of sunbed use, including restriction to use by adults only, should be put in place.**

Ultraviolet light, either through natural exposure or sunbed exposure, increases the risk of developing skin cancer. There are three main forms of skin cancer. Squamous and basal cell carcinomas (usually collectively referred to as NMSC) account for a third of all cancers but are rarely fatal and are rarely associated with distant spread. However, in relation to melanoma, which is associated with significant mortality, detection in its early stages increases a person's likelihood of survival. Medical and associated costs are also reduced.

In the development of skin cancer, using a sunbed leads to damage from ultraviolet radiation in the same way as sunlight exposure. Exposure in childhood is associated with even greater risks of subsequent melanoma. It is necessary to complement current efforts to promote safe sun practices and to reduce exposure to ultraviolet radiation, with the regulation and restriction of the use of sunbeds to use by adults only.

C.1.7 Radon

11 **The public should be made aware that radon measurements can be undertaken by the Radiological Protection Institute of Ireland. Consideration should be given to providing financial support for testing in high-radon areas and for any necessary remedial work, on a means-tested basis.**

Radon is a naturally occurring radioactive gas that originates from the decay of uranium in rocks and soils. When radon surfaces in the open air, it is quickly diluted to harmless concentrations, but when it enters an enclosed space, such as a house or other building, it can sometimes accumulate to unacceptably high concentrations. When inhaled into the lung, radon may damage cells in the lung and eventually lead to lung cancer. It accounts for approximately 9% of all cases of lung cancer.

C.2 Health inequalities

12 **The HSE should put in place arrangements to monitor inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes.**

Inequalities in health are differences in the experience of health or health services between various groups, whether defined by age, sex, geography, ethnicity or social class. Almost all health conditions show evidence of inequalities. They have been demonstrated to varying degrees in all health care systems. The occurrence of cancer and the experience that people have of services for cancer also demonstrate inequalities. Section B shows that these inequalities exist in survival from cancer and in many other aspects of cancer in this country.

There are a number of reasons for these inequalities in cancer. These include genetic factors and different exposure to risk factors such as smoking, alcohol and diet. They also include differences in the awareness of, and response to, cancer symptoms, lower uptake of screening and variations in access to high-quality services.

There is a need for a consistent focus on risk factors for cancer, incidence of cancer, access to services, and outcome from services to help to reduce health inequalities between various groups. The HSE should put in place arrangements to monitor inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes. The policy indicators proposed in Section G of this Strategy will provide an important means of maintaining a policy focus on cancer inequalities.

C.3 Screening

C.3.1 What is screening?

Screening is a means of detecting disease before it has developed to the point where it results in symptoms. It can allow detection of cancers at an early stage of invasiveness, or even before they become invasive. Screening aims to improve survival, limit morbidity and to improve the quality of life of those who have developed cancer.

Screening is different from most other forms of health care and there is often uncertainty about its purpose. Screening does not diagnose illness; its purpose is risk reduction. It is not a guarantee of diagnosis and cure; those who have a positive screening test require confirmatory diagnostic testing before definitive diagnoses can be established and appropriate treatment planned.

Screening may be population-based or focused on high risk groups. Population screening is aimed at an entire cohort group in the population, selected on the basis of general demographics, e.g. all women aged 50–64. High risk screening is usually based on more individual characteristics, e.g. family history.

Screening may be undertaken pro-actively or opportunistically. In **pro-active screening** members of a target population will attend for testing in a systematic programme that will cover the whole of that population over a defined period of time, e.g. BreastCheck. Conversely, **opportunistic screening** is a test for an unsuspected disorder carried out when a person visits a health professional for another reason, e.g. blood pressure screening.

C.3.2 Population-based screening for cancer

13 **Population-based screening programmes should only be introduced where their population health benefit can be demonstrated using the National Cancer Forum criteria.**

Given the complexity of issues surrounding screening for cancer, there is a need for the National Cancer Forum to provide advice based on a continuous examination of the evidence base for population-based screening, high risk screening and early detection of cancer. Its main role should be to consider evidence on an ongoing basis and to make recommendations relating to:

- the introduction of programmes of population screening for specific cancers
- the introduction of programmes of high risk screening for specific cancers
- the introduction of measures designed to enable early detection of cancer through means other than screening
- priorities in cancer screening and prevention (in overall cancer control)
- policy changes to existing screening programmes.

The Forum's activity in these areas is in keeping with international evidence and with similar national approaches to analysing these issues of complexity in other jurisdictions. This work shows that there is evidence pertaining to some specific cancers showing that population-based screening can improve population health in terms of survival, morbidity and quality of life. However, for other cancers the evidence is less clear. In spite of this, the predominantly healthy populations that population-based screening is aimed at generally perceive screening to be uncontroversial, with obvious benefits.

Whatever the beneficial effects of screening, there may also be negative side-effects on the screened population. The ethical responsibility attached to screening is therefore significantly higher than that attached to ordinary clinical practice. As a result, the introduction of population-based screening programmes for cancer should only be considered where clear evidence exists of benefit outweighing harm to the health of the whole population.

Criteria that should be satisfied before the introduction of population-based screening programmes were first published by the WHO in 1968 and have, in general, stood the test of time. However they require some modification in the light of the last 30 years' experience. In the development of the original criteria, insufficient emphasis was placed on the harmful effects of screening, the quality of the evidence on the effectiveness of screening was not specified, and the opportunity costs of implementing a screening programme were not considered.

Consequently, more comprehensive updated criteria have been agreed by the National Cancer Forum as a framework for guiding decisions concerning national population-based screening programmes (Box C.1). These criteria were then applied by the Forum in examining the case for population screening programmes for both colorectal and prostate cancer.

Box C.1:
National Cancer Forum criteria for decisions on the introduction of population-based screening

The condition

- The condition should be an important health problem
- The epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood and there should be a detectable risk factor, disease marker, latent period or early symptomatic stage
- All the cost-effective primary prevention interventions should have been implemented as far as is practicable.

The test

- There should be a simple, safe, precise and validated screening test
- The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed
- The test should be acceptable to the population
- There should be an agreed policy on the further diagnostic investigation of individuals with a positive test and on the choices available to those individuals.

The treatment

- There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than late treatment
- There should be agreed evidence-based policies covering which individuals should be offered treatment and the appropriate treatment to be offered
- Clinical management of the condition and patient outcomes should be optimised by all health care providers prior to participation in the programme.

The screening programme

- There should be evidence from high-quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity
- There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/intervention) is clinically, socially and ethically acceptable to health professionals and to the public
- The benefit from the screening test should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment)
- The opportunity cost of the screening programme (including testing, diagnosis and treatment) should be economically balanced in relation to expenditure on medical care as a whole
- There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards
- Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to the commencement of the screening programme
- All other options for managing the condition should have been considered (e.g. improving treatment, providing other services).

C.3.3 Breast cancer screening

14 **Breast screening should be extended to include all women aged between 50 and 69.**

There are approximately 1,600 new invasive breast cancer cases annually. Breast cancer remains the most common cause of cancer death for women.

The National Breast Screening Programme (BreastCheck) was established in 1998 with the aim of screening women aged between 50 and 64 with mammography every two years. It is a very successful model of care, consisting not only of mammographic screening but also the follow-up and surgical management of women who are screened positive within the programme. It has provided quality-assured multidisciplinary care to women within internationally accepted time limits. It is imperative that the programme is rolled-out nationally as quickly as possible in line with current plans.

The European Council recommends mammography screening in women aged between 50 and 69. Following national extension of the programme, the upper age limit should be extended to 69.

C.3.4 Cervical cancer screening

15 **The national roll-out of the Irish Cervical Screening Programme should be completed as a matter of priority.**

There are approximately 170 new cases of cervical cancer and approximately 76 deaths from cervical cancer annually. Cervical screening identifies abnormalities that may, if left untreated, develop into cervical cancer.

In 1996, the *Report of the Department of Health Cervical Screening Committee* recommended the introduction of a National Cervical Screening Programme. Phase one of the National Cervical Screening Programme began in the Mid-Western Area in October 2000. Under the programme, women in the 25 to 60 age group are being screened at five-year intervals free of charge. The Health Strategy commits the Government to the full extension of the programme. An evaluation of phase one of the programme was conducted by the former Health Boards Executive in 2004 and the findings of this review should inform the national roll-out of cervical screening.

C.3.5 Colorectal cancer screening

16 **A colorectal cancer programme should be established to encompass population screening, high risk screening and necessary developments in symptomatic colorectal cancer services. In preparation for this programme, the Department of Health and Children should establish a working group under the aegis of the National Cancer Forum to address a range of implementation issues.**

Colorectal cancer is the second most common cancer in Ireland and is a serious public health problem. The mortality-to-incidence ratio for this cancer is relatively high, with just over five deaths for every ten incident cases. Early detection can result in improved survival rates.

