



# NATIONAL CANCER STRATEGY

2017 - 2026



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# MINISTER'S FOREWORD



This National Cancer Strategy is all about people. It is about preventing cancer across our population, diagnosing cancer early, providing optimal care to patients and maximising their quality of life.

Ireland has made significant progress under the previous strategy. We now aim to take on the challenge of making further strides in cancer control such that survival rates can reach the top quartile of European countries by the end of the Strategy period.

Cancer prevention is a cornerstone of this Strategy as it offers the most cost-effective, long-term approach for cancer control. Cancer prevention sits fully into the Healthy Ireland approach in my Department.

As in other health matters, particular focus will be put on achieving integration across primary, acute and social care services. A key element in ensuring this is the strengthened governance and oversight role envisaged for the National Cancer Control Programme in providing leadership across the continuum of care.

The primary aim for all cancer services is to provide evidence-based care that is effective, safe, of high quality and patient-centred, supported by national standards and clinical guidelines. Annual reports on the implementation of this Strategy, together with the broader healthcare quality reporting system, will help in this regard, as well as keeping the public informed on progress.

With cancer survivorship numbers increasing significantly, optimising peoples' quality of life is a particular focus of patients. This emphasis on quality of life will be central in the implementation of the Strategy.

The Cancer Patient Forum made a huge contribution that impacted on all involved and resulted in a better Strategy. I thank the Forum members for their most willing engagement and I am committed to the continued involvement of patients in the implementation phase.

I would also like to acknowledge the contribution of the Cancer Strategy Steering Group, chaired most effectively by Professor John Kennedy. They worked enthusiastically, aided by inputs from many invited participants at their meetings, to finalise recommendations for a comprehensive Strategy.

I fully endorse this Strategy and I was delighted to present it to Government for approval. Now it's all about implementation.

**Simon Harris, T.D.**  
*Minister for Health*

# CHAIRMAN'S FOREWORD



The first Cancer Strategy, entitled **Cancer Services in Ireland: A National Strategy**, was published in 1996. Under the leadership of the late Professor James Fennelly, the Cancer Strategy Group identified the inferior Irish mortality figures for cancer compared to the European average and proposed a series of measures to reduce the death rate from cancer in the under 65 age group by 15 per cent in the ten year period to 2005. The extensive appointment of a broad range of cancer specialists, and the reorganisation of services, under the Strategy resulted in this goal being achieved well before the target date. The implementation of the recommendations in the Hollywood report, published in 2003, also had a hugely significant impact on the delivery of radiation therapy in Ireland.

Informed by the work of the National Cancer Forum chaired by Professor Paul Redmond, the second **National Cancer Strategy, A Strategy for Cancer Control in Ireland**, was published in 2006. This Strategy embraced the concept of cancer control that had emerged internationally and it included recommendations in relation to organisation, governance, quality assurance and accreditation across the continuum of cancer care. The establishment of the National Cancer Control Programme (NCCP) to *'formulate a whole population, integrated and cohesive approach to cancer'* followed in 2007. In parallel with the establishment of the NCCP, we have seen the embedding of cancer screening programmes in the healthcare system and the very significant improvements in delivery of radiation therapy. All of these developments have delivered continuing improvements in outcomes for Irish patients with cancer.

We are now faced with a different set of opportunities and challenges. Improving therapies have gratifyingly resulted in a greatly increased number of people who have survived cancer. Breathtaking advances in basic and translational science have resulted in a proliferation of novel diagnostics and therapeutics and this trend will continue. Such advances present great opportunities, but their integration into cancer care will present organisational and financial challenges. At the same time, our population is aging rapidly, driving a relentless increase in cancer incidence, and challenging clinicians to treat patients who have complex medical needs. Meanwhile, much of our

infrastructure is not up to international standards, at capacity and struggling to cope with the demands placed on it.

In this Strategy we map a route for cancer care over the next decade. However, given the accelerating rate of progress in the cancer field, the increasing recognition of the degree of complexity of cancer cases and the ten year Strategy period, issues will be addressed incrementally as short, medium and long-term goals. For example, immediate needs might involve addressing deficiencies in specialist cancer nursing and strengthening the role of the NCCP, while the development of comprehensive electronic patient records might be seen as a medium-term issue. Also, the centralisation of cancer surgical services, commenced several years ago, must be completed as expeditiously as possible.

However, it is more difficult to define the challenges which will arise in the later years of the Strategy period and so is proposed that the recommendations of the Strategy will be reviewed towards the end of 2021 to ensure that our aims and direction are appropriate to deliver optimum outcomes for patients.

In the words of Dr Christopher Wild, Director of the International Agency for Research on Cancer (IARC), '*we cannot treat our way out of the cancer problem*'. It is essential that we act now to reduce the incidence of cancer in the medium to long term. Aggressive programmes of public education, risk reduction, prevention and early detection must be promoted by the Department of Health and the NCCP, with extensive coordination across all stakeholders, notably primary care and the voluntary sector.

We must also continually strive for earlier diagnosis of cancer in patients. Only if we are successful in achieving these goals will we be able to minimise the extent of the cancer problem in the coming decades.

As is the case across the Strategy, I strongly believe that the most strenuous efforts must be made to target more deprived populations in cancer prevention and early diagnosis interventions. There is incontrovertible evidence of the enormous impact of socioeconomic status and deprivation on death rates from some cancers in Ireland. The causes are multifactorial, ranging from high smoking levels, and poor diet to inadequate access to timely diagnostic services. Apart from being the just approach, this represents the most effective way to ensure future optimal value for money for the health service.

Finally, I would like to acknowledge the extensive work undertaken by the members of the Cancer Strategy Steering Group and the Cancer Patient Forum in developing this report. In discharging the remit given to them by the Minister for Health, they were ably supported by the Department of Health team, comprising Michael Conroy, Keith Comiskey, Clodagh Murphy and Stephen McGettrick from the Cancer, Blood & Organs Policy Unit.

**Prof. M. John Kennedy**  
*Chairman*

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# EXECUTIVE SUMMARY

## The Need for this Strategy

This Cancer Strategy aims to meet the needs of cancer patients in Ireland for the next decade. The number of cases of cancer is expected to increase over the period of the Strategy, and to almost double by 2040. This is mainly due to an increasing and an aging population - cancer is a disease where the risk increases with age. The percentage of deaths attributable to cancer has risen from 20% in the 1980s to over 30% at present. At the same time, there are over 150,000 cancer survivors in Ireland now and a greater focus on the increasing numbers living with and beyond cancer is required.

Rapid advances have been made in cancer diagnostics and treatments. The objective is to ensure that cancer services respond to both the challenges and the opportunities for future development so that care is of a uniformly high quality across our population. This Strategy provides direction in developing and implementing policies for the control of cancer.

Many advances have been made in cancer control in the past decade. The previous strategy, **A Strategy for Cancer Control in Ireland (2006)**, led to the establishment of designated cancer centres and the reform of how cancer is diagnosed and treated. The National Cancer Control Programme, established in 2007, has led on the development of cancer services, such as rapid access clinics to improve early diagnosis, advances in hospital-based treatment and developments in more specialised areas such as hereditary cancer services. Other developments include the expansion of cancer screening and an emphasis on healthier lifestyles. Smoking cessation efforts have increased and the rate of daily smoking in the population over the age of 15 has now fallen to below 20%.

However, many challenges remain. Increased demand has led to capacity and resourcing issues, particularly in relation to staffing. There is now an increased awareness and demand for additional support for cancer patients after diagnosis, including survivorship programmes and psychosocial services. Greater integration with primary care and local services is required to ensure seamless patient pathways before, during and after treatment.

These and other issues were highlighted in an evaluation of **A Strategy for Cancer Control in Ireland (2006)** and in the public consultation undertaken to inform the development of this Strategy. While the Evaluation Report acknowledged that substantial progress had been made, it saw a need for improvements in the model of service delivery, increased staffing in nursing, health and social care professionals and physicians, increased focus on survivorship and a more robust infrastructure for research. Other priorities for a new Strategy identified through the Public Consultation include prevention, service reconfiguration and social and financial support.

## Reducing the Cancer Burden

Cancer prevention will be a cornerstone of this Cancer Strategy as it offers the most cost-effective, long-term approach for cancer control. The proportion of cancer incidence attributable to modifiable lifestyle and environmental factors is estimated to be in the 30% to 40% range. Of these risk factors, smoking has by far the biggest impact and, in implementing this Strategy, we will work towards the goal of making Ireland tobacco-free by 2025. We also need to increase our efforts to reduce the number of avoidable cancers through the promotion of healthy



lifestyles, in areas such as improved diet, more exercise and reduced alcohol intake. Prevention measures will be integrated with the overall health and wellbeing initiatives under the *Healthy Ireland* programme.

Reducing health inequalities is a priority of this Strategy, as lifestyle risk factors generally follow social, deprivation, gender and age patterns. Health inequalities are also associated with poor symptom awareness, delayed presentation and low uptake of services, including screening.

Detecting and diagnosing cancer early is a critical step in reducing mortality as a result of cancer. Efforts will continue to ensure that people take up the offer of cancer screening when invited through the BreastCheck, CervicalCheck and BowelScreen programmes. Broadened aged-based cohorts are envisaged for both BreastCheck and BowelScreen.

Further improvements in overall survival rates will require an emphasis on increasing the proportion of patients diagnosed at an earlier stage of their disease. Early diagnosis is influenced by many factors. Public and health professional awareness of the importance of early presentation is critical, and is complemented by clear, evidence-based GP referral guidelines, clear pathways to specialist care and timely access to diagnostic services. This Strategy sets out ways to strengthen the care pathway to diagnosis through Primary Care, and to provide additional diagnostic capacity for GPs, guided by referral criteria.

## Provision of Optimal Care

A broad objective of the Strategy is to have models of care in place that ensure that patients receive the required care, in a timely fashion, from an expert clinical team in the optimal location. The concept of a continuum of care will underpin the approach to patient services, from prevention, early diagnosis and evidence-based, high quality patient-centred treatment, to appropriate follow-up and support.

Much of our cancer treatment takes place in acute hospitals under the direction of specialist clinicians and multidisciplinary teams. This Strategy builds on progress made to date by supporting the key role of designated cancer centres in cancer treatment. Multidisciplinary team (MDT) working is a cornerstone of modern cancer care. MDT working has led to improved decision-making, more co-ordinated patient care and improvements in the overall quality of care. It is recommended that all patients diagnosed with cancer will have their case formally discussed at an MDT meeting.

Current services are coming under pressure and patient numbers will continue to increase across the period of this Strategy. A rolling plan of capital investment will be required to ensure that high-quality facilities are available for patients and staff, that our health personnel can progress in line with developments in cancer worldwide and that the potential for on-going improvements in outcomes is maximised.

Advances in molecular technology have resulted in improved cancer diagnosis, the use of more targeted therapies and better monitoring of treatment outcomes. The role of inherited predisposition to cancer is also being increasingly defined through the use of genetic testing. Developments in genomics have impacts far wider than cancer, but are key to improving cancer outcomes. The challenge is to ensure that the potential benefits of molecular cancer diagnostics and cancer genetics/genomics will be realised for all patients across the ten year strategy period.

Service improvements will be underpinned by evidence and best practice, and the centralisation of surgical services for more cancers will be progressed to ensure that optimal treatment is provided and outcomes are improved. Radiation oncology services will expand to meet demand.

The growth in both the incidence of cancer, and the prevalence of patients on active treatment with new drugs, is giving rise to a significant increase in the volume and complexity of medical oncology and haematology work. As treatments become more complex, there will be a need for medical oncologists and haematologists to specialise in particular cancer sites and treatment modalities. The total number of patients in receipt of Systemic Anti-Cancer Therapy (SACT) is expected to grow even faster than the number of new patients, as new drugs come on stream, as the duration of some treatments increases and as patients with advanced disease survive longer. In order to meet this rising demand, and to allow for a greater level of site specialisation, the number of medical oncologists and haematologists in Irish hospitals will need to be increased.

New-to-market cancer therapeutics are exceedingly expensive. The NCCP, with the wider HSE and the Department of Health, work together in advancing the process of securing such drugs at affordable cost once the European Medicines Agency (EMA) has approved them for clinical use. The scale of the costs involved, set against expectations of the availability of the latest effective drugs, will pose an on-going management challenge during the period of the Strategy.

Rare cancers, defined as those with an annual incidence of less than six cases per 100,000 comprise about 20% of all cancers, with approximately 5,200 new cases annually. There is a need for clear care pathways for the diagnosis and treatment of patients who have rare cancers, with particular emphasis on timely treatment planning at national MDT level, involving subspecialty expertise in diagnosis and treatment and with linkages to international centres of excellence for specialist advice and intervention.

Approximately 200 children and young adolescents (0-16 years of age) are diagnosed with cancer each year. All of these children are referred to the National Paediatric Haematology and Oncology Centre (NPHOC) to have their diagnosis established, treatment planned and follow-up mapped out. NPHOC also acts as an

advisory and response service for 16 shared care centres throughout the country. The development of a new children's hospital will provide the opportunity to establish an age-appropriate facility for adolescents and young adults with cancer. Services for this cohort, and transition arrangements to adult services, are a particular focus of this Strategy.

A primary aim of all cancer services is the provision of safe, high quality and patient-centred care. This involves care that is safe, evidence-based, appropriate, timely, efficient, effective, equitable and person-centred. Safety is fundamental to quality healthcare and cancer services will be enabled to deliver safe care, while balancing competing pressures and demands.

### **Maximise Patient Involvement and Quality of Life**

The development process for the Strategy saw the establishment of a Cancer Patient Forum, to provide a strong patient input and to consider how patient input into cancer services can be facilitated more broadly. It is proposed to establish a Cancer Patient Advisory Committee to facilitate continued patient input into cancer control measures. The Department of Health will ensure that patient representatives are involved in policy making, planning, practice and oversight of cancer services at local, regional and national levels. Service providers, including hospital groups, designated cancer centres and community healthcare organisations will also be encouraged to develop structures to facilitate patient and public input into cancer services.

Many people are now living significantly beyond cancer diagnosis and treatment and this trend will continue. Definitions of cancer survivorship differ, but it is broadly accepted that cancer survivorship begins at the time of diagnosis and continues until end of life.

In many cases the aim will be to return to work or to play a full part in life in whatever way is appropriate to the person. The needs of individuals will differ greatly. Cancer survivors can require life-long,

evidenced-based health care, both preventive and general medical, as well as psychosocial care and care specific to the cancer diagnosis involved. The NCCP, working with the cancer centres, the Irish College of General Practitioners, primary care services, patients and voluntary organisations, will develop and implement survivorship programmes for patients with cancer. These programmes will emphasise physical, psychological and social factors that affect health and wellbeing, while being adaptable to people with more specific survivorship needs following their treatment. Patients will also be offered Patient Treatment Summary and Care Plans as part of their support that will guide them towards self-management of their care. The emphasis in the Strategy is on maximising the quality of life of individuals diagnosed with cancer for as long as they live.