Screening for colorectal cancer may be population-based or focus on groups at particularly high risk. Population screening is aimed at an entire cohort in the population selected on the basis of general demographics e.g. everyone aged 50–74, and involves the detection of blood in faeces by faecal occult blood testing (FOBT). High risk screening is usually based on individual characteristics (e.g. family history) and employs more invasive screening tests such as colonoscopy. Colorectal cancer in high risk individuals tends to occur at younger ages that would not generally be covered through population screening. However, the great majority of colorectal cancers occur in people who do not fall into these high risk categories.

FOBT is the most rigorously studied population screening option for colorectal cancer. Four randomised controlled trials (RCTs) have demonstrated that FOBT reduces mortality from colorectal cancer. A meta-analysis of these studies in 1998 found that those screened have a 23% reduction in mortality. This would equate to over 200 prevented deaths each year in Ireland. However, FOBT has poor sensitivity and specificity and has to be repeated at regular intervals. As a consequence, large numbers of well persons may undergo further assessment that leads to anxiety and the risk of possible complications.

The decision to introduce a screening programme for colorectal cancer, therefore, requires the potential risks and benefits to be assessed and compared. The European Council has recommended FOBT screening for colorectal cancer in men and women aged 50 to 74 and that this should be seriously considered based on professional expertise and priority setting for health care resources within each EU member state.

The National Cancer Forum has been monitoring emerging evidence and trends in other countries in respect of colorectal cancer screening. The Forum is now of the view that colorectal cancer screening using FOBT should be introduced in Ireland. However, it believes that substantial work is required to address a range of issues as a prerequisite to the development of an implementation plan. A working group should be established under the auspices of the National Cancer Forum to address each of the following issues:

- **Defining a clear population screening programme** – There are different approaches internationally concerning which FOBT test should be used; which age ranges should be initially prioritised; at what intervals screening should take place; and what follow-up tests should be carried out for those with a positive FOBT. A process to decide on all these key aspects of the design of a population screening programme will be required. International research and pilot colorectal screening programmes are ongoing and may add further clarity to these issues. As a result they should be kept under review
- **Organisation of services** – Consideration is needed of how many screening centres will be required. Treatment pathways and protocols with appropriate capacity to ensure a prompt follow-up will also have to be defined for people who are found to have colorectal cancer or other conditions identified through a screening programme
- **Quality assurance** – As with other population screening programmes, a quality assurance system is a critical requirement and must be embedded in any programme from the outset. This should include risk management strategies to minimise the potential harmful effects of screening and follow-up
- **Call and recall system** – A colorectal cancer screening programme will require a population frame for the appropriate target population. This will include invitations to screening and follow-up, issuing of results and systematic tracking of all contacts
- **Symptomatic services** – A screening programme will increase the requirement for services for colorectal cancer, yet significant numbers of cancers will continue to present directly as a result of people experiencing symptoms rather than having been screened. It is necessary to ensure that services for those identified with cancer outside of a screening programme be reviewed and developed side by side with screening services to ensure that cancer services respond appropriately to the needs of both groups of patients
- **High risk screening** – As cancer in high risk groups frequently occurs outside the likely age ranges for population screening, a programme to detect these cancers will also be required as part of an overall programme of colorectal cancer screening.

C.3.6 Population-based screening programmes

17 **The Department of Health and Children in conjunction with the HSE and BreastCheck should plan the alignment of population-based screening programmes.**

BreastCheck is a statutory organisation separate from the Irish Cervical Screening Programme, which is provided by the HSE. The rollout of these programmes nationally provides an opportunity to align their management and governance. In addition, any future development in relation to colorectal cancer screening should align with breast and cervical cancer screening.

C.3.7 Prostate cancer screening

18 **Population-based prostate screening should not be introduced in Ireland at present. The National Cancer Forum should keep emerging international evidence on population screening for prostate cancer under review.**

Prostate cancer is the second most common cause of cancer deaths in men. There are approximately 1,150 new invasive prostate cancer cases annually. It is a disease of older men with the majority of cases occurring in the 70–74 year age group and the majority of deaths in the 80–84 year age group.

The natural history of this condition is not well understood. The optimum treatment for localised prostate cancer is also controversial. The options of surveillance, radiation oncology and radical surgery all have benefits and potential side-effects. There is no compelling data to demonstrate the superiority of any of these treatment options for an individual patient. There are ongoing large randomised controlled trials to determine the most appropriate treatment option for localised disease.

The principal screening tests for prostate cancer are digital rectal examination (DRE), serum tumour markers such as prostate-specific antigen (PSA), and transrectal ultrasound. At present there is no direct evidence on the effectiveness of these screening tests in reducing the mortality from prostate cancer. However, randomised controlled trials are under way in Europe and the US to examine the benefits of PSA and DRE as screening tools. Results from these trials will not be available until at least 2008.

There is currently insufficient evidence to recommend the introduction of a prostate screening programme. This issue should be reassessed when the results of RCTs are available.

C.3.8 Opportunistic testing for cancer

19 **Opportunistic testing of asymptomatic individuals for cancer is not recommended.**

There is a considerable level of testing which is regarded as screening by health professionals. Examples of this include cervical smear tests outside the National Cervical Screening Programme, PSA testing and mammograms in asymptomatic women outside the BreastCheck Programme. While many of these tests may well be carried out as diagnostic procedures, significant numbers are conducted in the belief that they constitute screening and carry with them the benefits associated with organised screening programmes.

However, without appropriate quality assurance mechanisms, clear referral and follow-up procedures, call and recall processes, among many other organisational attributes, this form of testing does not carry the benefits of organised population-based screening and may actually be injurious to health.

Opportunistic testing for cancer among asymptomatic people is therefore not recommended. However, it is recognised that there is a considerable volume of opportunistic testing taking place at present. Patients should not undergo such testing unless they and their attending health professionals both know and understand its significant limitations.

The HSE should develop information material, both for health professionals and for the general public, on the use of screening tests outside national screening programmes. In developing such information, it would be worthwhile to have particular regard to the Prostate Cancer Risk Management Programme in the UK. This programme is aimed at primary care clinicians advising and counselling asymptomatic men who are worried about prostate cancer.

C.4 Early detection

20 **The HSE should develop specific programmes that promote early detection of cancer.**

For many cancers, population-based screening is not supported by evidence. Early detection of cancer through other means, therefore, must be a key element of an overall National Cancer Strategy.

Early detection is an approach that promotes vigilance for signs and symptoms that may be indicative of early disease. It is based on the premise that it is easier to treat and cure the cancer if it is detected early. Detecting cancer early, before it has had a chance to spread, remains the best strategy for reducing cancer deaths. Examples of early detection include breast awareness, testicular examination and skin inspection, as well as early presentation for medical attention with worrying symptoms such as lumps, changing moles, abnormal bleeding, change in bowel habit and unexplained weight loss.

An important component of early detection initiatives is educating the public about early detection and the importance of recognising symptoms, performing self-examination, and early presentation with any suspicious symptoms. Such initiatives should also include programmes to increase public awareness of the early warning signs of cancer, including the warning signs of cancer in children, and use of cancer self-examination techniques and screening tests.

Section D

Managed Cancer Control Networks

Key messages

- All cancer care should be provided through a national system of four Managed Cancer Control Networks, each serving a population of approximately one million people
- Managed Cancer Control Networks will provide integrated primary, hospital, palliative, psycho-oncology and supportive care underpinned by a formal structure of clinical leadership
- A Network Director should be appointed by the HSE as soon as possible to each Managed Cancer Control Network to support and direct implementation of cancer policy. The Network Director will lead a team consisting of a lead clinician for each major site specific cancer and a lead clinician for each Cancer Centre within the network
- The HSE should develop care pathways for cancer care to link primary care, hospital care and other relevant services. They will be specific to major cancer types and will reflect guidelines and standards set down by HIQA
- A 'designated health professional' should be identified to provide patients, their families and carers with education, support and coordination in cancer care
- Cancer Centres that each serve a minimum population of 500,000 should be designated by the HSE as soon as possible. Ireland will require about eight such centres
- The National Network for Radiation Oncology Services should be established by the HSE in accordance with the timelines set by Government
- Patients should have their diagnosis established and their treatment planned by site-specific multidisciplinary teams
- There is a need for continued expansion in capacity which should be addressed by a needs assessment for cancer services with a particular emphasis on hospital-based cancer treatment that maximises the use of ambulatory care
- Service level agreements between the HSE and the private sector for specific cancer services – with centres licensed and accredited for such services – will enable a cooperative relationship between the public and private sector
- A National Cancer Genetics Policy should be developed by the National Cancer Forum
- Each Managed Cancer Control Network should have comprehensive specialist palliative care, psycho-oncology and psychosocial support services
- A partnership framework should be developed between the HSE and the voluntary sector.

D.1 Introduction

Cancer care is a dynamic process involving the interaction of many different elements of the health system. Although they are often considered separately (e.g. primary care versus hospital care, or palliative care versus cancer treatment), the overall quality and performance of services as delivered to patients is dependent in a very significant way on how well these elements integrate and coordinate with each other. Services must be planned and organised in a manner that facilitates integration so that, from the perspective of the user, the whole system operates in a complementary and efficient manner.

This section sets out a series of recommendations based on the findings set out in the Analysis section (Section B). They are aimed at creating a system – based on Managed Cancer Control Networks – that is fully integrated in addressing the needs of populations and patients with cancer. It identifies requirements for clinical leadership and quality systems that will enable the successful operation of these networks. The agenda for change extends to patients and the general public, and requires a growing awareness and acceptance of the requirement for services to be organised around specialist care as well as around appropriate technologies.

D.2 Managed Cancer Control Networks

21 **All cancer care should be delivered through a national system of four Managed Cancer Control Networks, each serving a population of approximately one million people.**

Cancer care has traditionally formed a hierarchy connected by clinical referral (i.e. local to regional to national). Patients are often transferred within and between services with varying levels of coordination and integration of care. This has not made best use of the knowledge, expertise, experience and technology that our system has to offer. The organisation of cancer services should ensure that patients receive the highest standards of care possible and that their care will not depend on where they live, where or to whom they initially present, or their knowledge of the services.

To achieve this, a national framework is required consisting of Managed Cancer Control Networks in which care is fully integrated between primary care, hospitals, palliative care, psycho-oncology and supportive care. This should take full advantage of the resources available to ensure the delivery of services that are of the highest quality and are equitable and accessible.

A Managed Cancer Control Network will feature the sharing of patients, expertise and resources. It will allow, for example, hospitals to cooperate to provide services when the population base of each is too small for them to do this in isolation. The emphasis in such a network will be on connection and partnership rather than isolation and self-sufficiency, on distribution of resources rather than centralisation, and on maximising the benefits for all patients.

The Health Service Executive should organise all the services it provides (primary, community and continuing care, as well as the National Hospitals Office) in four networks on a national basis, each serving a catchment population of approximately one million people. This is a tried model for cancer care in that cancer control networks in other countries are organised around similar population sizes. At this level each Managed Cancer Control Network should be self-sufficient in all but a small number of comparatively uncommon or complex cancers.

Establishing Managed Cancer Control Networks and operating them effectively will present new challenges to culture and attitudes across primary care, hospital care, palliative care, psycho-oncology and supportive care. Relationships between health professionals will have to be carefully and clearly defined if staff are to function effectively and realise their potential. Mobility of staff should be facilitated. As the key 'collegiate' resource within each network, consultants should have sessional commitments to the network as well as to specific institutions.

D.2.1 Managed Cancer Control Network Director

22 **A Network Director should be appointed by the HSE as soon as possible to each Managed Cancer Control Network to support and direct implementation of cancer policy.**

23 **A lead clinician for each Cancer Centre should be appointed. In addition, a clinician should be appointed to lead the development of cancer care pathways for each major site-specific cancer in partnership with all stakeholders within the network. The Cancer Control Network Director should head this team of lead clinicians.**

The National Cancer Forum, based on experience to date, on consultation with the current Regional Directors, and on evaluation of the 1996 National Cancer Strategy, is strongly of the view that the regional clinical leadership role needs to be strengthened. In particular, this should ensure that the Network Director has a meaningful role in cancer services in the network including resource allocation, priority setting, service planning and evaluation. The post should involve at least a half-time commitment.

The role of the Network Director should be to provide strong and effective clinical leadership in the implementation of cancer policy within a given network. The director will oversee the development and implementation of cancer care pathways for major site-specific cancers that reflect national policy and priorities and are based on guidelines and standards set down by HIQA.

There should be one director for each Managed Cancer Control Network. In order to ensure equity and balance between Cancer Centres (as defined in Section D.3), the postholder position should be rotated within a given network area every two to three years. The four Network Directors should be a significant resource within the national cancer programme of the HSE.

A lead clinician for each Cancer Centre should be appointed. In addition, a clinician should be appointed to lead the development of cancer care pathways for each major site-specific cancer in partnership with all stakeholders within the network. The Network Director should lead this team of senior clinicians.

These positions should be seen as key leadership positions in bringing cancer care in each network to the highest possible standard and as such should lead to identified individuals having a 2–3 session per week protected time commitment. As with the director position, these positions should be appointed as quickly as possible and rotated every two to three years.

It would be especially important in the early years that the persons appointed to these roles are senior clinicians from the Cancer Centres in the network. This will be essential to create the necessary buy-in during the process of developing and implementing the critical functions ascribed to the networks. It would be equally important that after the initial development phase these positions would involve clinicians drawn from other elements of the Managed Cancer Control Network.

D.3 Elements of the Managed Cancer Control Network

The following sections describe each of the elements that will comprise a Managed Cancer Control Network:

- primary care
- hospital care
- palliative care
- psycho-oncology
- supportive care.

D.3.1 Primary care

Primary care is usually the first point of contact with the health system. It acts as a gatekeeper for secondary care services. Patients usually begin the cancer care process in primary care with symptoms or signs being initially presented to general practitioners (GPs). The process usually involves referral into the acute hospital system and, if required, on to palliative care services or one of a number of community based services as they live with their cancer.

There is a wide variety of cancer care roles carried out in primary care at present (Box D.1) and its importance in relation to cancer services was recognised clearly in the first National Cancer Strategy. However, there is considerable scope to develop a much greater role for primary care in cancer control. The Primary Care Strategy, *Primary Care: A New Direction* provides a clear strategic focus for the development of primary care. The expansion and development of this model will ensure that primary care can have a greater impact on the burden of cancer.

This aim could be facilitated by ensuring that the contractual relationship with GPs reflects the requirement for a greater emphasis in primary care on health promotion and disease prevention activities (including national population screening programmes). It would be further facilitated by improved direct access to hospital-based diagnostic facilities from primary care.

Box D.1:
Primary care cancer services

Health promotion

- raising awareness of lifestyle-related risks for cancer
- smoking cessation initiatives
- alcohol advice and management services
- diet and exercise advice
- risk factor modification

Early detection and screening

- recognition of early signs and symptoms of cancer
- raising awareness of early signs and symptoms of cancer
- delivery of population-based screening programmes e.g. smear taking
- raising awareness and uptake of screening
- advice regarding nature of and indications for screening

Direct service provision

- palliative care
- managing social, nursing and other aspects of cancer care in the community

Communication

- explaining cancer to patients and families
- explaining cancer services to patients and families
- providing ongoing reassurance to patients and families
- explaining/interpreting hospital care services for families of cancer patients
- liaising with hospital care services

24 **The HSE should develop care pathways for cancer care to link primary care services, hospital services and other relevant services.**

Cancer care pathways can be described as a map that is followed by patients with the same or similar conditions between various services, centres and settings involved in the management of cancer. Care pathways should be at the heart of Managed Cancer Control Networks. The development of care pathways should guide the process of cancer care delivery within a particular network. Once drawn up, they will provide a source of information for primary care professionals on cancer care services within a given Managed Cancer Control Network in an integrated and organised manner centred around the needs of individual patients.

Primary care is pivotal in the coordination of the wide variety of services that patients may use. It therefore needs to see itself and be seen as a key partner in the delivery of effective secondary care services. This coordinating role should be reflected in care pathways that integrate all services.

25 **Improved cancer information services should be available to primary care.**

A significant challenge for primary care is the fact that GPs may see on average only one or two new diagnoses of cancer among their patients each year. However, they may see many patients who have cancer and others who have survived cancer. They must be able to differentiate between those patients whose symptoms may be due to cancer and the much larger number with similar symptoms due to other causes.

GPs and other primary care professionals need information about cancer and its symptoms. They need to know when, how and where to refer patients. They also need to understand the process of cancer care as delivered in hospitals and other settings. They need this information because they are often required to explain cancer to patients, to describe the process of care to patients and families, and to provide reassurance.

Information for primary care professionals concerning all aspects of cancer and its treatment should be available, using all media, to ensure that professionals have timely and trusted information on which to base decisions. HIQA will have a central role in the development of such services. This is dealt with in more detail in Section E.

26 **The HSE should develop programmes that support primary care professionals in the provision of cancer services.**

Continuing medical education and professional development programmes should be developed that ensure primary care professionals are fully aware, *inter alia*, of signs and symptoms of cancer, the role and use of screening and diagnostic technologies, indications for referral, and processes of specialist care.

27 **The HSE should ensure that systems are in place to identify and support a 'designated health professional' as a contact person for each individual cancer patient who may require it.**

Patients with cancer often have complex care processes to follow. Even in the event of well laid out care pathways, the course that an individual patient may follow can vary. Many patients may not be able to manage the coordination of their own care as well as managing their illness and may come to rely on others who can help them navigate through the system. The 'designated health professional' would fulfil this role. Designated health professionals provide patients, their families and carers with education and support and coordinate care through the continuum of care.