### **Enabling and Assuring Change**

The NCCP will continue to provide leadership and direction to the cancer system to ensure that service priorities are aligned with desired outcomes. They will work closely with the HSE Directorates, Hospital Groups and community healthcare organisations to lead service reorganisation and to ensure that integrated care pathways are provided for those affected by cancer. In working to ensure that the objectives of the Strategy underpin decisions on cancer care across the health services, the NCCP will lead service improvements, focusing in particular on funding and commissioning, as well as on oversight and performance review.

The positive impact of research activity, including clinical trials, on the care of patients is evident. An aim will be to develop a culture in the cancer care system that values research and is supportive of those who actively engage in it. Steps will be taken to build on progress already made to ensure that cancer research is aligned with cancer control priorities and integrated with cancer care. The NCCP will establish a National Cancer Research Group to improve the coordination of cancer research and to foster a supportive environment for research within

the health service and the universities. This Group will also develop proposals for a coherent and integrated approach to cancer biobanking, in line with broader, national developments in the area.

Change is required across our cancer services to give effect to the Strategy vision. A major focus will be placed on workforce planning, underpinned by service specifications that embrace a major and increased role for clinical nurse specialists and advanced nurse practitioners, as well as for health and social care professionals, in patient assessment, delivery of treatment, survivorship and end-of-life care. An early emphasis will be placed on addressing workforce gaps in areas such as medical oncology, urology and nursing.

A focus on delivering results will be maintained throughout the Strategy period. An annual report will be published by the Department of Health, with input from other stakeholders, on the implementation of the Strategy, with particular focus on the implementation of the recommendations and the degree to which Key Performance Indicators are being met. The recommendations will themselves be reviewed at the halfway point of the Strategy, to assess their continued relevance and effectiveness in the delivery of optimum outcomes for patients. International co-operation in relation to the various aspects of cancer prevention, care, research and survivorship will be promoted and strengthened.



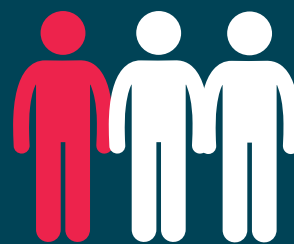
# SECTION A

## THE NEED FOR THIS STRATEGY

- 1 Introduction
- 2 Cancer in Ireland
- 3 Strategic Content
- 4 Vision

**2x**

The number of cancers will **almost double** by 2040



**1 in 3** will develop cancer in their lifetime

**20,800**  
New Cases of invasive cancer per year

Overall  
**Five year**  
survival rate  
is **61%**



**Over 8,600**  
cancer deaths  
per year





# INTRODUCTION

## 1.1. Developments in Cancer Services

Nearly every household in Ireland has been touched by cancer in some way, whether that is through our own health, or that of a relative, neighbour or friend. In 2013, cancer caused about one-third of all deaths in Ireland. It is important that we take a national, strategic approach to cancer control. The first cancer strategy, **Cancer Services in Ireland: A National Strategy** was published in 1996. That strategy brought coherence to the development of cancer services and involved the appointment of a broad range of cancer specialists. A 15% reduction in premature (under 65 years) cancer mortality was achieved by 2003.

The second Strategy, with a population health approach, followed in 2006 - **A Strategy for Cancer Control in Ireland**. This strategy focused on population needs, reform and reorganisation of the way cancer services were delivered with a particular focus on centralisation of confirmatory diagnosis, treatment planning and surgery. Clear, evidence-based policy direction, strong leadership, the establishment of the National Cancer Control Programme (NCCP) and strong working relationships all contributed to the progress made under this strategy. The main areas of achievement include the designation of cancer centres, equal access to high quality treatment, multidisciplinary management of cancer patients, the development of rapid access clinics, developments across cancer screening, radiation oncology and medical oncology, as well as reduced smoking levels.

Following the publication of that Strategy, the NCCP was established as an executive arm of the Health Service Executive (HSE) in 2007. The objective of the NCCP was to establish a comprehensive system of cancer control, primarily covering prevention, early detection, treatment and follow-up. The NCCP also set standards and guidance for the delivery of cancer care and ensured the monitoring and oversight of cancer services. It provided leadership for a change programme to ensure that cancer services were organised and delivered in an effective manner, based on clinical criteria and international evidence.

The NCCP's 2015 **Report on the Implementation of 'A Strategy for Cancer Control in Ireland 2006'**<sup>1</sup> provides a comprehensive report on the work of the NCCP to that point. This report was a key source in informing members of the Evaluation Group on the organisation of cancer services in Ireland prior to the evaluation process outlined in Section 3.2.

**DID YOU KNOW?**  
**THE FIVE YEAR**  
**SURVIVAL RATE FOR**  
**BREAST CANCER IS 82%**

1 <https://www.hse.ie/eng/services/list/5/cancer/pubs/reports/7%20year%20report.pdf>





## 1.2. Development of this Strategy

In April 2015, the Minister for Health established a Steering Group under the chairmanship of Professor M. John Kennedy to provide guidance and advice to the Department in the development of a new cancer strategy.<sup>2</sup> The establishment of the Steering Group was supported by the publication of the report of the Evaluation Group on **A Strategy for Cancer Control in Ireland (2006)**. That report was commissioned by the Department and conducted during 2014 in preparation for the development of a new strategy.

Also in April 2015, a Cancer Patient Forum<sup>3</sup> was established to represent the views of patients and patient groups, and to provide them with a meaningful role in the development of the Strategy. Members of the Forum represented patients or organisations with experience of many cancer types and from various parts of the country. The Forum was represented on the Steering Group to more readily facilitate a patient input and to ensure that all members of the Forum were always fully informed on issues relating to the development of the Strategy.

The Department of Health conducted a public consultation in June and July 2015 to obtain the views of the public and of organisations on current cancer services and priorities for the future.

<sup>2</sup> The list of Steering Group members and Terms of Reference is at Appendix A

<sup>3</sup> The list of Cancer Patient Forum members and Terms of Reference is at Appendix B.

# CANCER IN IRELAND

## 2.1. Introduction

Cancer is a major cause of mortality in Ireland. Cancer and cardiovascular disease were each responsible for about one-third of all deaths in 2013<sup>4</sup>. In the population under 65, cancer was the cause of half of all deaths in women, and the cause of over one-third of all deaths in men. The percentage of deaths attributable to cancer has risen from 20% in the 1980s to over 30% at present. The most recent summary statistics for cancer in Ireland are displayed in Table 2.1<sup>5</sup>.

**Table 2.1** Summary statistics for cancer in Ireland 2012-2014

|  | Females | Males  | Total   |
|--|---------|--------|---------|
| Number of new cases per year*                                    | 9,703   | 11,101 | 20,804  |
| Incidence rate (cases per 100,000 per year)                      | 384     | 483    | -       |
| Cumulative lifetime risk of diagnosis (to age 74)                | 27%     | 33%    | -       |
| Number of deaths per year (2011-2013)                            | 4,065   | 4,590  | 8,655   |
| Mortality rate (deaths per 100,000 per year, 2011-2013)          | 149     | 204    | -       |
| Cumulative lifetime risk of death (to age 74)                    | 10%     | 13%    | -       |
| Number of people with cancer alive in 2014 (diagnosed 1994-2014) | 71,062  | 68,464 | 139,526 |
| Percentage of national population with cancer in 2013            | 3%      | 3%     | 3%      |

\* all invasive cancers, excluding non-melanoma skin cancers. Source NCR.

Apart from the obvious losses to individuals, families and society, such mortality rates have significant economic consequences<sup>6</sup>.

<sup>4</sup> Unless otherwise stated, data in this chapter are sourced from the National Cancer Registry.

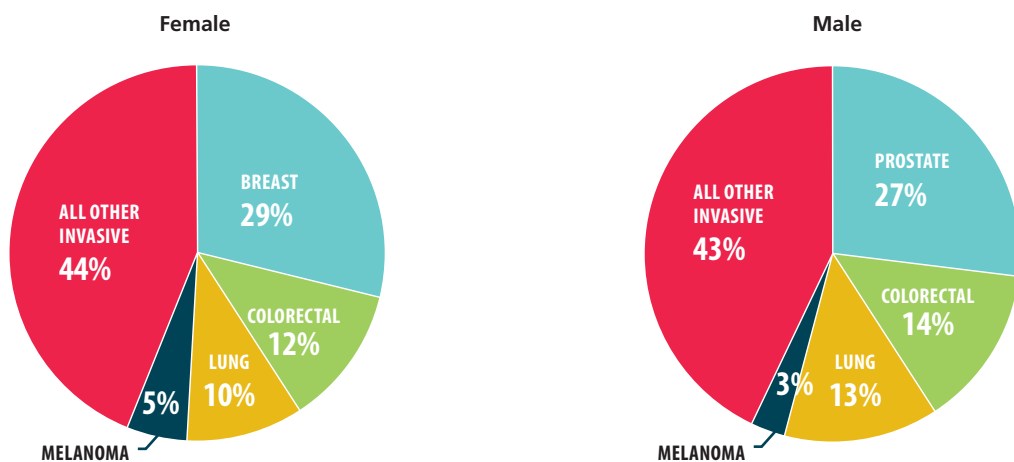
<sup>5</sup> Unless otherwise stated, all cancer statistics in this Strategy refer to invasive cancers, excluding non-melanoma skin cancer.

<sup>6</sup> A National Cancer Registry study (funded by the Health Research Board) published in 2016, estimated that the projected deaths from all invasive cancers in Ireland between 2011 and 2030 will result in lost productivity valued at €73bn; €13bn in paid work and €60bn in household activities: <https://bmccancer.biomedcentral.com/articles/10.1186/s12885-016-2854-4>

## 2.2. Cancer Types

Four cancer types make up more than half of all newly diagnosed cancers (excluding non-melanoma skin cancer) - breast, colorectal, lung, and melanoma in women (56%), and prostate, colorectal, lung and melanoma in men (57%) (Figure 2.1).

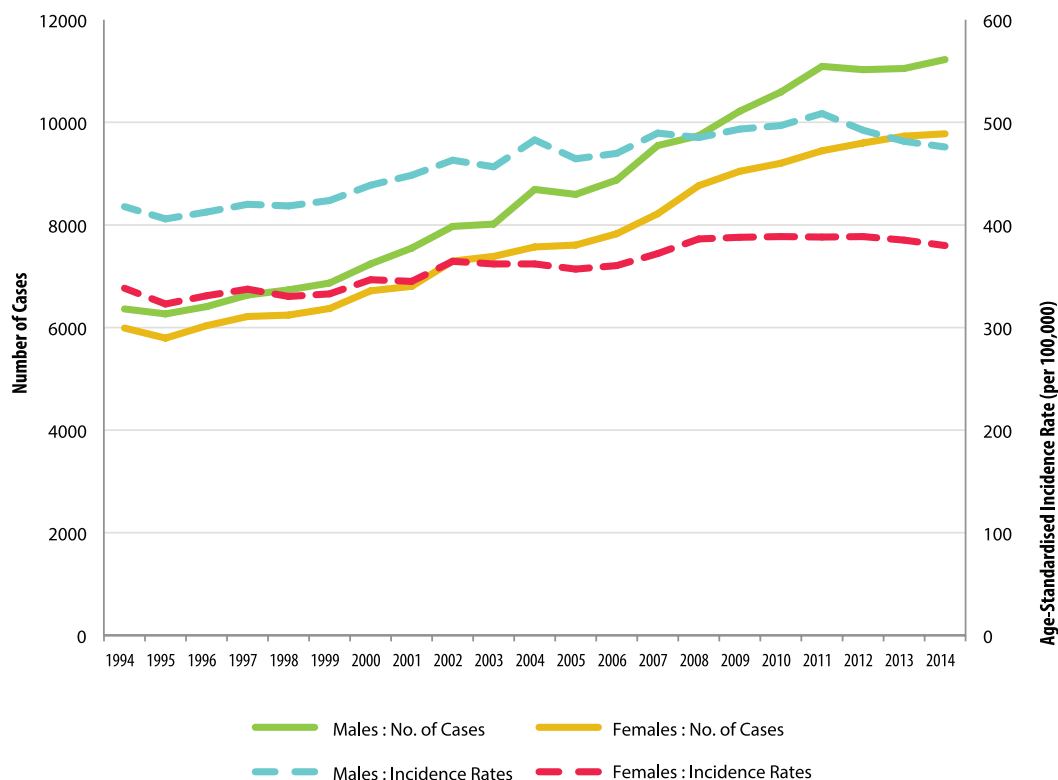
Figure 2.1 Percentages of the common cancer types, 1994-2014



## 2.3. Trends in Cancer Incidence

The number of cancer cases has been increasing by about 3% a year since 1994, but the age-standardised incidence rate, a measure of the risk of developing cancer at any given age, has been increasing by only about 1% a year (Figure 2.2; Table 2.2). Trends in death rates have been downwards over the same period (by 1.5% per year in men and 1.1% per year in women on average). There are a number of reasons why cancer incidence rates have been increasing slightly, including increases in risk factors such as obesity, alcohol consumption and sun exposure and the impact of screening. Much of the increase in the number of cancer cases and deaths is attributable to the growth in the population over 65 years of age; 62% of male patients with cancer and 53% of female patients during 1994-2014 were aged over 65 (Figure 2.4).

Figure 2.2 Trends in cancer incidence, 1994-2014



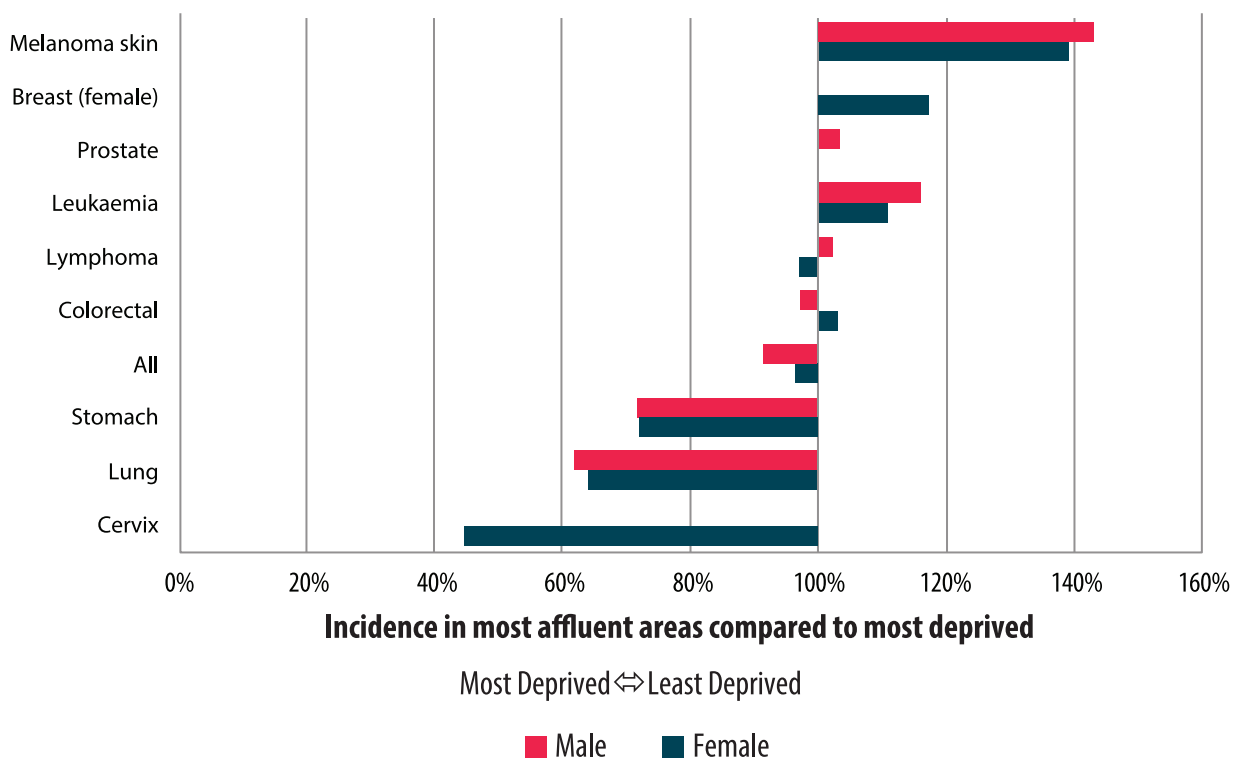
The rate of increase varied by cancer site (Table 2.2). The increase was higher for numbers of cases than for age-standardised rates. For the common cancers, trends in rates ranged from a fall of 0.8% annually for lung cancer in men to an annual increase of 5.0% for melanoma in men and 3.7% for prostate cancer. Most of the latter increase is believed to be due to increased diagnosis, as a result of widespread Prostate Specific Antigen (PSA) testing, rather than any increase in the underlying risk of developing the cancer. On the other hand, the increase in melanoma risk seems to be due to changing patterns of sun exposure and has been accompanied by an increase in death rates of 5% per year for men.

**Table 2.2** Average annual increase in numbers and age-standardised rates for the five commonest cancers, by gender, 1994-2014

|                 | Number |         | Rates |         |
|-----------------|--------|---------|-------|---------|
|                 | Males  | Females | Males | Females |
| All cancers     | 3.4%   | 2.9%    | 1.0%  | 0.9%    |
| Colorectal      | 2.4%   | 1.8%    | 0.0%  | -0.1%   |
| Lung            | 1.6%   | 4.1%    | -0.8% | 2.3%    |
| Melanoma        | 7.5%   | 4.7%    | 5.0%  | 2.5%    |
| Breast (female) | -      | 3.6%    | -     | 1.4%    |
| Prostate        | 6.1%   | -       | 3.7%  | -       |

There is a higher incidence of cancer in more deprived populations. Overall cancer incidence is slightly but significantly higher in the most deprived 20% of the population, by approximately 10% for males and 4% for females, having adjusted for age<sup>7</sup> (Figure 2.3, below). Of the individual cancers examined, cervical, lung and stomach cancers show strong patterns of increasing incidence with increasing deprivation, with age-standardised rates about 120%, 60% and 40% higher, respectively, in the most deprived compared with the least deprived fifth of the Irish population. Breast cancer and melanoma show the opposite pattern, i.e. decreasing incidence with increasing deprivation, with age-standardised rates about 15% lower and 30% lower, respectively, in the most deprived populations.

**Figure 2.3** Relative incidence rates of some cancers in the most affluent and most deprived areas, 2008-2012.



## 2.4. Projections of Cancer Incidence

The population over 65 years is estimated to more than double, from 536,000 to 1,146,000, in the 25 years from 2011 to 2036<sup>8</sup>. This ageing of the population will drive a large increase in the number of new cancer cases over the next few decades. Table 2.3 shows the increases expected if no changes are assumed in risk factor prevalence in the near past or future<sup>9</sup>.

<sup>7</sup> Data in relation to deprivation are provided by the NCR. The Pobal Haase-Pratschke 2006 Index of Deprivation at Electoral Division level is used, i.e. an area-based measure of deprivation incorporating information from the 2006 national Census; this describes populations and is assigned to patients based on their place of residence.

<sup>8</sup> Based on data from Census 2011 (CSO).

<sup>9</sup> The data in Table 2.3 are based on projections published by the National Cancer Registry

<http://www.ncri.ie/sites/ncri/files/pubs/Cancer%20projections%20for%20Ireland%202015%20-%202040.pdf>

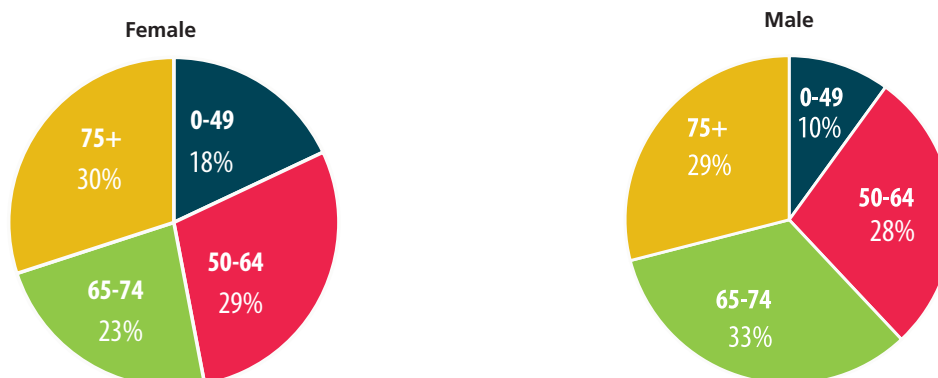
**Table 2.3** Projections of cancer numbers to 2025 and 2040 and % increase from 2010; demographic factors only

|                | All excluding NMSC |            | Colorectal |            | Lung       |            | Breast     |            | Prostate   |            |
|----------------|--------------------|------------|------------|------------|------------|------------|------------|------------|------------|------------|
|                | Est number         | % increase | Est number | % increase | Est number | % increase | Est number | % increase | Est number | % increase |
| <b>Females</b> |                    |            |            |            |            |            |            |            |            |            |
| <b>2010</b>    | 9,266              | -          | 1,041      | -          | 957        | -          | 2,891      | -          | -          | -          |
| <b>2015</b>    | 10,192             | 10%        | 1,185      | 14%        | 1,013      | 6%         | 3,209      | 11%        | -          | -          |
| <b>2025</b>    | 12,849             | 39%        | 1,550      | 49%        | 1,334      | 39%        | 3,937      | 36%        | -          | -          |
| <b>2040</b>    | 16,787             | 81%        | 2,178      | 109%       | 1,862      | 95%        | 4,701      | 63%        | -          | -          |
| <b>Males</b>   |                    |            |            |            |            |            |            |            |            |            |
| <b>2010</b>    | 10,436             | -          | 1,430      | -          | 1,307      | -          | -          | -          | 3,222      | -          |
| <b>2015</b>    | 11,816             | 13%        | 1,686      | 18%        | 1,477      | 13%        | -          | -          | 3,541      | 10%        |
| <b>2025</b>    | 15,639             | 50%        | 2,277      | 59%        | 2,012      | 54%        | -          | -          | 4,687      | 45%        |
| <b>2040</b>    | 21,655             | 108%       | 3,224      | 125%       | 2,889      | 121%       | -          | -          | 6,426      | 99%        |

While demographic change will be the main factor driving an increase in cancer numbers, trends in risk factor prevalence will also have an impact. In the UK population, 40% of the total cancer risk (44% in males, 35% in females) has been attributed to five lifestyle factors - tobacco, diet, overweight/obesity, alcohol and low physical activity<sup>10</sup>. The attributable risks in Ireland are likely to be similar.

## 2.5. Age at Diagnosis of Cancer

Cancer is largely a disease of older people. As outlined in Figure 2.4 below, 62% of cancers in men and 53% in women, were diagnosed in those aged 65 and over. The median age at diagnosis ranged from 32 years for testicular cancer to 72 years for bladder cancer in men, and from 45 years for cancer of the cervix to 76 years for cancer of the lip in women.

**Figure 2.4** Age at diagnosis, all malignant cancers (excluding NMSC) 1994-2014

<sup>10</sup> Parkin, D.M., L. Boyd, and L.C. Walker. The fraction of cancer attributable to lifestyle and environmental factors in the UK in 2010. *British Journal of Cancer*. 2011.





## 2.6. Cancer Stage at Diagnosis

Stage<sup>11</sup> at diagnosis, that is how much the cancer has grown and spread, is probably the most important determinant of survival (Table 2.4).

**Table 2.4** Survival at one and five years for cancers diagnosed 2008-2012; by stage at diagnosis

| Cancer type       | Survival at one year after diagnosis |          | Survival at five years after diagnosis |          |
|-------------------|--------------------------------------|----------|--|----------|
|                   | Stage I                              | Stage IV | Stage I                                | Stage IV |
| Colorectal cancer | 98%                                  | 49%      | 95%                                    | 10%      |
| Lung cancer       | 71%                                  | 16%      | 40%                                    | 3%       |
| Breast cancer     | 99%                                  | 48%      | 94%                                    | 19%      |
| Prostate cancer   | 99%                                  | 78%      | 93%                                    | 36%      |
| Pancreatic cancer | 37%                                  | 14%      | 17%                                    | 4%       |
| Ovarian cancer    | 95%                                  | 51%      | 83%                                    | 15%      |

Stage at presentation varies with cancer site, but has not changed much over time (Figure 2.5). One challenge is to increase the proportion of patients diagnosed at an earlier stage of their disease. If this can be achieved, for example by improving access to diagnostics, by expansion of rapid access clinics, by improved education of the population and by greater uptake of available screening programmes, then, not only will survival be improved, but significant efficiencies will be achieved in the health system. Indeed, since the introduction of BreastCheck, the national cancer screening programme for breast cancer, there has been an increase in the percentage of cancers diagnosed at an early stage<sup>12</sup>.

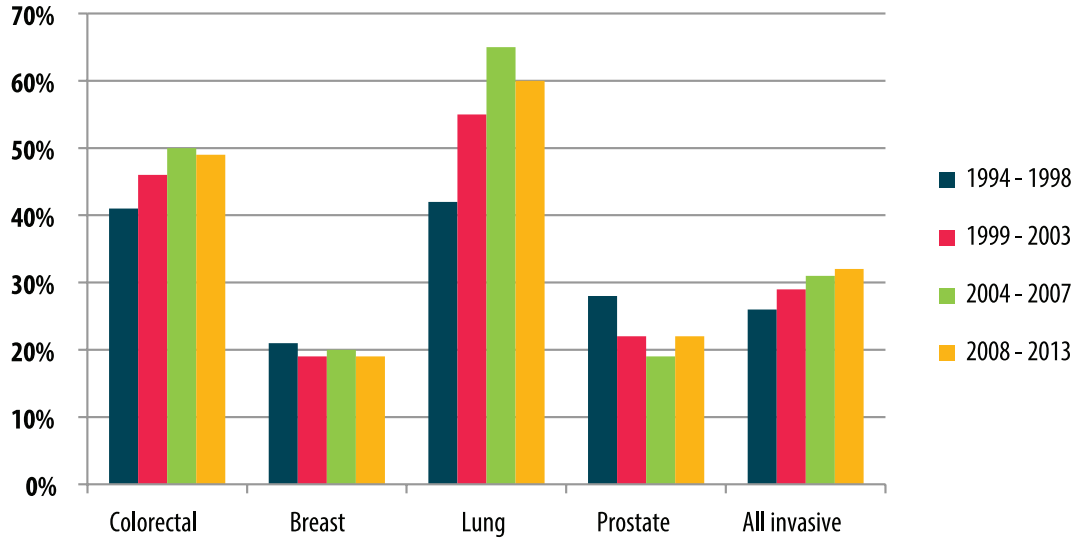
It should be noted that the apparent gradual increase in late stage cancer for some cancer types seen over the last few years in Figure 2.5 is probably due to improved diagnostic methods, which show up cancer spread much more sensitively than in the past, rather than to any real change in stage distribution. This is referred to as stage migration.

<sup>11</sup> Cancer staging is the process of determining how much cancer is in the body and where it is located. Staging describes the severity of an individual's cancer based on the magnitude of the original (primary) tumour as well as the extent to which the cancer has spread in the body. Understanding the stage of the cancer helps doctors to develop a prognosis and design a treatment plan for individual patients.

<sup>12</sup> National Cancer Registry of Ireland, Cancer Projections for Ireland 2015 – 2040 (2014).

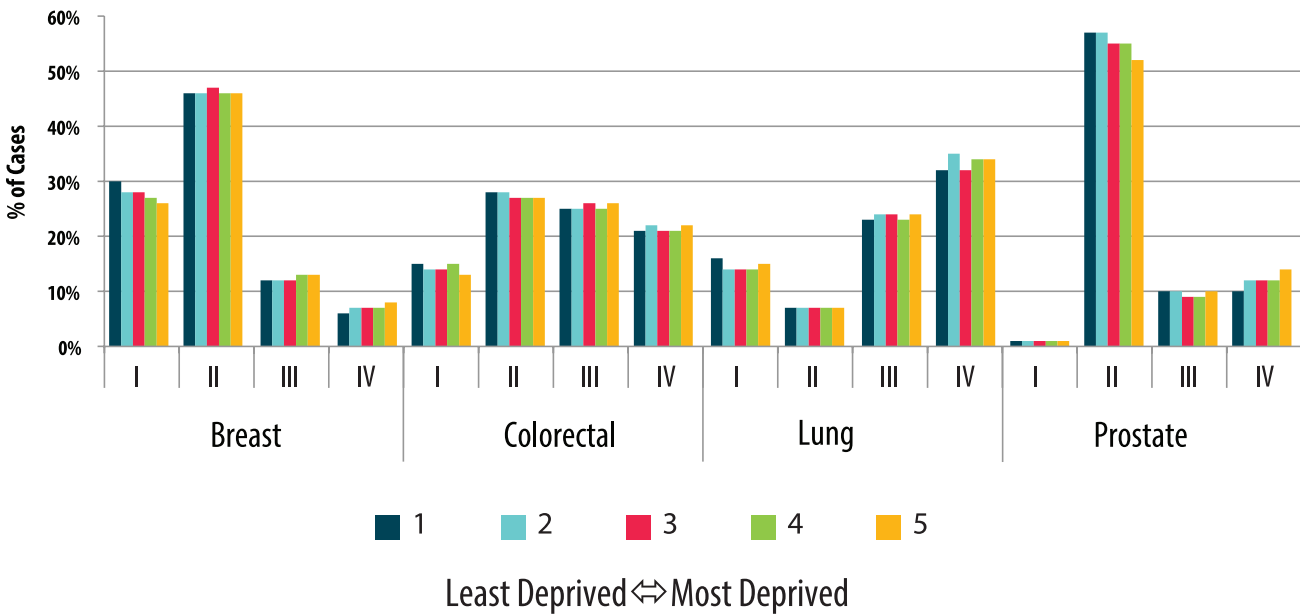


**Figure 2.5** Percentage of late stage (III and IV) cancers by site and year of diagnosis



There is only limited evidence of any variation in stage at presentation with deprivation of the area of residence, including lower proportions of early-stage or higher proportions of later-stage cancers among more deprived populations for breast and prostate cancer (see Figure 2.6 below).