D.3.2 Hospital care

Cancer care in hospitals faces significant challenges to enable it to meet the aim of providing appropriate and timely access to services that are of the highest standards of quality by international standards. Hospital services need to expand to ensure that they meet the needs of an ageing and changing population. Paradoxically, the analysis set out in Section B shows that there are too many hospitals and too many consultants providing surgical care for many types of cancers.

In addition to this fragmentation of cancer care, the analysis also raises considerable uncertainty about the ability of smaller hospitals to adapt and implement future changes in the delivery of cancer care, especially for complex cancers. Several factors contribute to this uncertainty, including having too low a caseload to maintain clinical expertise in the use of complex diagnostic and treatment techniques, staff training, quality assurance and risk management strategies.

28 **Cancer Centres that each serve a minimum population of 500,000 should be designated by the HSE as soon as possible. Ireland will require about eight such centres.**

It is clear that the hospital sector must address the need for continued expansion of capacity while limiting cancer care to a smaller number of Cancer Centres which then come together in Managed Cancer Control Networks to pool knowledge, expertise, experience, skills and technology. There is clear evidence that people who have surgical treatment for many common cancers in centres with higher throughput, experience better quality of care and better survival rates. Services that take place in such centres are generally characterised by the following features:

- care is more specialised, thus increasing the likelihood of better survival
- there are higher caseloads of patients, increasing the experience and ability to sub-specialise of individual clinicians and clinical teams
- diagnosis and treatment planning is conducted by multidisciplinary teams
- care delivery is informed by evidence-based guidelines
- audit and other quality assurance programmes are in place
- there is participation in clinical trials and other forms of cancer research
- undergraduate and postgraduate teaching takes place.

Cancer Centres should serve a minimum population of 500,000 and must be networked to all other elements of the health system. This catchment size will ensure that there is a balance between geographical access and the need to ensure that caseload and other economies are maximised. A smaller size will prevent minimum evidence-based thresholds for breast cancer surgical care being achieved. Breast cancer is chosen as a benchmark because it is one of the commonest forms of cancer and because the evidence relating the organisation of services to the outcome of care is stronger for breast cancer than for any other cancer type.

While a population of 500,000 would provide sufficient workload for the management of breast, prostate or colon cancer, it could not support the management of more complex but less common cancers, such as cancer of the pancreas or the oesophagus. Some Cancer Centres should therefore provide a higher level of care for certain types of cancer, based on their existing subspecialty expertise and on the need for larger volumes than would present in a single Cancer Centre. Examples of such expertise would include BreastCheck, oesophageal surgery, pancreatic surgery, haematological malignancy and radical prostatectomy.

No single centre should lead on all such services within the network. Rather, the Cancer Centres within a Managed Cancer Control Network should work together to provide services it would not be appropriate to replicate in all Cancer Centres. Cancer Centres should be seen as equal partners within each network, rather than being related in a hierarchical fashion. A network consisting of two or three Cancer Centres would provide a level of comprehensiveness unattainable by a single centre.

Individual centres may also function as national centres; all services of a particular nature for the country may either be delivered or directly led by them. Existing examples in this regard include paediatric oncology, surgery for transplantable hepatobiliary malignancy, stem cell transplantation, neurological tumours and bone cancer.

It is important that the HSE designates Cancer Centres as soon as possible so they can begin to plan their development, to ensure that they can best fulfil their role in terms of appropriate staffing and infrastructure.

The development of Cancer Centres should allow for certain circumstances in which care may need to be delivered in other centres (non-cancer centres) for pragmatic reasons such as patient convenience. It is essential that this should happen only under the direct supervision of a Cancer Centre. The Cancer Centre should retain responsibility for the diagnosis and all aspects of treatment planning. This is the model that is successfully operating in the field of paediatric oncology.

29 **The HSE should conduct a needs assessment for cancer services with a particular emphasis on hospital-based cancer treatment that addresses the need for continued expansion in capacity and maximises the use of ambulatory care.**

There has been substantial expansion in cancer services in recent years. However, the analysis conducted in the preparation of this Strategy shows that there will be a continued need for services to expand to meet the rising needs in the coming years. The need for additional capacity throughout the Managed Cancer

Control Network and in particular in the hospital system, will have to be carefully planned to take account of the need to reorganise and reform care within the existing hospital system and to maximise the efficient utilisation of infrastructure and services.

Length of hospital stay for cancer in Ireland compares unfavourably with many other EU15 countries. While the reasons for this are likely to be multifactorial, it may represent inefficiency in the process of care in hospitals. It is in the interest of patients and the service as a whole that best possible use is made of hospital-based services.

Hospital care can be provided on an ambulatory basis, as in day case or outpatient services, or it can be delivered on an in-patient basis. Patients would prefer not to spend unnecessary time in hospital and one of the aims of cancer treatment provision should be to maximise the potential role of ambulatory care to ensure that people are managed as in-patients only where ambulatory care is not possible or appropriate. Sufficient dedicated cancer bed capacity should be available to provide necessary in-patient services.

There is a need for the HSE to plan the development of cancer service capacity at both national and network levels in a way that maximises the use of ambulatory care. These developments should be based on detailed needs assessments for hospital care that take account of:

- changing demography and epidemiology
- existing levels of service provision
- current developments such as radiation oncology, BreastCheck etc.
- the provision of cancer care as an integrated programme delivered by specialised teams
- the need to align developments within the HSE with Managed Cancer Control Networks and a limited number of Cancer Centres
- the need to ensure equity in the provision of hospital care between networks
- trends in medical technology.

In order for additional capacity to be developed in the interim, the HSE may choose to enter into service level agreements with the private sector. Such interactions may improve cooperation between the public and private sectors. However, in order to ensure that minimum safety and quality standards are equivalent in both the public and private sectors, service level agreements between the HSE and the private hospital sector should only be developed with private hospitals that have been licensed for the provision of those services and participate in ongoing national accreditation processes as described in Section E.

30 **The National Network for Radiation Oncology Services should be established by the HSE in accordance with the timelines set by Government.**

In July 2005, the Tánaiste and Minister for Health and Children announced a National Network for Radiation Oncology Services. This plan represents a major expansion in radiation oncology services that will bring Ireland into line with its future capacity requirements and with international best practice.

It will ensure that cancer services are fully integrated by arranging for services to be provided by multidisciplinary teams covering the modalities of surgical oncology, medical oncology and radiation oncology. The National Radiation Oncology Network is based on the major recommendations of the Expert Group Report *The Development of Radiation Oncology Services in Ireland* approved by the Government in September 2003.

Given the major shortfall in existing radiation oncology services documented in this Report, it is imperative that the National Network for Radiation Oncology Services should be established as quickly and efficiently as possible and in accordance with the timelines set by Government.

31 Patients should have their diagnosis established and their treatment planned by site-specific multidisciplinary teams.

Cancer services are best provided by teams of clinicians (doctors, nurses, allied health professionals and other specialists) who work together effectively. Team working brings together staff with the necessary knowledge, skills and experience to ensure high-quality diagnosis, treatment and care. Together with Recommendation 27, this will also improve the coordination and continuity of care for patients. Irrespective of the type of cancer, or the point in the system where a patient initially presents, care planning and delivery by an appropriate specialist team is essential.

There is good evidence that patients with many common cancers are more likely to survive and to experience better outcomes if they are treated by specialist teams. Patients need to be assured therefore that their care is being provided by specialist teams. Progress has been made in establishing multidisciplinary teams for some cancers and in some institutions. However, the provision of cancer care by specialist teams needs to be developed as a consistent feature of care across the various types of cancer within each Managed Cancer Control Network.

The Network Director of each Managed Cancer Control Network should seek to ensure the establishment of inter-Cancer Centre or inter-network case conferences where appropriate to major site-specific cancers, so as to ensure that the best available expertise and skills are brought to bear on patient care.

32 The HSE should conduct a review of the number of centres required for the management of symptomatic breast disease to bring them into line with designated Cancer Centres.

The Report of the Sub-Group of the National Cancer Forum on the Development of Services for Symptomatic Breast Disease (2000) recommended the development of fourteen centres, on the basis of a minimum annual caseload of 100 new cases of breast cancer. This volume of activity is necessary to guarantee quality care for women with breast cancer.

BreastCheck is being rolled out nationally. Taken together with the recommended extension in the upper age limit for screening to 69, screening can be expected to reduce the number of women who present with symptomatic breast cancer by one third to one half. It will, therefore, bring a number of previously identified centres below the minimum recommended caseload. Consequently, the number of centres required for the management of symptomatic breast disease must be reviewed to ensure that they align with the Cancer Centres to be designated by the HSE.

33 The HSE should conduct a national needs assessment for rare cancers.

A number of highly specialised areas of oncology have not been addressed to the extent that they should. Examples include neuro-oncology and ocular oncology. There is a requirement to ensure that the needs of patients requiring highly specialised national services can be met. This will require the HSE to plan developments in these areas on the basis of a national needs assessment for rare cancers. There will continue to be a need for recourse to international services in exceptional circumstances.

34 A National Cancer Genetics Policy should be developed by the National Cancer Forum.

Major advances have been made in recent years in cancer genetics. Because of easy access to cancer cells (from blood or bone marrow), genetic abnormalities in haematological malignancies (leukaemias and related disorders) are now well documented. These abnormalities not only serve as a very useful diagnostic tool but have also allowed stratification of patients into different risk groups in terms of prognosis and treatment. An understanding of the molecular basis of the genetic abnormalities has facilitated the development of a new generation of effective anti-cancer drugs.

The increasing worldwide understanding of the role of genetics in the provision of cancer care is leading to an increased demand for the development of services in the area and presents major medical, organisational and financial challenges that need to be addressed to ensure patients get the highest quality care. The opportunity now exists to bring policy into line with medical advances in the area.

The National Centre for Medical Genetics at Our Lady's Hospital for Sick Children, which has received significant recent funding for staff and equipment, provides a national diagnostic service for patients with acute and chronic leukaemia and related malignancies. It is imperative that this national service is maintained at its current level of activity and expertise and avails of future developments in technology in this important area of cancer care.

A National Cancer Genetics Policy should be developed by the National Cancer Forum. The plan should address the organisation, development and priorities in the following key areas: (i) inherited familial pre-disposition to cancer; (ii) cancer risk profiling of persons without inherited mutations; and (iii) molecular diagnostics and molecular therapeutics.

D.3.3 Palliative care

What is palliative care?

Palliative care is the continuing active total care of patients and their families, at a time when the expected medical outcome is no longer cure. It responds to physical, psychological, social and spiritual needs, and extends to support in bereavement. The goal of palliative care is to ensure the highest possible quality of life for both the patient and their family. Specialist palliative care services are those services with palliative care as their core specialty and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine.

The Report of the National Advisory Committee on Palliative Care, 2001

35 **The HSE should ensure that each Managed Cancer Control Network has a comprehensive specialist palliative care service.**

The Report of the National Advisory Committee on Palliative Care (2001) describes a comprehensive palliative care service and acts as a blueprint for its development. The service should support the patient wherever the patient may be – at home, in hospital, in residential care, or in a specialist palliative care unit.

The HSE should ensure that each Managed Cancer Control Network has a comprehensive specialist palliative care service to meet the needs of patients and families. This will enable a range of benefits including the incorporation of palliative care into patient care plans at an appropriate stage in the management of their disease; an enhancement of the palliative care capacity of primary care; integrated care pathways and multidisciplinary teams that incorporate palliative care services.

36 **A formal linkage should be established between the National Cancer Forum and the National Council for Specialist Palliative Care.**

The Tánaiste and Minister for Health and Children has established a National Council for Specialist Palliative Care in line with the recommendations of *The Report of the National Advisory Committee on Palliative Care*. Its role is to advise on the development and implementation of national policy on palliative care services in

Ireland. In order to ensure effective integration of policy, there should be formal links between the National Council for Specialist Palliative Care and the National Cancer Forum.

D.3.4 Psycho-oncology

37 **The HSE should ensure that access to comprehensive psycho-oncology and psychosocial support is provided for cancer patients and their families in each Managed Cancer Control Network.**

Multidisciplinary psycho-oncology services need to be provided to identify and manage distress in cancer patients. Structures should be developed in each Managed Cancer Control Network to ensure that each Cancer Centre has a dedicated psycho-oncology service and is capable of meeting the psychosocial needs of patients and their families. An important part of meeting this obligation will be the provision of ongoing training for cancer team members to ensure effectiveness in the management of psychosocial distress in cancer patients. Training should include communication, the detection of psychosocial problems, provision of support to patients and families, and identification of the need for onward referral as necessary.

D.3.5 Supportive care

All patients with cancer deal with issues that cause some level of distress at some stage. Regardless of prognosis, the initial diagnosis of cancer is still perceived as a life-threatening event. While many patients cope well, a high proportion develops significant psychosocial distress. More than a third of patients experience anxiety and/or depression. However, most busy oncology services are not currently set up to reliably detect distressed patients. Evidence shows that when people experiencing cancer receive good social and psychological support, their quality of life improves.

Cancer support services

The main policy developments in cancer support services in Ireland have been informed by *Cancer Support Services in Ireland: Priorities for Recommendation* (1999) and *The Report of the National Advisory Committee on Palliative Care* (2001). The latter is dealt with in Section D.3.3. *Cancer Support Services in Ireland: Priorities for Recommendation* found that there was an absence of adequate formal psychosocial support services. It made a series of recommendations for the development of supportive care services.

The voluntary sector in Ireland has, to date, been the mainstay in the provision of supportive care for cancer patients in the community. The Irish Cancer Society has been a major provider of nursing services to patients with cancer and has also made other major advances in support services such as help-lines, help promotion campaigns, printed literature and public information days. The Society also aids the development of support groups by offering professional advice and assistance to those affiliated to the Society.

A range of voluntary cancer support groups, centres and advocacy groups exists throughout the country providing invaluable assistance and support to patients. Examples include ARC Cancer Support Centres, Reach to Recovery, EuropaDonna and Canteen. In addition, about 400 self-help groups exist throughout Ireland. They provide support for cancer patients and their families, especially in dealing with emotional and practical challenges of the disease.

Future direction of supportive care services

38 **A partnership framework should be developed between the HSE and the voluntary sector.**

Significant work is done by the voluntary sector and merits continued support, particularly in the development of supportive care. Practical help, for example dealing with everyday concerns of patients and their families in relation to financial strains, hidden costs and transport issues, is of particular value.

The necessary expansion of these roles is best carried out by the voluntary sector. There would, however, be a benefit in seeking to develop a more structured partnership with the voluntary sector to ensure the provision of services on a consistent national basis in a manner that best complements services provided by other sectors and organisations.

39

A code of practice should be developed for self-help groups, support groups and support centres.

Support groups and self-help groups exist nationwide. Cancer support centres, set up near Cancer Centres but independent of them, are recent and successful developments. Their further development, with integral outreach services to ensure widespread patient access would be beneficial to patients and to the system as a whole.

The development of a code of practice for the spectrum of support groups and self-help groups would be beneficial. This would greatly strengthen supportive care. There is no umbrella body at present to which all self-help and support groups are affiliated. Affiliation to the Irish Cancer Society of these voluntary groups would constitute a progressive step forward.

Section E

National Framework for Quality in Cancer Control

Key messages

- The health system must deliver quality assured cancer control services based on best practice internationally. A National Framework for Quality in Cancer Control is required to achieve this objective
- HIQA should establish national site-specific multidisciplinary groups to develop guidelines for quality in major site-specific cancers
- All patients should receive care in designated Cancer Centres and services that are licensed and participate in continuous accreditation mechanisms devised by HIQA for the management of cancer
- The establishment of HIQA, which will subsume the National Cancer Registry, provides a significant opportunity to develop a cancer surveillance system that will build on the existing system of cancer registration
- Mandatory notification of cancer should be put in place through appropriate legislation
- HIQA should ensure that the public has access to high-quality up-to-date information about all aspects of cancer
- GPs should have comprehensive information that enables informed referral and other management decisions
- Health technology assessment is a key component of evidence-based practice. HIQA should convene a national group representative of the stakeholders in cancer care to determine priorities for health technology assessment.

E.1 A National Framework for Quality in Cancer Control

40 HIQA should establish a National Framework for Quality in Cancer Control.

It is essential that the health system is capable of delivering and quality-assuring cancer control services that are based on best practice internationally and deliver the best possible health return for a given level of investment.

The analysis set out in Section B shows significant gaps in the performance of cancer services and clearly demonstrates the need for specific measures to enhance and measure the quality of services. In addition, it identifies a need to strengthen the information base of all aspects of cancer care and to provide assessment mechanisms for the rapidly advancing technological environment.

One of the reasons why care has not always reflected the highest possible standards is that a national mechanism to develop, implement, monitor and update cancer control plans and guidelines has not existed. In order to ensure that all elements of cancer control conform to best practice and that this can be demonstrated, HIQA should establish a National Framework for Quality in Cancer Control consisting of:

- National Quality in Cancer Control Groups for major site-specific cancers
- A statutory system of licensing and accreditation that should apply to both public and private sector services
- An information model and infrastructure to meet the information needs of patients, professionals, managers and policy-makers
- A model of health technology assessment.

Each of these elements of the National Framework for Quality in Cancer Control is outlined in the following sections.

E.2 National Quality in Cancer Control Groups

41 HIQA should establish site-specific multidisciplinary groups at a national level to develop guidelines for quality in major cancers.

HIQA should convene groups at a national level (National Quality in Cancer Control Groups) to address quality in respect of major site-specific cancers. These groups will produce guidance for all common cancers. The precise cancers to be addressed at any given time should reflect national cancer priorities and should be agreed between HIQA and the Department of Health and Children.

National Quality in Cancer Control Groups should broadly address each of the following areas:
- evidence-based guidance and standards
- performance indicators which relate to the guidance and standards
- information and data requirements
- arrangements for the monitoring and updating of the guidance.