**Figure 2.6** Percentage of cases at each stage (I-IV), by cancer type and area deprivation category, 2008-2012.



## 2.7. Cancer Survival

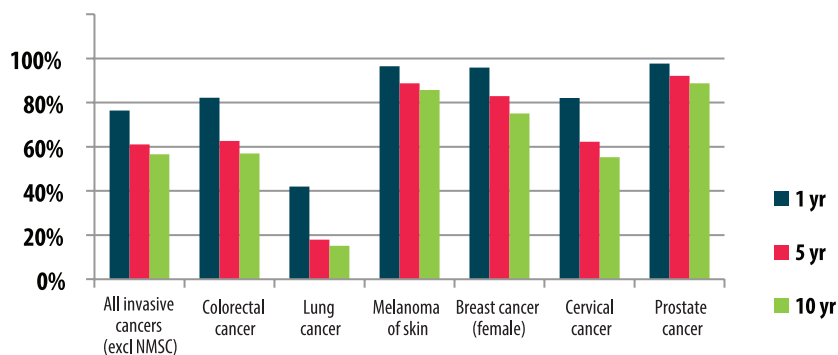
### 2.7.1 One-, five- and ten-year net survival for patients followed up in 2010-2014

Overall net survival from invasive cancer (excluding non-melanoma skin cancer) is currently estimated as 76% at one year from diagnosis, 61% at five years, and 57% at ten years (Figure 2.7). For the common cancers the best ten year survival is for prostate cancer (89%) and the worst for lung (15%).

**10 YEAR SURVIVAL RATE FOR PROSTATE IS 89%**

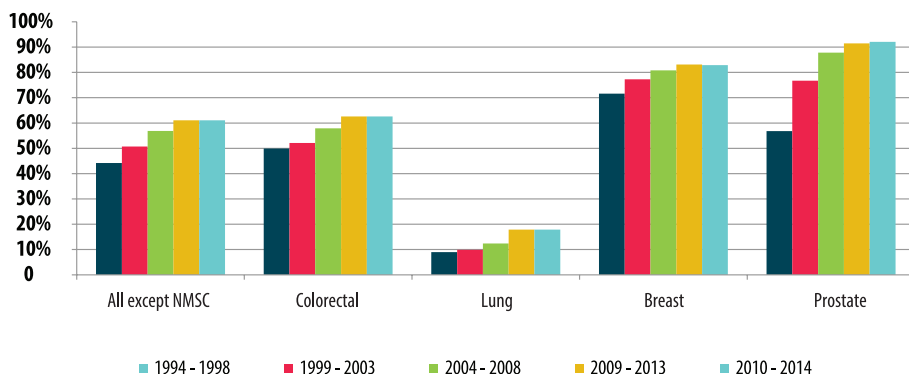
**10 YEAR SURVIVAL RATE FOR LUNG IS 15%**

**Figure 2.7** One-, five- and ten-year net survival (age standardised) for the more common cancers (2010-2014)<sup>13</sup>



There has been a steady increase in five-year survival since the period 1994-1998 (Figure 2.8). The largest relative increase has been in lung cancer, and the smallest in breast cancer. This is quite probably because there is more potential for improvement in cancers with a poorer survival.

**Figure 2.8** Five-year net survival (age standardised), 1994-2014



<sup>13</sup> This is the most up-to-date available estimate of survival for recent cancer patients, and is based on follow-up of all cases alive at any point during 2010-2014, supplemented by follow-up 2009-2014 for cases diagnosed in 2009. The estimate includes medium/longer-term follow-up information from pre-2010 – for example, patients diagnosed in 2001 who survive nine years up to 2010 contributed to the survival estimate between nine and ten years.

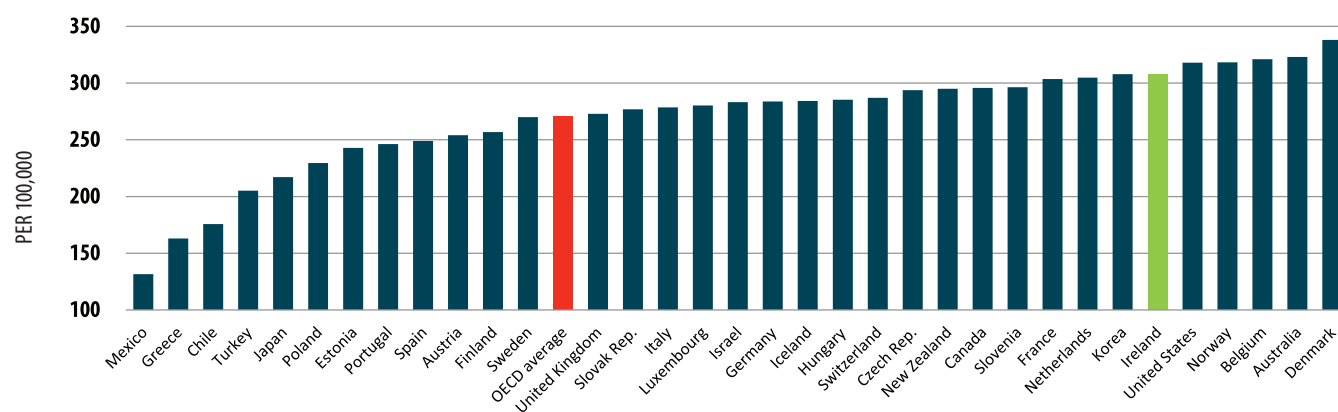
## 2.8. International Comparisons

The main cancer control data sets used internationally are incidence, mortality and survival. International comparisons provide important pointers towards our rates of progress, though differences between how health systems are structured, and the availability of useable, timely comparative data need to be borne in mind.

### 2.8.1 Incidence

OECD reports show variations in the incidence of cancer in the OECD 34 countries (Figure 2.9)<sup>14</sup>. Incidence rates for breast and prostate cancer in Ireland are above the OECD 34 average, as is the overall cancer incidence rate. This emphasises the necessity of developing prevention and health promotion policies aimed at reducing cancer incidence.

**Figure 2.9** Cancer incidence rates in OECD 34 countries, 2012 (age standardised).

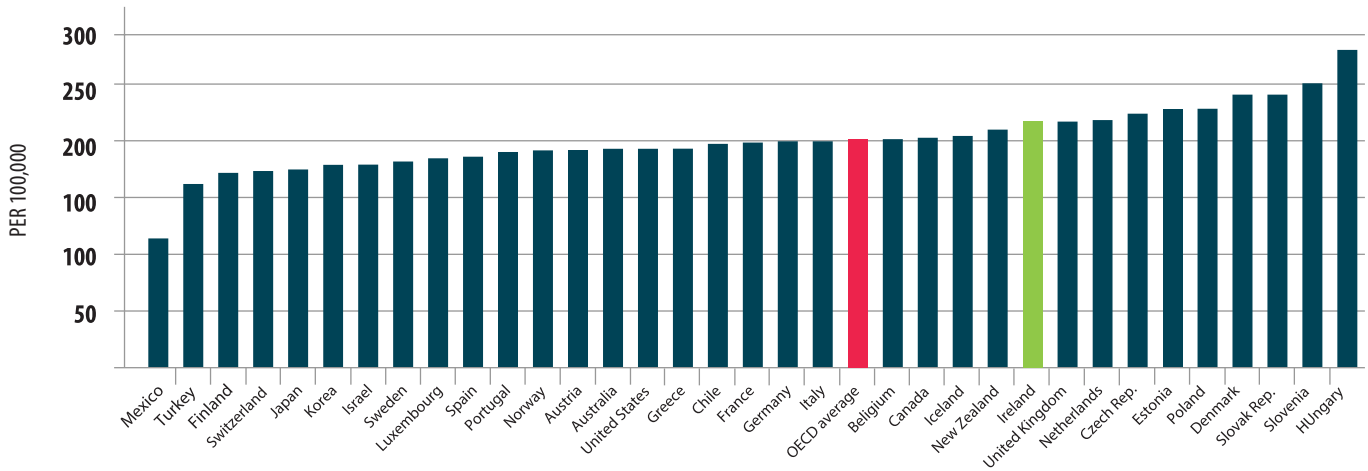


### 2.8.2 Mortality

OECD reports confirm that cancer continues to be a major cause of mortality internationally. When compared with OECD 34 countries, the overall cancer mortality rate in Ireland is above the average (Figure 2.10). Early detection of cancer and effective treatments are priorities in this strategy to address our mortality rates.

<sup>14</sup> OECD, Health at a Glance (2015)

**Figure 2.10** Cancer mortality rates in OECD 34 countries, 2013 or latest year available (age standardised).



**2.8.3 Survival**

The CONCORD 2<sup>15</sup> project has provided comparative survival data for a number of European countries for 2000-2004 and 2005-2009 (Table 2.5). Survival for Irish patients improved for all cancer types studied over these periods. However, these international comparisons show that, with the exception of prostate cancer, Irish survival rates for the common cancers remained below the median. Although Irish survival rates improved in all cases over the period, our ranking changed very little. International comparisons of cancer survival rates across countries will always be subject to time lags, and the main impacts of the 2006 National Cancer Strategy had not been felt in the period up to 2009.

**2.8.4 Lessons from international comparisons**

While the provision and organisation of cancer services in Ireland has been transformed over the course of the last two decades, and outcomes for Irish patients have been substantially improved, there is still much scope for improvement. Chapter 3 assesses the impact of previous cancer control strategies and identifies priorities for the future. This includes consideration of the cancer control strategies in other countries, many of which have lower mortality and higher survival rates. An aim of this Strategy is that cancer survival rates will be in the top quartile of European countries by 2025 (see Key Performance Indicators, Chapter 17).

15 Claudia Allemani et al., Global surveillance of cancer survival 1995-2009: analysis of individual data for 25,676,887 patients from 279 population-based registries in 67 countries, The Lancet (2015).

**Table 2.5** Net survival (%) for common cancers by country and year of diagnosis

| Country        | Colon     |           | Lung      |           | Breast    |           | Prostate  |           |
|----------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
|                | 2000–04   | 2005–09   | 2000–04   | 2005–09   | 2000–04   | 2005–09   | 2000–04   | 2005–09   |
| Austria        | 60        | 63        | 16        | 18        | 81        | 83        | 90        | 91        |
| Belgium        | 64        | 65        | 15        | 17        | 85        | 85        | 92        | 93        |
| Czech Republic | 51        | 55        | 11        | 12        | 78        | 80        | 76        | 83        |
| Denmark        | 52        | 56        | 10        | 11        | 81        | 82        | 64        | 77        |
| Estonia        | 49        | 52        | 11        | 12        | 70        | 72        | 67        | 73        |
| Finland        | 61        | 63        | 12        | 12        | 87        | 87        | 90        | 93        |
| France         | 60        | 60        | 14        | 14        | 87        | 87        | 89        | 91        |
| Germany        | 62        | 65        | 15        | 16        | 84        | 85        | 89        | 91        |
| Iceland        | 61        | 65        | 15        | 15        | 88        | 85        | 80        | 84        |
| <b>Ireland</b> | <b>54</b> | <b>59</b> | <b>10</b> | <b>13</b> | <b>78</b> | <b>80</b> | <b>84</b> | <b>88</b> |
| <b>(rank)</b>  | <b>15</b> | <b>14</b> | <b>19</b> | <b>15</b> | <b>18</b> | <b>17</b> | <b>11</b> | <b>10</b> |
| Italy          | 60        | 63        | 14        | 15        | 86        | 86        | 89        | 90        |
| Latvia         | 42        | 45        | 14        | 16        | 70        | 71        | 65        | 74        |
| Lithuania      | 52        | 52        | 8         | 8         | 70        | 72        | 81        | 92        |
| Malta          | 58        | 56        | 9         | 11        | 76        | 76        | 83        | 85        |
| Netherlands    | 58        | 60        | 12        | 15        | 84        | 85        | 83        | 86        |
| Norway         | 58        | 62        | 12        | 15        | 84        | 86        | 82        | 86        |
| Poland         | 46        | 50        | 12        | 13        | 72        | 74        | 69        | 74        |
| Portugal       | 56        | 60        | 10        | 13        | 81        | 83        | 87        | 89        |
| Romania        |           | 58        |           | 16        |           | 75        |           | 80        |
| Russia         | 36        | 41        | 15        | 16        | 62        | 71        | 64        | 70        |
| Slovakia       | 50        | 50        | 10        | 11        | 74        | 72        | 63        | 66        |
| Slovenia       | 53        | 56        | 10        | 11        | 78        | 80        | 73        | 78        |
| Spain          | 56        | 59        | 12        | 13        | 82        | 84        | 85        | 87        |
| Sweden         | 59        | 63        | 13        | 16        | 86        | 86        | 86        | 89        |
| Switzerland    | 61        | 63        | 15        | 17        | 84        | 86        | 86        | 88        |
| UK             | 51        | 54        | 9         | 10        | 79        | 81        | 80        | 83        |

(Note: some countries are represented by one or more regional registries without national population coverage)



# STRATEGIC CONTEXT

## 3.1. Introduction

The development of this Strategy included an examination of the current state of cancer care and a consideration of the requirements for the future. These included:

- 1 An evaluation of the **A Strategy for Cancer Control in Ireland (2006)**.
- 2 A public consultation process.
- 3 An examination of international models of cancer control.

## 3.2. Evaluation of 'A Strategy for Cancer Control in Ireland', 2006

In preparation for the development of the third strategy, an independent evaluation of the 2006 strategy, **A Strategy for Cancer Control in Ireland**, was commissioned by the Department of Health. The purpose of this evaluation was to assess the outcomes of the recommendations from the 2006 strategy and to assess the overall impact of the Strategy on the burden of cancer. The evaluation also considered Ireland's position in terms of developments internationally and made a number of recommendations for the future.

*Patient and public involvement in strategy formulation, service development and evaluation should be integral to the next national cancer strategy*

EVALUATION GROUP

The Evaluation Group<sup>16</sup> found that significant progress had been made across the whole cancer control system in Ireland since the publication of the 2006 strategy. The Group noted that cancer prevention policies had been developed, progress had been made in the early detection of cancer through screening programmes and dedicated clinics had been established for symptomatic breast, lung and prostate referrals. The Group also noted that national referral guidelines and pathways had been developed for many cancers and that quality assurance programmes had been developed for histopathology, endoscopy and radiology.

They singled out the establishment of the NCCP as the most significant factor in driving the required change in the cancer system. They also identified a number of areas that required attention and made a number of recommendations to improve the cancer control system. These are listed in detail in the Report of the Evaluation Group<sup>17</sup>.

<sup>16</sup> The Evaluation Group comprised Professor Pádraig Warde (Chairman, Interim Vice President of Clinical Programs & Quality Initiatives of Cancer Care), Professor Harry de Koning (Professor of Public Health and Evaluation of Screening at the Erasmus University Medical Centre, Rotterdam) and Professor Alison Richardson (Clinical Professor of Cancer Nursing and End-of-Life Care at the University of Southampton and Southampton General Hospital).

<sup>17</sup> The Evaluation Report is available from the Department of Health website at the following location: <http://health.gov.ie/blog/publications/national-cancer-strategy-2006/>



The Group made a number of recommendations on how the cancer system should be organised, including hospital admissions policies, the organisation of hospital care and palliative care. The recommendations encompassed a range of areas within cancer control from prevention and primary care to treatment, post treatment care, and patient involvement. Staffing issues were considered, and deficiencies in oncology nursing and medical oncology in particular were highlighted. The report also outlined a number of structural or legislative measures that were considered important to allow the cancer system to operate to its full capabilities, including mandatory notification of cancer diagnoses.

The Evaluation Group was impressed with progress in the cancer control system in Ireland since the publication of **A Strategy for Cancer Control in Ireland in 2006**. However, they also clearly identified key areas that require further attention. Their view was that while progress had been made, we remain significantly behind the countries that are leading the way in cancer control.

### 3.3. Public Consultation 2015

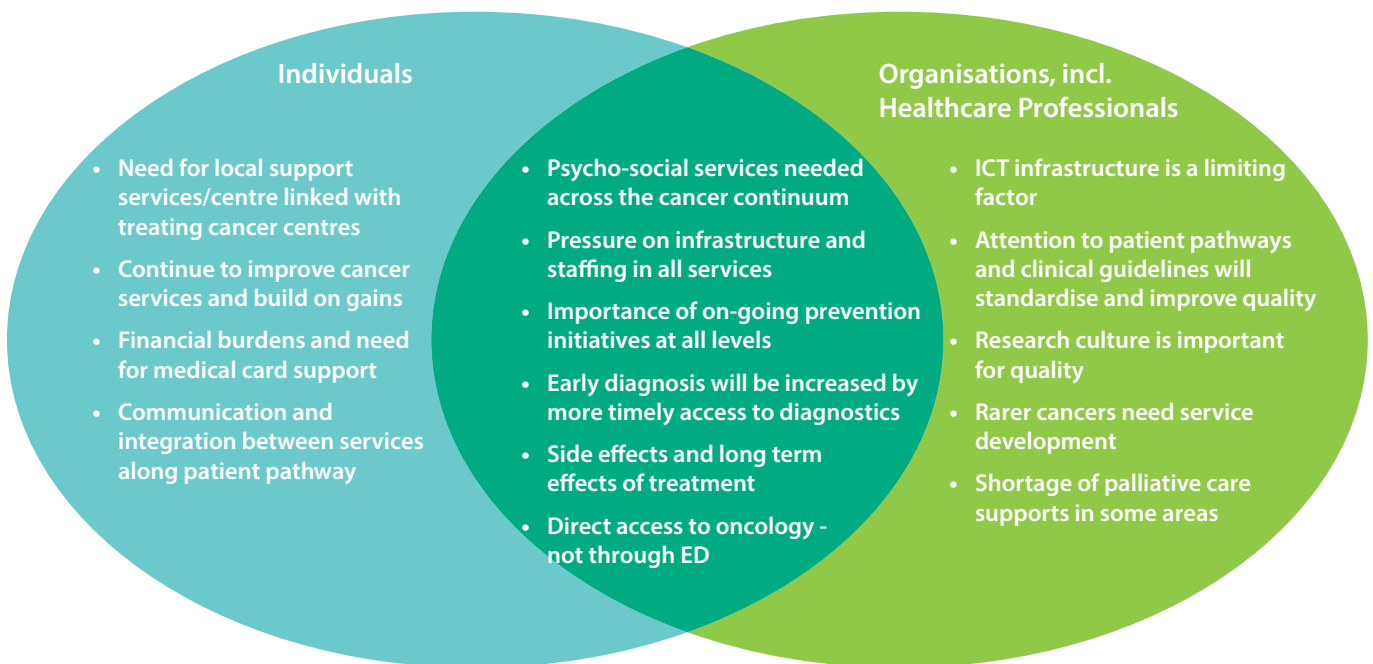
A public consultation process was launched by the Minister for Health in summer 2015. The consultation utilised a questionnaire which sought the views and priorities of the public and interest groups on a number of key issues that were identified by the Steering Group as being relevant for a new strategy.

A total of 221 submissions was received. The majority of submissions (67%) were submitted by individual members of the public. The remaining submissions were submitted by organisations, or on behalf of organisations.<sup>18</sup>

#### 3.3.1 Consultation findings

Figure 3.1 below illustrates the main themes that emerged in the submissions. There was considerable overlap between the views of individuals, and those of organisations and healthcare professionals.

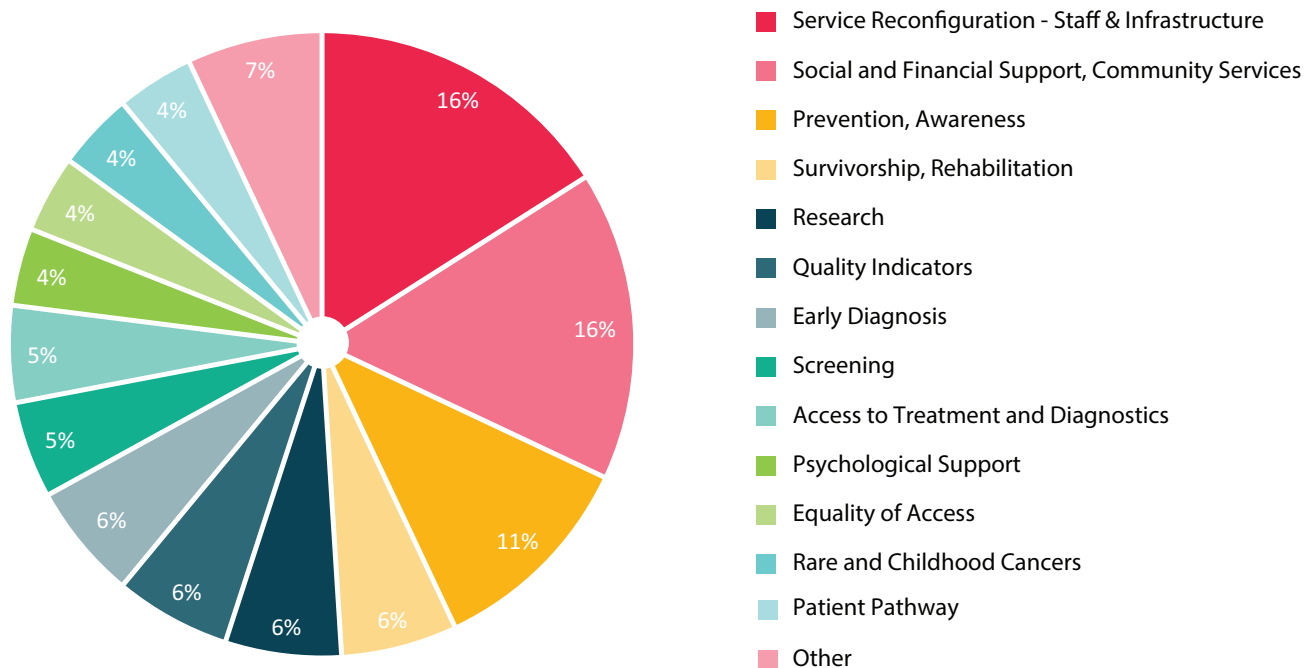
Figure 3.1 Issues identified in the public consultation



18 <http://health.gov.ie/blog/publications/a-report-on-the-public-consultation-to-inform-the-development-of-a-national-cancer-strategy>

The main priorities identified are illustrated in Figure 3.2 below.

**Figure 3.2** Identified public submission priorities for new cancer strategy



The three priorities most commonly identified were:

- service reconfiguration, both human and physical infrastructure;
- social and financial support for patients with cancer and development of community based services; and
- cancer prevention and continuing increase in public awareness.

### 3.3.2 Conclusions from public consultation

The public submissions recognised and appreciated that progress has been made in the last two decades in the development of cancer services and that there are opportunities to build on that progress. Several issues emerged as being important to both organisations and individuals. These included the pressure on infrastructure and staffing at all levels; the importance of prevention initiatives; the lack of psycho-social services available to patients and families; the impact of the side effects and

long-term effects of treatment; and the importance of direct access to re-admission to oncology services for patients with cancer (rather than through Emergency Departments). Individuals making submissions saw the new strategy as continuing and accelerating the reforms initiated in previous strategies.

The results of the public consultation were presented to the Strategy Steering Group and the Patient Forum. Full consideration was given to the views expressed in the public consultation in the development of this National Cancer Strategy.

### 3.4. International Context for Cancer Control

In recent years a European Commission Joint Action - European Partnership for Action Against Cancer (EPAAC) - was established and its remit included providing guidance and assistance to Member States in formulating cancer strategies and establishing cancer control programmes. National Strategies are now in place in almost all Member States. In 2014, a new Cancer Control Joint Action (Cancon) was initiated, with the aim of reducing the cancer burden in the EU, raising cancer survival rates and reducing cancer mortality.

An Expert Group on Cancer Control was also established by the European Commission in 2014. This works to assist with drawing up legal instruments, policy documents, guidelines and recommendations on cancer control at the request of the Commission. It also facilitates the exchange of information on experiences, policies and practices.

In addition to participating in the collaborative work at European level, Ireland is also a member of the International Agency for Research on Cancer (IARC) which is the dedicated cancer research agency of the World Health Organisation. IARC coordinates and conducts research on the causes of cancer and develops scientific strategies for cancer prevention and control.

The World Health Organisation Policies and Managerial Guidelines provide a framework for the development of national cancer programmes underpinned by evidence-based policy. It has long been recognised internationally that a comprehensive approach to cancer programmes at national level offers an effective way to bring together the dedicated leadership and resources that are necessary to develop and implement policies to reduce the burden of cancer.

### 3.5. A Strategic Approach to Cancer Control in Other Jurisdictions

Cancer strategies are being developed and updated in various countries on an on-going basis. The specific goals of these strategies vary depending on the cancer services that are already in place, the efficiency of these services, how services are linked with one another and the stakeholders involved in monitoring and implementing those services. However, the overall aim of these strategies is similar: to provide essential cancer services to the population, in as integrated and efficient a manner as possible. A number of key themes have emerged in cancer strategies around Europe in recent years. These include:

- increased focus on prevention and early diagnosis;
- safe, high quality and patient-centred care;
- service delivery;
- addressing inequalities;
- supporting those living with and beyond cancer;
- measurement of outcomes; and
- innovation and modernisation.

#### 3.5.1 Prevention and early diagnosis

Prevention, both primary and secondary, is identified internationally as key to reducing the burden of cancer in the population. A population approach, supported by policy and legislative measures, is required to encourage and support people to live healthier lives, and to reduce the prevalence of cancer risk factors such as tobacco and alcohol consumption, obesity, lack of physical activity and UV radiation exposure.

The large evidence base that exists to demonstrate that exposure to tobacco products leads to an increased risk of cancer has ensured that anti-tobacco programmes form a key part of cancer control programmes around the world. The World Health Organisation's Framework Convention on Tobacco Control seeks to limit the use of tobacco worldwide and has been signed by 180 countries. In addition to this Framework, individual countries have

enacted their own policies for tobacco control, for example the introduction of bans on workplace smoking in Ireland, the UK and Denmark, the ban on the point of sale display of tobacco products in Ireland and the UK and the ban on smoking in cars where children are present in Ireland. The enactment of legislation which requires plain packaging to be used for tobacco products is another example. In Australia, all tobacco products must be sold in plain packaging, and France and the UK have introduced standardised or plain packaging legislation. Standardised packaging of tobacco products is scheduled to commence in Ireland in late 2017.

Prevention measures to address alcohol consumption, diet and physical activity levels and occupational and environmental risk factors are also commonly in place in countries with national cancer control plans. For example, Sweden has reduced alcohol consumption through the use of policies regulating where alcohol can be sold and how it is taxed. Scotland's Supporting Healthy Choices Voluntary Framework supports consumers to make healthier choices and reduce their sugar intake. The ASA registry in Finland requires companies to report on what carcinogens they use and which workers are exposed to them. Since its establishment, there has been a significant reduction in the number of employees exposed to carcinogens in the course of their work.

In addition, diagnosing cancer at an early stage improves survival and leads to less aggressive forms of treatment. Evidence-based screening programmes can identify precancerous lesions and facilitate the early diagnosis of cancer, and are essential to a comprehensive cancer strategy. In 2003, the Council of the European Union recommended that member states implement screening programmes for colorectal, breast and cervical cancer, and this has been adopted in many countries including Ireland. Increasing access to, and the capacity of, diagnostic services, as well as creating rapid referral pathways, are also recognised as crucial to early diagnosis.

### 3.5.2 Patient-centred care

Patient-centred care is widely recognised internationally as best practice and a core component of a high quality health service. Patients must be provided with the appropriate information to make informed decisions. Effective communication is highlighted as crucial to ensure understanding and to facilitate a partnership approach to care between patients and their healthcare providers. Patients must know what is happening, and the reason why it is happening, at each step of their care.

National cancer control plans in countries such as Norway, England and France have emphasised that patient involvement in cancer care is crucial to a high-quality cancer service. For example, Norway has committed to developing an online resource that makes it easier for citizens to interact with the healthcare services, and that will in time allow patients to access information about their health and to contact healthcare professionals.

### 3.5.3 Service delivery

It is agreed internationally that patients should have timely access to safe, high quality care that incorporates evidence-based best practice and sustainable models of care. Patients should have equitable access to the most advanced treatments available in their jurisdiction, based on individual clinical need. In the era of personalised medicine, a programme to ensure that new cancer treatments are evaluated in a standardised manner is vital to ensure that the introduction of new treatments is equitable and sustainable.

In this regard, the Norwegian Directorate of Health, in collaboration with the hospitals, the Norwegian Knowledge Centre for the Health Services and the Norwegian Medicines Agency, is in the process of developing a new national system for the evaluation of the methods used within the health service. This system will cover medicines, medical equipment, procedures and diagnostic methods, and will be used in prevention, assessment, diagnosis, treatment, follow-up and rehabilitation.

**FOUR**  
CANCER TYPES  
MAKE UP  
**1/2 OF ALL**  
CANCERS

---

5 YEAR  
SURVIVAL  
RATES HAVE  
**IMPROVED**  
FROM **45%** TO  
**61%** IN THE  
PAST DECADE

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Similarly, Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020 recommends that NHS England and Public Health England should work with Monitor (the sector regulator for health services in England) and other bodies to consider how to develop better health economic evaluation of new service models and interventions.