National Quality in Cancer Control Groups will therefore require substantial involvement of clinicians and other staff involved in the direct delivery of cancer care. This will ensure that, to the greatest degree possible, the standards and guidelines are 'owned' by cancer care professionals and other stakeholders.

The National Cancer Forum views the recent initiative of the Tánaiste and Minister for Health and Children in setting up the National Quality in Cancer Control Group for Symptomatic Breast Disease Services under the auspices of the Irish Health Service Accreditation Board as an excellent model for the development of similar National Quality in Cancer Control Groups for other site-specific cancers. Its terms of reference are shown in Box E.1.

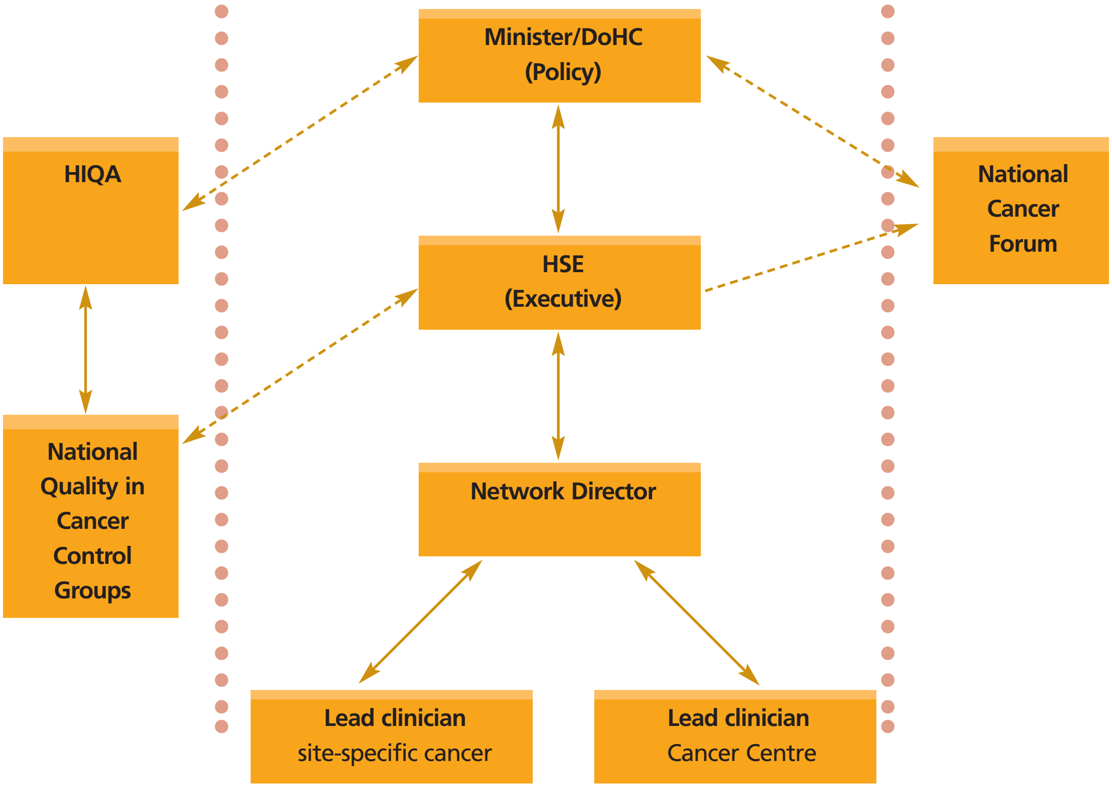
Box E.1
Terms of reference of the National Quality in Cancer Control Group for Symptomatic Breast Disease Services

Having regard to international best practice and best available evidence and the requirements regarding quality assurance as set out in the Report to the National Cancer Forum on the Development of Services for Symptomatic Breast Disease, to:

1. develop an agreed set of guidelines for the interdisciplinary management of breast cancer
2. convene relevant subspecialty groups to develop subspecialty specific guidance for surgery, pathology, radiology, medical oncology and radiation oncology
3. develop an agreed set of interdisciplinary performance indicators for the management of symptomatic breast cancer
4. convene relevant subspecialty groups to agree on subspecialty specific performance indicators for surgery, pathology, radiology, medical oncology and radiation oncology
5. agree a minimum dataset of information to be collected in each unit which would enable the performance indicators set out to be generated
6. establish information technology requirements to gather the agreed minimum dataset
7. set out a plan to enable the implementation of these guidelines and performance indicators, having regard to the existing service planning process
8. continually update guidance and performance indicators for the management of symptomatic breast cancer
9. produce an annual report based on the agreed performance indicators.

Figure E.1 shows key national relationships for quality in cancer control. The Minister has overall responsibility for cancer policy and is supported in that role by the National Cancer Forum. The HSE is responsible for implementation of policy and should do so by developing the Network Director and clinical lead roles on a geographic and cancer site-specific basis as described in the section on Managed Cancer Control Networks. HIQA will convene the individual National Quality in Cancer Control Groups in order to develop guidance and standards.

Figure E.1 Key national relationships for quality in cancer control



E.3 Licensing and accreditation

42 **HIQA should develop a system of licensing and accreditation of Cancer Centres and services that should apply to both the public and private sectors. The system of licensing and accreditation should be given statutory effect.**

Given the evidence of variation in the performance of cancer services in Ireland set out in Section B, there is a requirement to license and accredit Cancer Centres and services* through the development of national licensing and accreditation systems. While these will reflect international experience, a system that is Irish-designed and reflects the requirements of this country is necessary. This will drive improvement in quality and safety of cancer services by providing a mechanism to apply evidence-based standards.

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* *In this context, services applies to other cancer services that take place in the network but outside the designated Cancer Centres and includes diagnostic and other services in private hospitals, palliative care etc.*

It should be necessary for each Cancer Centre and service that participates in the provision of cancer services to be licensed for the provision of those services. Centres and services that are licensed should – as a condition of licensing – participate in ongoing accreditation processes aimed at continually raising standards. This will require the development of a statutorily based licensing and accreditation scheme that should apply to all services, both public and private.

Criteria for licensing and accrediting Cancer Centres and services should be based on international best practice models and should conform to standards and guidelines developed by the National Quality in Cancer Control Groups. These should include case volume, multidisciplinary care, clinical structure, process and outcome of care, user satisfaction etc. Only centres that meet licensing standards should be designated as Cancer Centres. Once licensing and accreditation mechanisms have been devised and implemented, no patient should receive care outside of Cancer Centres and services that are licensed for the management of cancer.

E.4 Information and cancer control

Accurate, timely and relevant information is a central requirement of a strategy for cancer control. Good information underpins appropriate decisions, whether by patients, health professionals, researchers, managers or policy-makers. Consistent availability and use of health information leads to better-informed patients and a better-informed public, improved service delivery, enhanced quality and efficiency and effective planning. This is necessary for the development of a high-quality cancer control system in Ireland.

E.4.1 Cancer surveillance

43 **HIQA should develop a cancer surveillance system that will build on the existing system of cancer registration.**

In the health arena, surveillance consists of the ongoing collection, analysis and dissemination of data of public health importance to allow for the planning and implementation of health policy. Cancer surveillance provides a quantitative portrait of cancer and its determinants in a defined population and allows the effectiveness of cancer policy to be evaluated. It also raises questions that form the basis for cancer research and interventions for cancer prevention and control. Cancer surveillance functions include:

- monitoring trends in cancer incidence, prevalence and survival over time and between different geographic areas, social groups, and other defined populations
- evaluating the effectiveness of cancer prevention and screening
- evaluating the quality and outcomes of cancer care
- evaluating the impact of environmental and social factors on cancer risk
- supporting investigations into the causes of cancer
- providing information in support of cancer genetic counselling services for individuals and families at higher risk of developing cancer.

The development of cancer surveillance will allow services to be planned and evaluated in keeping with evolving needs for services. The establishment of HIQA, subsuming the National Cancer Registry, provides a significant opportunity to make early progress on the development of cancer surveillance.

44 **Mandatory notification of cancer should be put in place through appropriate legislation.**

Cancer reporting needs to be as complete and as accurate as possible. Many countries, and some individual states in the US, have put in place legal requirements for notification of cancer in order to protect the integrity of cancer registration. The National Cancer Registry has been a very successful element of the cancer services here. A legal requirement to notify cancer cases to HIQA would preserve this function, which is vital to planning, evaluation and research in cancer. The Department of Health and Children should pursue this as matter of urgency.

45 **HIQA should ensure that a minimum national dataset should be collected for all cases of cancer.**

Cancer surveillance will require unified national approaches to information standards, information collection and the technology required to underpin these activities. This will require that data from hospitals and other notification sources be released more frequently, ideally each month. A minimum national dataset should be collected for all cases of cancer. This will ensure that standard, comprehensive and appropriate information is collected on all cancers. It should reflect similar developments in related areas, such as the minimum dataset for palliative care. It will require information collected by HIQA to be extended to include risk factor surveillance (including lifestyle-related risk factors), as well as process and outcome of care indicators relating to all aspects of care from prevention to palliation.

E.4.2 Information for patients, families and carers

46 **HIQA should ensure that the public has access to high-quality up-to-date information about all aspects of cancer.**

Access by patients to the right information at the right time is a vital component of cancer care. Empowered and informed members of the public can make better decisions that can, for example, help to prevent cancer. This empowerment can also enable earlier detection of cancer, and when a diagnosis of cancer is made, enable patients to participate more fully in decisions about their care.

The principal strategic benefit to the system of empowering and informing patients in this way is improvement in the health of the population. It will also improve public accountability in that people will be more empowered to have a say in matters that directly bear upon their health and their lives.

HIQA, in partnership with the voluntary sector, should produce cancer-related information for the public, consumers, patients, relatives and carers. This should be easily accessible and understood by those of different educational standards and cultures and should be trusted by users. It should cover causation, prevention, early detection and screening, diagnosis and treatment, pathways of care and ‘What to do’ guides.

E.4.3 Information for health professionals

47 **General practitioners should have comprehensive information that enables informed referral and other management decisions.**

GPs have a particularly important role in the control of cancer as reflected in Section D. Many patients will consult a GP to explore symptoms and it is at this level that the diagnosis of cancer will often be initially suspected. The decision the GP makes in terms of referral direction and timing can have an important bearing on the process and outcome of care that a patient may experience.

It is therefore necessary for the GP to be as informed as possible about services available. This will require that Managed Cancer Control Networks and Cancer Centres supply all GPs with a range of information designed to ensure informed and appropriate decisions. This should include information relating to care pathways, waiting times, caseload for site-specific cancers and implementation of quality standards according to external quality assurance processes.

48 **Information systems and information technology should be developed by the HSE to support the management and delivery of cancer services.**

Information systems and information technology should support the management and delivery of patient care services as well as their quality assurance through audit, accreditation and other processes. The development of electronic care records would facilitate a number of developments to support cancer care such as:

- integrated care pathways
- integration of hospital care with primary care and other services
- access to evidence and knowledge resources
- decision support systems
- costing of interventions and processes of care
- audit
- accreditation.

E.5 Health technology assessment

49 **HIQA should establish a Cancer Health Technology Assessment Panel.**

Health technology assessment (HTA) is a key component of evidence-based practice. It involves the application of the best available evidence about the medical, organisational, social, ethical and economic implications of the development, diffusion and use of health technologies. These aspects are usually specific to the technology being examined. HTA has a vital role in ensuring that care technologies, including drugs, are used in a manner appropriate to their ability to maximise health gain and achieve value for money.

The knowledge base of technology assessment is multidisciplinary, spanning clinical science, epidemiology, sociology, anthropology, bio-statistics, law, business management and economics. Experts who assess drugs, devices, tests, procedures and other types of health care technologies and interventions seek to derive credible findings from numerous and sometimes contradictory studies of widely varying quality.

Research findings are published in detailed reports that serve a principal objective of disseminating results in a form useful to decision-makers who are in a position to use them. By identifying and communicating how limited health care resources can be most effectively applied, technology assessment can assist in policy development and planning efforts. The analytic frame applied in assessment activity may take into consideration any or all of the following concerns:

- the benefit of using a technology or procedure for a particular clinical problem
- the safety of the technology
- the implications of using the technology
- considerations of costs, cost benefits and volume of services.

HIQA will oversee the development of HTA and promote its use to inform vital policy decisions, from initial evaluation to implementation, monitoring and review of outcomes. It will draw upon HTA work carried out in other countries. HTA structured on this basis will enable the system to:

- speedily introduce technologies with proven, significant health benefits
- ensure that technologies which are introduced meet appropriate evidence-based standards
- continuously monitor the effectiveness of technologies after introduction.

HIQA should convene a national group representative of the stakeholders to determine priorities for health technology assessment in cancer care. The initial emphasis should be on diagnostic and therapeutic technologies, including drugs that are new to the system. These health technology assessments should identify the levels in the system at which a given technology should be provided. It should also – where appropriate – identify the relevant disciplines to provide a given technology.

Resource allocation processes within the HSE should ensure that technologies of proven benefit are rapidly disseminated through appropriate services. These processes must have substantial involvement from relevant clinical disciplines and this will require appropriate information to be available to ensure that technologies are applied in this way. The Cancer Health Technology Assessment Panel should monitor and report annually on the distribution and utilisation of new technologies throughout the cancer care system to ensure effectiveness, fairness and equity.

Section F
Thinking ahead

Key messages

- Shortages of personnel in the cancer workforce are limiting current capacity and impairing service quality, education and research
- The HSE should develop a National Cancer Workforce Plan to ensure that there are adequate highly skilled cancer care staff across all cancer-related disciplines
- Cancer education and research are essential components in the development, implementation and evaluation of a national cancer control programme
- Ireland needs to address cancer control at all levels with the assistance of a comprehensive research portfolio, encompassing all fields of cancer research
- The National Cancer Forum, in partnership with the Health Research Board, should advise on the development of a specific plan for cancer research
- The percentage of cancer patients enrolled in clinical trials is a marker of quality of care. There should be improved cancer clinical trial access for patients.

F.1 Cancer human resources

50 **The HSE should develop a National Cancer Workforce Plan designed to fully implement national cancer policy.**

Shortages of personnel in the cancer workforce are limiting current capacity and impairing service quality, education and research. Shortages can result in delayed treatment, disruption of referral patterns and interference with multidisciplinary programmes of clinical care, education and research. Many elements of the cancer control system are operating at present with reduced staffing while facing increasing caseloads. Cancer caseload is rising inexorably due to increasing incidence, expanded indications for treatment and growing prevalence of cancer survivors, all of which place additional demands on the cancer workforce.

Although cancer system requirements can be predicted using population-based models, the difficulties in obtaining accurate up-to-date information and data impede planning and policy development. Currently, it is difficult – or impossible – to obtain data on workforce numbers, vacancies, work life issues and supply factors such as training programme intakes and migration. Human resources planning must address technology change, evolution of workplace roles and changes in service delivery.

There is a clear need for a National Cancer Workforce Plan to be developed by the HSE to support the operational planning needs of the cancer system. This should further inform the development and expansion of both undergraduate and postgraduate education programmes to ensure that existing and projected workforce needs can be met. The absence of such a plan in the past has led to supply shortages in critical components of services. The rapid pace of change in demography and in technology makes this need all the more pressing.

The essential requirement of human resource planning for the cancer workforce should be the capability to collect, analyse and disseminate reliable information and data to inform all elements of the system where policies, plans and decisions regarding human resource aspects of cancer are made. This should consist of the following components and activities:

- an accurate and comprehensive registry of cancer control personnel, developed and maintained by the HSE. Individuals should be registered by discipline with data compiled and maintained from multiple sources including professional associations, the HSE and training programmes
- adequate stakeholder participation and communication in the development and maintenance of the National Cancer Workforce Plan
- an annual report describing the cancer workforce inventory and a database reporting on staffing needs and vacancies by discipline, geographic area, cancer programme or centre or other parameters as required
- a focus on the development of cancer nursing roles that reflects recent successful developments in oncology nursing and maximises the potential role that nurses can play in all aspects of cancer care
- appropriate linkages to processes to determine and implement workload-planning standards by professional disciplines, taking into account care delivery systems, role and practice models, and technical change and workforce evolution
- coordination between organisations and authorities responsible for training members of the cancer workforce
- research on issues of compensation, benefits, work life satisfaction and career development for cancer professionals to improve the attractiveness of career opportunities and enhance recruitment and retention of staff
- research and ongoing assessment of service delivery models, technical change in the workforce, including role development and evolution of different types of staff in an ever-changing health care environment, focusing on comprehensive, patient centred and community-based care of cancer patients.

F.2 Research

Research is a key factor in promoting health, combating disease, reducing disability and improving quality of care. Cancer research* is an essential component in the development, implementation and evaluation of a national cancer control programme. A scientific basis needs to be established for identifying the causes of cancer and for specifying effective strategies for the prevention, treatment and control of cancer, as well as for evaluating overall programme performance. Ireland needs to address cancer control at all levels with the assistance of a comprehensive research portfolio, encompassing all fields of cancer research.

F.2.1 Scope of cancer research

Cancer research is wide-ranging, extending over a number of key areas including:

- **epidemiological research**, which relates to the study of the distribution and determinants of disease in populations
- **prevention research**, which encompasses research into health promotion and education, screening and other early detection initiatives
- **laboratory research**, which has been a major activity in Ireland, particularly in cell and molecular biology. Extensive laboratory-based research programmes exist at various major hospitals
- **clinical research**, which is concerned with the study of the natural history of the cancer process in humans and the assessment of efficacy and toxicity of treatment
- **translational research**, which is concerned with the integration of bench and clinical research for the benefit of cancer patients and those at risk of developing cancer
- **health services research**, which is a wide-ranging, multidisciplinary field that investigates the structure, processes and effects of health care services.