### **3.5.4 Addressing inequalities**

Inequalities in cancer care are recognised internationally and it is clear that cancer risk factor prevalence is disproportionately distributed in society. Variation in screening uptake rates and in access to diagnostics and treatment are widespread. Identifying ways to address these inequalities is an essential part of a national cancer strategy.

The Detect Cancer Early programme in Scotland aims to reduce differences in cancer survival rates between the most affluent and least affluent areas. Since its introduction, this programme has seen a 14% increase in stage I diagnoses in the most deprived areas of Scotland. Also, an objective of the Norwegian strategy Together – Against Cancer is to ensure that cancer prevention is undertaken in a way that counteracts inequalities in health.

### **3.5.5 Support for those living with and beyond cancer**

More people are surviving with, and living beyond, cancer. Recognition of the on-going health and wellbeing needs of survivors, as well as the consequences of their treatment, is important. The development of individualised ‘care plans’ is put forward in many jurisdictions as an enabler to addressing the physical, psychological and social needs of patients beyond the treatment phase. The provision of appropriate end-of-life care is also seen as an essential part of a modern cancer strategy.

England’s cancer strategy recommends the development of a national metric on quality of life by 2017, which would enable better evaluation of long-term quality of life after treatment. Scotland’s Beating Cancer: Ambition and Action aims to identify how best to ensure that all patients are given a Treatment Summary so that they are informed about the care they received and can use that information in interactions with other clinicians and health and social care professionals in the future.



### 3.5.6 Measurement of outcomes

Measurement of outcomes is a vital part of the implementation of a cancer strategy. It is important that outcome targets are put in place from the beginning and that performance is measured against these. Review of performance against targets is an on-going process, and targets themselves may need to be changed over time. An example is the New South Wales Cancer Plan Performance Index, against which progress in meeting their objectives is measured. Also, the Cancer Quality Council of Ontario has developed indicators to track progress on outcomes in cancer care on a range of areas, including prevention, screening, diagnosis, treatment, recovery and end of life care.

### 3.5.7 Innovation and modernisation

It is recognised internationally that considerable resources are required to fund a comprehensive cancer service. The provision of modern equipment, more personalised medicine and access to the latest technologies and treatments comes at a high initial cost. In addition, the provision of the appropriate skill mix of staff, not only in the direct cancer treatment services, but across primary care and in areas such as radiology and pathology requires additional investment. Training and retention of sufficient numbers of staff to address current workforce deficits is most important. However, this is very challenging in the context of the international market for such trained personnel.

Cancer care is evolving rapidly and it is vital to ensure that research is a strong component of cancer services. The aim is to devise clear programmes of research within available resources, targeted at priority areas and leading to improvements in outcomes and the patient experience. The importance of encouraging patient involvement in clinical trials has been emphasised in cancer control plans from a number of jurisdictions, such as France, England and Slovenia.



### 3.6. Priorities for the Next Ten Years

A number of high level conclusions can be drawn from this analysis which allow clear priorities to be established for the third National Cancer Strategy. Overall, the progress seen to date justifies the continuation of the current overall approach to cancer control. This involves a whole of population approach that deals with all aspects of cancer in a planned way. It emphasises the need for high quality cancer care that is equitably available to all cancer patients. It also involves continuous monitoring, with a view to improving the quality of cancer care.

The projected growth in incidence and prevalence of cancer illustrates the need for a range of cancer control actions to prevent and treat cancer in an effective manner and to support those living beyond cancer. While prevention strategies can have a significant impact on cancer incidence, it will take some time before this impact is seen. Already most cancer services in Ireland are at full capacity. Further actions, such as improving earlier detection, providing more effective treatments, and transforming how we provide services to those with a cancer diagnosis across the patient pathway, are required in order to reduce the burden of cancer.

Significant reorganisation of cancer services in particular in relation to diagnosis, treatment planning and initial treatment has taken place since the 2006 Cancer Strategy. This is evident in the case of breast cancer and rare cancers. However, progress remains to be made on a number of common malignancies.

There is growing appreciation nationally and internationally of the positive role that can be played through the involvement of informed and empowered patients and citizens in cancer care. This should involve meaningful roles in the development, oversight and operational planning of cancer services. Patients with cancer are in a unique position to inform, to personalise and to improve the co-ordination of their own care.

There have been many significant scientific, technological and therapeutic advances in cancer diagnosis and treatment in recent years. In particular, diagnostics and treatments that exploit a better understanding of the molecular basis of cancer biology offer great hope for the future. It is essential that this Strategy provides a clear and structured mechanism to evaluate the evidence in respect of the efficacy and effectiveness of each of these developments and to ensure their incorporation into well organised patient centred care pathways that are fully audited and evaluated. Existing services, particularly diagnostic services, are challenged by limits on access.

The NCCP must play a strong role in ensuring the incorporation of evidence based care pathways into the delivery of the services offered to patients with cancer in a manner which ensures that issues of access are appropriately addressed. The end goal must be that access to, and experience of, cancer diagnosis and treatment is related only to the clinical need of patients who must use these services. This will require that future provision for molecular diagnostic services, histopathology, radiological services, endoscopic services and other diagnostics are strategically planned so that they can achieve these goals within the resources that are and will be made available for cancer.

A particular existing challenge in respect of cancer and other services is ensuring that they are delivered equitably and that patients achieve equity in outcomes irrespective of age, sex, geographic location and social class. It follows that significant enhancement of our information capacity is required to enable transparent public reporting of process and outcome indicators in a way that allows us to assess the degree to which equity is being achieved across our cancer services.

Significant work has been done in recent years to strengthen our procedures for the incorporation of evidence based diagnostics and treatments into routine clinical practice through the National Clinical Effectiveness Committee (NCEC) and nationally mandated Clinical Guidelines. Further





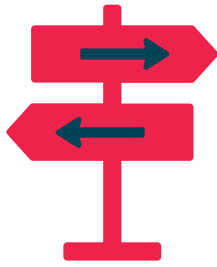
developments in this regard will be required in respect of cancer care to ensure that the goals of equal access and equal outcome for clinical need can be met. Additionally, the policies and procedures in respect of prioritisation of new drugs and new technologies must continue to be strengthened and made more transparent and explicit to ensure access is determined by clinical need and that maximum value in terms of cancer outcomes can be achieved for a given level of investment.

Much progress has been made in establishing links with health authorities in Northern Ireland to improve cancer services for people on the island of Ireland. Opportunities for cross-border co-operation in relation to cancer services will continue to be pursued with a view to achieving mutual benefit. Similarly, international co-operation in relation to the various aspects of cancer prevention, care, research and survivorship will also be promoted and strengthened.

*Healthy Ireland - A Framework for Improved Health and Wellbeing 2013-2025* provides for a co-ordinated cross-government means of tackling social determinants

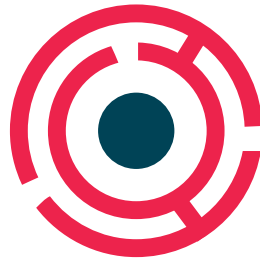
of health and major lifestyle risks for cancer. There is encouraging evidence of progress in respect of many of the common lifestyle related risk factors, in particular in relation to tobacco consumption. It is clear however, that further progress is needed through effective, strategic and operational alignment between the National Cancer Control Programme and the goals of *Healthy Ireland*.

The NCCP has existed since 2007. It is reasonable that this Strategy give consideration to how best to strengthen the authority of the NCCP, which seeks to achieve a common standard of prevention, diagnosis, treatment and outcome in respect of cancer care across the country, when there is clear evidence that progress in respect of centralisation of many cancer services has not been universal. Aligning investment, new developments, staffing, indemnity and performance management and regulation with the objectives and requirements of the structure, process and outcome of cancer care pathway delivery is essential to ensure that the governance and management of cancer control services is fully aligned with the requirement to reduce the burden of cancer in all its manifestations.



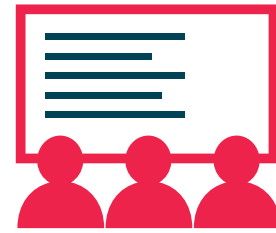
### What has worked well in cancer control in Ireland

- Clear, evidence-based policy direction
- Strong leadership and oversight
- Programmatic approach to cancer control and establishment of the NCCP
- Designation of eight cancer centres
- Screening programmes
- Rapid Access Clinics
- Multidisciplinary team working
- Treatment standards and protocols
- Strong community support for cancer care



### Challenges

- The projected increase in cancer cases
- The requirement to address the needs of cancer survivors
- The need to ensure that cancer control measures are delivered equitably - and achieve equitable outcomes
- The pressure on infrastructure and resources
- The difficulties in attracting and retaining qualified people to work across our cancer services
- To achieve a balance between the benefits and costs of new drugs/ treatments
- To achieve a continuum of care across primary, secondary and tertiary services
- To attain a strong focus on outcomes through the integrated model of care



### Lessons

- Integrated approach to cancer control
- Cancer prevention as a key area of focus
- Importance of improving early detection and diagnosis
- Centralisation of care provides for optimal treatment
- Survivorship care and psychosocial support needs to be developed
- Importance of patient input
- Need for on-going evaluation
- Value of learning from international developments
- Importance of strong governance and management

# VISION

## 4.1. Introduction

Progress seen to date justifies maintenance of the approach of cancer control: that is a whole population, broad approach that deals with all aspects of cancer in a planned way stressing the measurement of need and ensuring that high quality cancer care is consistently available to all cancer patients.

Ireland is currently placed around mid-table (See Table 2.5, Chapter 2) in the survival by country statistics for common cancers across Europe. Survival rates are an important measure of performance. We must now aim to make further strides in cancer control such that survival rates can reach the top quartile of European countries by the end of the Strategy period. Fulfilling this aim will be particularly challenging given the expected continued improvements in other countries. This aim is reflected in the table of Key Performance Indicators in Chapter 17.

Our vision is one in which all aspects of cancer control, from the promotion of healthy living, more specific prevention measures, optimum treatment and quality of life measures across the patient cancer journey and beyond, are addressed, backed up by solid governance, workforce planning and research.

Together we  
will strive  
to prevent  
cancer and  
work to  
improve the  
treatment,  
health and  
wellbeing,  
experiences  
and outcomes  
of those  
living with  
and beyond  
cancer.

The following goals and their associated objectives have been identified as being critical to the achievement of the vision:

## Goals and Objectives

### 1 Reduce Cancer Burden

Ensure prevention programmes are prioritised to reduce cancer incidence

Improve symptom awareness in the population

Increase early diagnosis

Focus on social inequalities

### 2 Provide Optimal Care

Ensure effective and equitable treatment throughout the care pathway to improve outcomes for all patients

Further develop treatment facilities and infrastructure

Maintain a strong focus on patient safety and quality assurance

Ensure that appropriate palliative care supports are in place

### 3 Maximise Patient Involvement and Quality of Life

Strengthen the role of patients in the planning and delivery of cancer care, including through the establishment of structures for patient involvement

Develop and implement survivorship care programmes

### 4 Enable and Assure Change

Strengthen the role of the NCCP in the oversight of cancer control and in implementing the recommendations of the Strategy.

Ensure ongoing workforce planning to fulfill changing needs

Utilise technology, research and data to create a sustainable, high quality and accountable cancer service

Build better systems and processes to ensure evidence-based prioritisation and service delivery.

## 4.2. Goal: Reduce the Cancer Burden

The population over 65 years of age is estimated to more than double, from 0.536m to 1.146m in the 25 years from 2011 to 2036. Given the relationship between ageing and cancer incidence, this will lead to a significant increase in the number of new cancer cases.

It is projected that the number of cancer cases (excluding non-melanoma skin cancer) will increase by 50% in men and by 39% in women in the 15 years from 2010 to 2025. This can be expected to accelerate beyond that time period.

These projections confirm the challenge we face in dealing with cancer over the coming years. This Strategy will highlight three key areas of focus that will impact positively on cancer incidence rates and stage at diagnosis in the future:

- the implementation of prevention programmes to reduce the incidence of cancer;
- an increase in symptom awareness and health care seeking behaviour in the population; and
- an increase in the number of cancers diagnosed at an early stage.

It is estimated that 30% to 40% of cancer incidence is attributable to modifiable risk factors. Supporting Irish people to stop smoking, lose weight, eat healthily, take more exercise, moderate their alcohol intake and reduce their exposure to the sun will have a major impact on future rates of cancer incidence. Encouraging those who are eligible to participate in screening programmes will contribute to early diagnosis. Creating awareness around warning signs suggestive of cancer will also help to ensure that more cancers are diagnosed at an early stage. A significant effort is required to ensure that prevention and awareness campaigns have a particular focus on addressing health inequalities. Targeted efforts will also be made by the National Screening Service (NSS) to achieve as high an uptake rate as possible for cancer screening by those affected by social inequalities.

## 4.3. Goal: Provide Optimal Care

The concept of a continuum of care will underpin the approach to patient services, from prevention, early diagnosis, and evidence-based high quality patient-centred treatment, to appropriate follow-up and support. Achieving a true continuum of care will require improved integration between primary, secondary and tertiary services. This will allow patients to easily move between community and hospital settings in line with their care needs.

Significant progress has been made already in the provision of cancer treatment, much of it taking place in acute hospitals under the direction of specialist clinicians and multidisciplinary teams (MDTs). This Strategy builds on that progress by supporting the key role of designated centres in cancer treatment. There is also a need for clear care pathways for the diagnosis and treatment of patients who have rare cancers, with particular emphasis on timely treatment planning at national MDT level, involving subspecialty expertise in diagnosis and treatment and with linkages to international centres of excellence for specialist advice and intervention. Appropriate palliative care supports will also be provided, both for management of symptoms and end of life care.

The designated cancer centres will be further developed to ensure that they play an optimal role in diagnosis, treatment planning and delivery, education and research. An aim of this Strategy will be that investment in cancer centres will have the goal of ultimately establishing at least one comprehensive cancer centre.

Safety is fundamental to high quality health care and cancer services must be supported to deliver safe care, while balancing competing pressures and demands. Active leadership, governance and clinical commitment to quality will be shown at all levels of cancer care to assure patient safety.

#### **4.4. Goal: Maximise Patient Involvement and the Quality of Life of Those Living With and Beyond Cancer**

Many people are now living significantly beyond cancer diagnosis and treatment and this trend will continue. In many cases the aim of cancer care for patients will be to return to work, or to play a full part in life in whatever way is appropriate to the person.

This Strategy will aim to create an environment that empowers patients to become active participants in their own healthcare and supports them in making decisions about their treatment. Programmes will be put in place to ensure that patients are supported to return to their normal life as much as is possible following treatment. Individual patients will have different requirements for survivorship care and this will be taken into consideration in the development of survivorship programmes.

Structures will be put in place to facilitate patient involvement in policy development and planning of cancer services. This will ensure that the patient voice is represented at all stages of the cancer continuum, during and after their treatment, as well as in service planning.

#### **4.5. Goal: Enable and Assure Change**

Change is required across our cancer services to give effect to the Strategy vision. This will include increases in workforce numbers, as well as changes in workforce composition and deployment, with the aim of providing safe, high quality and patient-centred care.