In reviewing the challenges posed by cancer and the scope for improving cancer services, the 1996 National Cancer Strategy emphasised the clear case for establishing a more formal and coordinated approach to cancer research, with particular reference to clinical research. The evaluation of the 1996 National Cancer Strategy pointed to the significant increase in capacity that has taken place in cancer research since 1997, but found that there was considerable scope to further increase capacity for research, to achieve a better balance between clinical and non-clinical research, and to develop the research infrastructure needed to coordinate and govern cancer research.

The Health Strategy acknowledged the ongoing need for research with the aim of improving survival and quality of life for patients. The National Health Research Strategy *Making Knowledge Work for Health* (2001) provided a framework for the development of health research to enhance health and quality of life and to ensure that Irish research compares favourably with research elsewhere. It proposed the establishment of research and development functions within health agencies.

F.2.2 Cancer research capacity

The Health Research Board (HRB) is a statutory body that promotes, funds, commissions and conducts medical, epidemiological and health services research in Ireland. It works closely with partners in Northern Ireland, the United States and Europe to promote health research on the island of Ireland. The HRB is the main channel of public funding for research at national level. Other sources of health research funding are varied and include voluntary bodies (e.g. Irish Cancer Society), Science Foundation Ireland, pharmaceutical companies, multinational organisations and charities.

This funding has helped to significantly improve the capacity for cancer research here in recent years. In addition, specific initiatives have led to the establishment of world-class basic research facilities in a number

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* *For the purposes of this strategy, cancer research includes all research relevant to cancer control, e.g. research on smoking cessation.*

of third-level institutions. In spite of this, the capacity for health services research and – to a lesser extent – epidemiological research is less well developed.

F.2.3 All-Ireland NCI Cancer Consortium

The National Cancer Institute (NCI) is the world leader in developing, conducting and supporting research in cancer control. The All-Ireland NCI Cancer Consortium was launched in 1999 as a trilateral partnership between the governments of Ireland, Northern Ireland and the United States, represented by the NCI. The major research goals of the Consortium are to enhance clinical research, conduct joint clinical research studies and sponsor formal scholar exchanges.

The Consortium has been instrumental in the development of a clinical trials infrastructure in Ireland. This model has led to the funding, by the governments on both parts of the island, of a number of hospitals or groups of hospitals to support them in carrying out high-quality research clinical trials. An all-island clinical trials group coordinates the trial activity of funded hospitals. The Consortium supports joint research fellowships, research collaborations and prevention fellowships. There is a significant potential to further develop research in cancer control on the island under the Consortium.

F.2.4 The way forward

51 **The third National Cancer Forum, in partnership with the HRB, should advise on the development of a specific plan for cancer research.**

The need for high-quality research on all aspects of cancer is critical. While excellent research is currently being conducted in Ireland in most fields of cancer control, it is far better developed in some fields than others. There is a need to establish a strategic and continuing process for identifying, overseeing and facilitating cancer research.

Funding is a recognised research development issue; the effort required to attain funding is time-consuming and resource intensive, demanding skill and experience in application. Most funding for research goes to topics chosen by investigators and has typically supported the high-profile areas of laboratory-based biomedical research and clinical research, both producing work of the highest international calibre. However, this now needs to be balanced with specific earmarking of funding for other areas such as epidemiological and health services research in order to fully inform planning related to cancer control. A recurring impediment to proactive research is the absence of dedicated research time, for health professionals. There is a need, therefore, to provide for dedicated research sessions in the contracts of appropriate health professionals.

There is a need for a specific plan for all cancer research, to ensure a strategic approach, to reach consensus on cancer research themes, to identify gaps in current research and opportunities, and to foster an effective, inclusive research function. This will help to coordinate funding initiatives, reduce duplication and guide the development of a critical mass of research activity across Ireland to meet priorities in cancer research. A specific function should be to improve the quality and use of information that would support the evaluation of programmes, treatments and outcomes.

A key element of such a plan will be the development of a formal partnership of cancer research funders. The Department of Health and Children, the Health Service Executive, the Health Research Board, the Irish Cancer Society, Science Foundation Ireland and other funders should agree a policy of national funding for cancer research that would be at the heart of a national cancer research plan. This will help ensure the identification of dedicated funding for less-developed areas of cancer research, particularly epidemiology and health services research.

The All-Ireland NCI Cancer Consortium, and other cooperative initiatives involving Northern Ireland and the European Union, should enable international collaboration in the area of cancer research to be considerably strengthened. Our small size means that we will always benefit more from international partnerships in research than from working alone.

52 There should be improved clinical trial entry for patients, both in terms of the number of trials conducted and the enrolment to them.

While entry of cancer patients into clinical trials has improved, it should be further developed. This will be achieved by raising both the number of trials that take place and the number of patients who are enrolled in them. In many other systems, the percentage of cancer patients recruited into clinical trials is a marker of quality of care. It is not just that trial patients do better – the culture change that occurs in an institution undertaking clinical research is also very important. Clinicians in these circumstances are reported to become more open to scientific approaches, more likely to comply with guidelines, and generally to improve their evidence-based care. In order to ensure that this is addressed as a key element of cancer service provision, a specific target should be set for recruitment of patients into clinical trials in each network and each Cancer Centre.

53 Ireland should establish a national tissue bio bank to support research and service delivery.

Ireland should establish a national tissue bio bank that is based on international standards and collects appropriate data on stored samples. The initial aim of such a development will be to support research, but as technology develops it may have a more direct service delivery benefit.

54 The HRB should establish a national cancer research database.

A national database containing information on all cancer research would prove an invaluable asset to cancer researchers nationally and internationally. All cancer research undertaken in Ireland should therefore be captured and classified using a standardised system. This will greatly facilitate the coordination of cancer research as well as facilitating insight into the overall national balance and direction of cancer research.

Section G
Policy indicators

55 **The HSE should present a report on policy indicators each year to the National Cancer Forum.**

A set of cancer policy indicators was developed through a process that involved the examination of international approaches and an assessment of the evidence supporting cancer indicators. The indicators were chosen to cover the major areas of cancer control policy at a high level, rather than to match specific recommendations of this Strategy.

The HSE should present a report on policy indicators each year to the National Cancer Forum on a national basis and from each of the four Managed Cancer Control Networks. It is important that the Third National Cancer Forum establishes clear targets that are consistent with the vision set out at Section A.1.3. The first report on policy indicators from the HSE will allow targets to be set for each policy indicator. These targets should then be reviewed annually by the National Cancer Forum.

The importance of policy indicators should be reflected in the early development of systems that enable their measurement, mainly through the development of cancer surveillance as outlined in Section E. The Third National Cancer Forum should work with HIQA and the HSE to develop data definitions, standards and technical requirements that allow these indicators to be reported. This will allow the Forum to advise the Minister and the Department of Health and Children on the impact that this Strategy is having on cancer.

The specific indicators are set out in Table G.1.

Table G.1: Cancer policy indicators

No.	Indicator
1	Percentage of the population who are smokers by age, sex and social class
2	Percentage of the adult and childhood populations who are overweight or obese by age, sex and social class
3	Percentage of the population who consume more than the recommended alcohol weekly limits by age, sex and social class
4	Incidence of major site-specific cancers, to include at a minimum lung, breast, prostate and colorectal cancer
5	Incidence of invasive and in-situ melanoma
6	Uptake of screening and incidence of interval breast cancers in populations covered by BreastCheck
7	Percentage of women, in the target age-groups, for whom population based cervical cancer screening is available
8	Percentage uptake of screening in areas covered by the Irish Cervical Screening Programme
9	Stage of presentation of common cancers: appropriate stage indicators should be defined for lung, breast, colorectal and cervical cancers
10	Percentage of patients with cancer whose care is consistent with national, multidisciplinary guidelines, as developed by HIQA
11	Trends in quality of life for cancer patients, determined by ongoing quality of life measurement, at different stages in the care pathway for major cancers
12	Waiting times from diagnosis to definitive treatment for major cancers
13	Percentage of patients waiting for longer than one month from the time of diagnosis to the start of treatment
14	Percentage of breast cancer patients undergoing therapeutic surgical procedures who do so in a designated breast cancer treatment centre
15	Survival rates: a. 5-year Relative Survival Rate for Breast Cancer b. 1-year Relative Survival Rate for Lung Cancer c. 5-year Relative Survival Rate for Prostate Cancer d. 5-year Relative Survival Rate for Colorectal Cancer
16	Mortality rates: a. Direct Age Standardised Mortality rate (5-year, all ages) for all causes of cancer b. Direct Age Standardised Mortality rates (5-year, all ages) for the top six causes of cancer mortality
17	Percentage of cancer patients seen by a member of a Specialist Palliative Care Team
18	Percentage of cancer patients dying by place of death (home, hospice, hospital)
19	Percentage of cancer patients participating in clinical trials