The NCCP has an integral role to play in the implementation of the recommendations of this Strategy. It will continue to provide leadership and direction to the cancer system to ensure that service priorities are aligned with desired outcomes.

The positive impact of research activity, including clinical trials, on the care of patients is evident. An aim will be to develop a culture in the cancer care system that values research and is supportive of those who actively engage in it.

There will be a strong focus on meeting performance, quality and outcome targets across the implementation of the Strategy.



# SECTION B

## REDUCING THE CANCER BURDEN

- 5 PREVENTION
- 6 SCREENING
- 7 EARLY DIAGNOSIS

### OBJECTIVES

- Ensure prevention programmes are prioritised to reduce cancer incidence
- Improve symptom awareness in the population
- Increase early diagnosis
- Focus on social inequalities

**30 - 40%**  
of cancers are  
**preventable**

**900**   
**cancers**  
each year are as  
a result of **alcohol**

  
**19%**

of the population  
are daily **smokers**



**BreastCheck** has  
detected **8,500**  
cancers to date

**94%** of those diagnosed  
with **stage I** breast  
cancer are alive  
**five years** later  
compared to **19%**  
diagnosed at **stage IV**



# PREVENTION

## 5.1. Introduction

Cancer prevention must be a cornerstone of the cancer strategy as it offers the most cost-effective, long-term approach for cancer control<sup>19</sup>. The proportion of cancer incidence attributable to modifiable lifestyle and environmental factors is estimated to be in the 30% to 40% range.

Modifiable lifestyle or environmental risks exist for many cancers. Of these, smoking is by far the most important. Others include excess body weight, poor diet, physical inactivity, alcohol consumption, specific infections, radiation (ultraviolet and ionizing, including radon) and occupational hazards. Prevention measures will be undertaken as part of, or in tandem with, the overall health and wellbeing initiatives under the *Healthy Ireland* programme.

It is vital that we are effective in getting the message across to the population that each person can impact significantly on their own level of risk of developing cancer. The fact that there is a considerable time lag in prevention interventions feeding through to incidence figures increases the challenge. However, the evidence that past changes in behaviour in regard to smoking under previous strategies has led to current better health for individuals is something that we can build on to drive further behavioural change.

Reducing health inequalities is a priority of this Strategy. Lifestyle risk factors generally follow social deprivation, gender and age patterns. Smoking is a key contributor to socio-demographic inequalities. Health inequalities are also associated with poor symptom awareness, delayed presentation and low uptake of services, including screening. Where appropriate, a robust prevention programme will first focus its efforts on the most deprived populations.

## 5.2. Evolving Prevention Initiatives in Ireland

Effective health promotion and disease prevention initiatives result in less chronic disease and in a reduction in some healthcare costs. The Government has already initiated policy to improve our nation's health through ***Healthy Ireland - A Framework for Improved Health and Wellbeing 2013-2025***, which sets the overarching context in which a focus on cancer prevention will be driven as a cornerstone of this Strategy. *Healthy Ireland* takes a whole-of-Government and whole-of-society approach to improving health and wellbeing, with a focus on prevention, reducing health inequalities and keeping people healthier for longer. The goals of *Healthy Ireland* are to increase the proportion of people who are healthy at all stages of life, to reduce health inequalities, to protect the public from threats to health and wellbeing and to create an environment where every individual and sector of society can play their part in achieving a healthy Ireland.

The initial implementation of *Healthy Ireland* in the health services is focused on strategic priorities which will embed health and wellbeing goals into reform objectives. It identifies the development of a *National Brief Intervention Model* as a key driver to support and leverage the leadership role of healthcare professionals and teams in *making every contact count*. This Model aims to exploit the opportunities that arise for providing health advice and intervention across the many interactions with patients and the public and to strengthen the capacity of healthcare professionals to incorporate prevention and support for behaviour change as a routine part of healthcare delivery. The NCCP and cancer care services have a significant leadership role to play in driving this culture of making every contact count to support a focus on cancer prevention.

19 World Health Organisation, Cancer Prevention: <http://www.who.int/cancer/prevention/en/>



The NCCP will develop a cancer prevention function to support the implementation of *Healthy Ireland* and to fulfil an important part of its role as a comprehensive cancer control programme. The NCCP will prioritise the implementation of evidence-based interventions to reduce cancer lifestyle risks and to increase public protection from known carcinogens. It will also address emerging areas for prevention in high risk groups, e.g. chemoprevention. The NCCP will work with the Department of Health, other Directorates of the HSE and voluntary organisations such as the Irish Cancer Society to ensure a co-ordinated approach. Cancer awareness and prevention initiatives will prioritise disadvantaged populations and hard to reach groups. The **European Code Against Cancer** (2014)<sup>20</sup>, which focuses on actions that individuals can take to prevent cancer, will continue to inform policy formulation and will feed into public awareness campaigns on cancer prevention.

## Recommendations

- 1 The Department of Health will ensure that policies under the *Healthy Ireland* framework are implemented in full and that opportunities to address cancer prevention measures under those policies are maximised. In particular, measures aimed at further reducing smoking levels will be pursued.
- 2 The NCCP will develop a cancer prevention function, working in conjunction with the broader *Healthy Ireland* initiative, and will lead in relation to the development and implementation of policies and programmes focused on cancer prevention.

Lead: DoH

Lead: NCCP



20 World Health Organisation, European Code Against Cancer: <http://cancer-code-europe.iarc.fr/>

## 5.3. Cancer Risk Factors

### 5.3.1 Smoking

Smoking is the main cause of preventable mortality in Ireland and results in 5,950 deaths, including 2,900 cancer deaths each year. At least 85% of lung cancers are due to smoking, and smoking also causes over half of oral cavity, pharyngeal, oesophageal and laryngeal cancers. **Tobacco Free Ireland**, the national tobacco control strategy, has the key goal of making Ireland tobacco-free by 2025 (defined as a prevalence rate of less than 5% - (KPI no. 1). Two key themes underpinning **Tobacco Free Ireland** are the protection of children and the denormalisation of smoking.

A modelling analysis of the effect of tobacco control policies in Ireland over the period 1998-2010 has suggested that these policies were responsible for a 22% relative reduction in smoking prevalence by 2010 - equating to 1,716 fewer deaths due to smoking by 2010 and fifty thousand fewer deaths due to smoking by 2040.<sup>21</sup>

Where health personnel provide smoking cessation advice, support and pharmacological treatment, smoking cessation success rates among their patients are doubled. Implementation of the National Brief Intervention/making every contact count model and training, in relation to smoking cessation as a core component of undergraduate health education programmes, will facilitate prevention and support for behaviour change becoming a routine part of healthcare practice and delivery.

### 5.3.2 Obesity

Excess body weight increases the incidence of a variety of cancers such as colon and breast cancers. Approximately 400 new cases of colorectal and breast cancer combined each year in Ireland are due to excess body weight. **A National Obesity Policy & Action Plan**<sup>22</sup> was published in September 2016 and takes a cross-sectoral approach to tackling the multitude of determinants which impact on levels of overweight and obesity in the population.

### 5.3.3 Diet and physical activity

Healthy eating and physical activity confer multiple health benefits and can significantly reduce the risk of a range of diseases, including cancer. High consumption of fruit and vegetables reduces the risk of several cancers such as those of the colon, oesophagus and stomach and more than one in ten bowel cancers are linked to a low fibre diet. Physical inactivity is increasingly recognised as a leading risk factor for poor health and is associated with higher risk of colon and breast cancers. The **National Obesity Policy & Action Plan** and the **National Physical Activity Plan** detail a range of actions to promote and support healthier food choices among the population.

### 5.3.4 Alcohol

Each year, 900 newly diagnosed cancers in Ireland are caused by alcohol. Over half of cancers in the upper aerodigestive tract are caused by alcohol, and when combined with smoking, the risk of developing these cancers increases. The public health approach to addressing alcohol misuse, including the Public Health (Alcohol) legislation, aims to reduce overall consumption as well as patterns of harmful use.

21 L.M. Currie, K. Blackman, L. Clancy et al, 'The Effect of Tobacco Control Policies on Smoking Prevalence and Smoking-attributable Deaths in Ireland Using the Ireland SS Simulation Model', Tobacco Control 22 (2013)

22 Healthy Ireland, A Health Weight for Ireland: Obesity Policy and Action Plan (2016); <http://health.gov.ie/wp-content/uploads/2016/09/A-Healthy-Weight-for-Ireland-Obesity-Policy-and-Action-Plan-2016-2025.pdf>

The *Healthy Ireland Survey* (2016) of almost 7,500 people aged 15 and older provides robust data on cancer risk factors to inform prevention priorities. The main findings relevant to cancer lifestyle risk factors are:

## SMOKING

# 23%

of the Irish population aged 15 and over are **smokers** compared with 29% in 2007.



This is made up of **19%** who are daily smokers and **4%** who are occasional smokers. This compares with an average of **24%** of the EU-28 population who were smokers in 2014, **19%** of whom were daily smokers and **5%** of whom were occasional smokers. (European Health Interview Survey).



Recruitment of new smokers continues with **20%** of **15-24 year olds** currently smoking. This compares to an average of 24% among the EU-28 countries in 2014.

(European Health Interview Survey)

Smokers want to quit with **48%** having made an attempt to quit during the last year.



# 18%



of the population are exposed to **second hand smoke** on a daily basis. This compares to a **22%** average among EU-28 countries in 2014. (European Health Interview Survey)

**Smoking prevalence is higher** among those living in most deprived areas **35%**

## ALCOHOL



# 75%

of the population drinks alcohol and 55% of these do so at least **once a week**. This compares with an average of 29% of the EU-28 population who drank alcohol at least once a week. (European Health Interview Survey)

# 37%



of drinkers binge drink on a typical drinking occasion – 54% of those aged under 25.



## DIET & NUTRITION

**27%**  **5**

eat five portions of fruit and vegetables a day. This compares with an EU-28 average of 14% in 2014. (European Health Interview Survey)

**60%** eat snack foods every day with **42%** eating **six or more** portions daily.



**14%**

drink sugar sweetened drinks daily, rising to 22% of those aged **15-24**.

## WEIGHT



**37%** normal  
**37%** overweight  
**23%** obese.

(Data from 2015 Healthy Ireland Survey)

**Men** are more likely to be overweight than women (43% compared to 31%); the proportion of men and women who are obese is closely aligned (men: 25%; women: 22%).



## PHYSICAL ACTIVITY

**32%**

of the population reports being highly active.



## SEXUAL HEALTH

**54%** of men who most recently had sex with men did not use a condom. (2015 Data)



### 5.3.5 Sexual health

A number of sexually transmitted infections (STIs) can lead to an increased risk of developing cancer. People living with Human Immunodeficiency Virus (HIV) have an increased risk of Kaposi sarcoma, lymphoma, and a number of other cancers, while people chronically infected with the Hepatitis B virus are at an increased risk of developing liver cancer. Infections with high-risk types of Human Papilloma Virus (HPV) cause nearly all cervical cancers, as well as most anal cancers and many oropharyngeal, vaginal, vulval, and penile cancers. The first **National Sexual Health Strategy**<sup>23</sup>, which was published in 2015, takes a nationally coordinated approach to address sexual health and wellbeing and to reduce negative sexual health outcomes.

Since 2010 first year post-primary girls are offered HPV vaccination as part of the national vaccination programme to prevent cervical cancer. In at-risk populations, this vaccine can reduce the risk of HPV associated malignancies, which include most cervical cancers as well as some vaginal, vulval, oropharyngeal, anal and rectal cancers. It is absolutely vital that there is a high uptake rate of this vaccine to ensure herd immunity.

The vaccine is also available for men, between the ages of 16 and 26, who have sex with men, as this cohort does not benefit from the herd immunity provided by vaccinating girls. The international evidence and policy considerations in relation to HPV vaccination for adolescent males will continue to be monitored. The health technology assessment examining the extension of the HPV vaccination programme to adolescent males will be completed as a priority.

### 5.3.6 Ultraviolet radiation

Non-melanoma skin cancer (NMSC) is the most common cancer diagnosed in Ireland. Ultraviolet radiation (UVR), whether natural or artificial, causes over 95% of skin cancers (both NMSC and melanoma). More than 75% of the Irish population has a Celtic type complexion (Fitzpatrick Skin Type 1 and 2) which greatly increases skin cancer risk. Melanoma incidence is increasing by 5% per year in men, and 3% per year in women.

## Recommendation

- 3 The Department of Health will develop a national skin cancer prevention plan and oversee its implementation as a priority. The plan will prioritise children, outdoor workers, sunbed users and those who pursue outdoor leisure activities.

Lead: DoH

<sup>23</sup> Department of Health, National Sexual Health Strategy 2015-2020 (2015).

### 5.3.7 Radon

Radon, a radioactive gas, is naturally produced in the ground from uranium present in small quantities in rocks and soil. It presents a significant radiation health risk. The National Radon Control Strategy (2014)<sup>24</sup> points the way to address this significant cancer risk.

### 5.3.8 Occupational hazards

Most occupations do not pose a cancer risk. The ban on workplace smoking greatly reduced exposure to second hand smoke. In Ireland, the most common occupational hazard is ultraviolet radiation to outdoor workers.

Occupational related cancers are preventable and strong workplace regulation, worker education and surveillance are needed.

### 5.3.9 Additional cancer risks specific to women

Hormone replacement therapy (HRT) increases the risk of breast and ovarian cancer and uterine cancer risk is linked to oestrogen-only HRT. For every 1,000 women taking HRT at age 50 for a period of five years, two extra cases of breast cancer will arise and one extra case of ovarian cancer. For women who are contemplating starting HRT or for those already using it, a discussion with their doctor on risks versus benefits is essential.

Breast feeding, especially cumulative breastfeeding for over one year, has a protective effect on breast and ovarian cancer risk. Despite the evidence of the importance of breastfeeding for a wide range of health benefits for both mothers and babies, rates in Ireland remain among the lowest in the OECD. **Creating a Better Future Together: National Maternity Strategy 2016-2025** emphasises that particular focus is required to improve support for breastfeeding in the health services, as well as highlighting that a broader societal change is required in order to promote a more positive culture around breastfeeding.

### 5.3.10 Secondary and tertiary cancer prevention

Additional cancer risks exist for those who have been treated for cancer previously. Therefore, it is important that cancer prevention initiatives target cancer patients and ensure that they are fully informed of warning signs. These initiatives should also inform patients with regard to the actions they should take if they have concerns about their health.

## 5.4. Chemoprevention and Other Prevention-focused Medications

Chemoprevention for higher risk groups involves the use of medication to prevent the development of cancer in well people. While some research has involved the general population, chemoprevention has primarily focused on those known to be at increased risk of cancer, e.g. due to a strong family history, lifestyle risks or the diagnosis of a premalignant, or predisposing, condition.

Opportunities for chemoprevention have been identified from epidemiological and molecular research and these have led to the testing of a range of agents in randomised controlled trials. Even where agents show promising risk-reduction in clinical trials, challenges remain in ensuring clinical application. These include the careful consideration of the risks versus benefits in a well population, and how best to define the population who would benefit.

The challenge for all such medications is the identification of those populations at risk of the relevant cancer and the balance between benefit and adverse effects. The NCCP prevention programme should evolve over the next decade to evaluate and ultimately implement chemoprevention strategies with the relevant professional bodies (e.g. the ICGP) as the available data support such interventions.

<sup>24</sup> Department of Environment, Community and Local Government, National Radon Control Strategy (2014)

## 5.5. Future Prevention Initiatives

While major strides have been made in promoting cancer-preventing behaviours in recent years, there is still much to be done. As more evidence emerges regarding the development of cancer, and the environmental and lifestyle risks that can contribute to cancer, there will be a need to identify the most effective prevention methods. This will need to be done in a timely manner to ensure that as many cancers are prevented as possible.

In order to facilitate this, the NCCP will develop a systematic, evidence-based mechanism to ascertain the potential benefits and the cost-effectiveness of various initiatives which will inform future cancer prevention programmes.

### Recommendation

- 4 The NCCP will develop a systematic, evidence-based mechanism to ascertain the potential benefits and the cost-effectiveness of various initiatives (including chemoprevention) which will inform future cancer prevention programmes.

**Lead:** NCCP



# SCREENING

## 6.1. Introduction

The primary aim of cancer screening programmes is to detect early cancerous (or pre-cancerous) cells, with the aim of reducing cancer mortality in an asymptomatic population. Evidence based cancer screening programmes are an important element of cancer control in Ireland. Specific cancer screening programmes have been recommended by international bodies such as the World Health Organisation (WHO) and the European Union (EU), based on evidence in regard to the reduction in cancer deaths. EU Health Ministers unanimously adopted a recommendation on cancer screening in 2003. Organised, population-based screening programmes have been demonstrated to show reductions in morbidity and mortality related to cancer.

Standards and quality assurance systems are essential to ensure that screening programmes provide safe and effective services that are in line with international guidelines. Such quality assurance and programme monitoring are key components of the three cancer screening programmes in Ireland and thus ensure that screening services are provided to the highest standard.

## 6.2. Breast Cancer Screening

Until recently, BreastCheck, the national breast cancer screening programme, has offered breast cancer screening with biennial mammography to women aged 50-64 years. The screening programme was extended to women aged 65-69 years in 2015. Implementation of this extension for the approximately 100,000 women in this cohort has commenced on an incremental basis and it will be completed by the end of 2021. The decision to extend the target screening population was based on evidence from EU and international guidelines for population-based breast cancer screening.

To date the programme has provided over 1.37m mammograms to over 480,000 women and in excess of 8,500 cancers have been detected. The most recent BreastCheck report, published in January 2016, reports a cancer detection rate of 6.5 per 1,000 women screened (KPI no. 8).



### 6.3. Cervical Cancer Screening

CervicalCheck, the National Cervical Screening Programme, offers cervical cancer screening, using a cervical smear test, to women aged 25-60 years - an eligible population of 1.1m women. Overall coverage in the five year period to mid-2015 was 78.7%, approaching the 80% target set by the screening programme (KPI no. 9).

The introduction of HPV testing, initially for women post treatment (2012) and more recently for women with low grade abnormalities (2014), means that a significant proportion of women attending colposcopy now have a combined smear and HPV test. The addition of a HPV test (on the same sample) for this group of women allows a longer interval between smear tests, as well as progressively allowing more women to be discharged to primary care for routine screening (rather than having annual surveillance screening following treatment).

CervicalCheck has introduced HPV triage, which involves HPV reflex testing of low grade cytological abnormalities identified in primary care screening. HPV testing is being considered as the primary screening mechanism for cervical cancer. The Health Information and Quality Authority (HIQA) has undertaken a HTA to independently evaluate the clinical, financial, ethical and organisational implications of establishing HPV testing as the primary screening test for cervical cancer.

**CERVICALCHECK**

**PROVIDE**

**SMEAR TESTS TO**

**1.1M  
WOMEN**



**BOWELSCREEN**

**DETECTED**

**521**



**CANCERS**

**BETWEEN 2012 & 2015**



## 6.4. Colorectal Cancer Screening

BowelScreen, the National Bowel Screening Programme, was introduced in 2012 with a phased implementation plan targeting men and women aged 60-69 years. The total eligible population is approximately 0.5m, and the first round of screening was completed at the end of 2015 (KPI no. 10). BowelScreen is one of the first national screening programmes to utilise the faecal immunochemical test (FIT) as the primary screening test. From 2016, BowelScreen has moved to a two year round of screening, rather than the initial three year round. Efforts will continue to increase uptake rates, including addressing the lower uptake rate among men when compared to women. Evidence supports the extension of bowel cancer screening to the full population aged between 55 and 74 years.

As the number of patients requiring colonoscopies arising from the BowelScreen programme looks set to grow, a significant development of endoscopy services will be required. An Endoscopy Working Group has been set up in the HSE to address these issues, and the recommendations of this Group will inform the future development of these services.

## 6.5. Future Developments in Cancer Screening

With rapid discoveries and developments in the world of genomics, and specifically cancer genetics, it is likely that more personalised and tailored cancer screening approaches will evolve over the period of the Strategy. Areas of particular interest include the cancer control and surveillance services for those with an inherited familial predisposition to breast, ovarian and colorectal cancer. The development of such a programme will be prioritised. The aim should be to provide equitable access to surveillance for all patients on a national basis.

While no further population screening programmes are currently recommended, it is imperative that all cancer screening services continue to carry out an active research programme to inform improvements in approach, methodology and testing technology.

## Recommendations

- 5** The HSE will ensure that the appropriate endoscopy capacity is provided in hospitals to allow for the expansion of BowelScreen to all aged 55-74 by end-2021.

**Lead: HSE**

- 6** The NCCP will draw up a plan by end-2017 for the development of an integrated cancer control and surveillance service for defined population subgroups with an inherited familial predisposition to cancer (e.g. breast, ovarian and colorectal).

**Lead: NCCP**



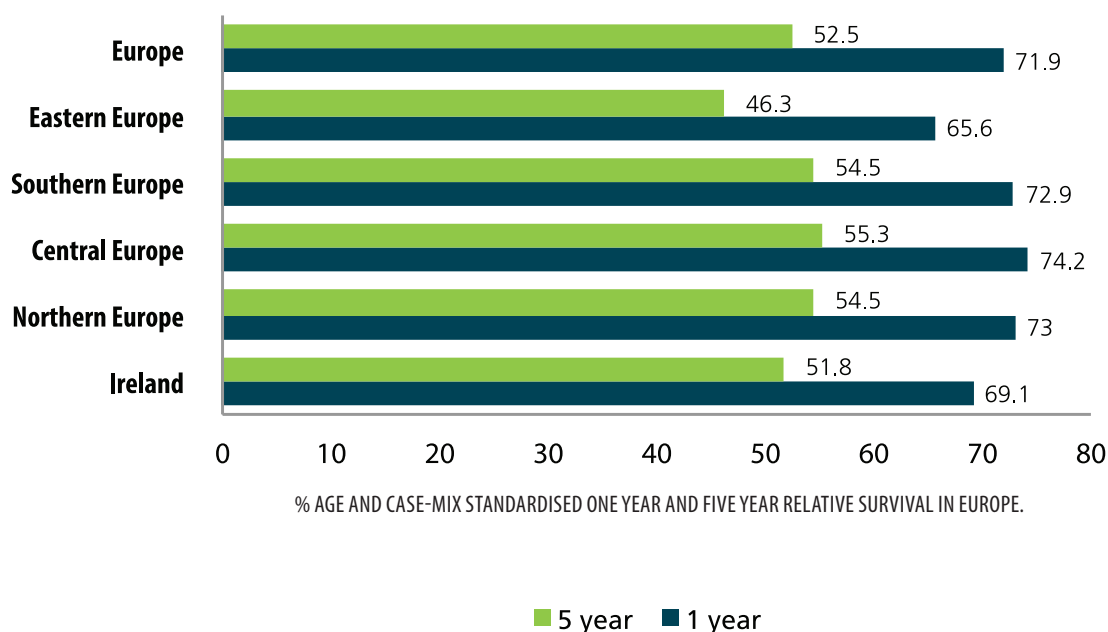
# EARLY DIAGNOSIS

## 7.1. Introduction

Determinants of cancer survival are complex and multi-factorial. They include tumour biology, patient factors (such as smoking) and the availability of high quality screening, diagnostic and treatment services. Diagnosing cancer at its earliest possible stage is a critical first step to achieving higher survival rates, reducing treatment severity and improving the quality of life of patients. Ireland's cancer outcomes are steadily improving. Between 1994 and 2012 the overall five year age-standardised cancer survival rate increased from 44.5% to 61% (See Figure 2.8, Chapter 2).

However, despite these significant improvements, a survival gap continues to exist between Ireland and the best performing European countries (See Figure 7.1, below). Further improvements in overall survival rates will require an emphasis on increasing the proportion of patients diagnosed at an earlier stage of their disease.

**Figure 7.1** Age and case-mix standardised one year and five year relative cancer survival in Europe (2000-2007)<sup>25</sup>



<sup>25</sup> P. Baili et al. Age and case-mix standardised survival for all cancer patients in Europe 1999-2007: Results Eurocare-5. A population-based study. Eur J Cancer (2015).

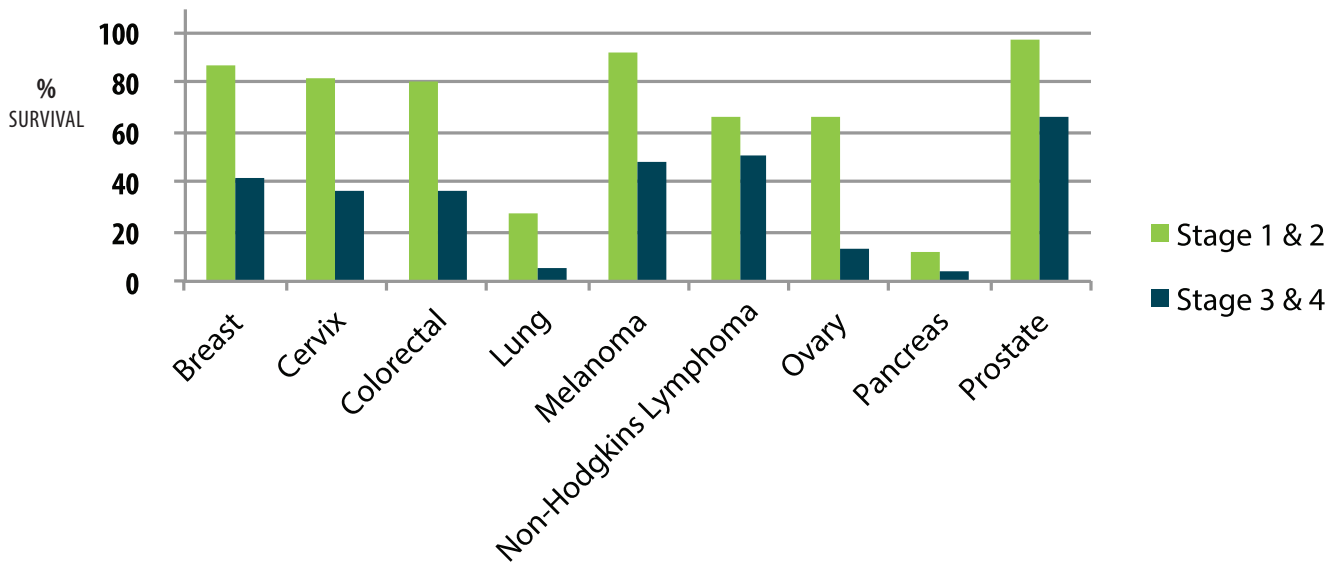
## 7.2. Earlier Diagnosis Improves Survival

Enhancing early diagnosis will alter the landscape of cancer in Ireland by reducing mortality and improving survival and quality of life. Patients who can recognise clinical features suspicious of cancer, and who seek early medical intervention, are generally more likely to have less advanced disease and better prospects for treatment.

When cancers are diagnosed at stages I and II, longer term survival is considerably better than for those patients

diagnosed with stage III and IV disease (Figure 7.2). For example, when malignant melanoma is diagnosed at stage I and II over 90% of patients are alive ten years later, compared with 48% diagnosed at stage III and IV. When lung cancer is diagnosed at stages I or II, two-thirds of patients survive at least a year compared with one-quarter diagnosed with stage III or IV disease. A similar pattern exists for other cancers, as outlined in Figure 7.2 below (KPI no. 4).

Figure 7.2 Net ten year survival rate by stage at diagnosis in Ireland (2008-2012)



### 7.2.1 Deprivation, late diagnosis and poorer outcomes

While the relationship between deprivation and cancer is multi-faceted, certain cancers are more likely to be diagnosed in deprived groups. Much of this inequality relates to higher smoking rates in deprived populations resulting in an increase in incidence of smoking related cancers. In addition it has been demonstrated that people living in geographic areas with higher levels of deprivation are more likely to have higher cancer mortality rates once they are diagnosed. In their efforts to raise awareness and manage cancer service performance, the NCCP need to focus, in particular, on deprived areas, hard to reach groups and minority populations where cancer outcomes are currently poorest.

### 7.3. Making Earlier Diagnosis a Reality

Early diagnosis is influenced by many factors. Public and health professional awareness of the importance of early presentation is critical, and is complemented by efficient GP referral guidelines, clear pathways to specialist care and timely access to diagnostic services.

#### 7.3.1 Improving public awareness – the ‘unusual or persistent’ symptom

Raising public awareness of the ‘unusual or persistent’ symptom, such as unexplained lumps, bleeding, change in body function, skin lesions, pain or weight loss is a critical first step in early diagnosis. Health professionals have an important role in improving public awareness and in encouraging prompt medical attention. However, many patients do not recognise warning signs. Those who do recognise worrisome clinical features may still delay seeking medical help for a wide variety of complex reasons, including normalising of symptoms, misplaced stoicism, fear of a diagnosis and lack of confidence in the health system.

Public awareness campaigns, that highlight key symptoms and give specific patient advice, are successful. This has been demonstrated by the National Awareness and Early Diagnosis Initiative in the UK (NAEDI). Research on the impact of the UK ‘Be Clear on Cancer’ campaign found that there was a 9.1% increase in the number of lung cancers diagnosed during the campaign (700 more cancers than prior to the campaign), as well as a significant increase in the proportion of patients who received surgical resection as a first definitive treatment. This suggests an increase in diagnosis of patients at an earlier stage of the disease. Multi-media campaigns to inform and educate the public are effective in promoting earlier diagnosis of cancer. The results of such campaigns should be measured and reported upon on a regular basis (KPI no. 2).

*I wish I had been  
more aware that  
constant fatigue  
and recurrent  
cough are not  
normal*

RESPONDENT, PUBLIC CONSULTATION

### Recommendation

- 7 The NCCP and the HSE Health & Wellbeing Directorate, in partnership with the voluntary sector, will develop a rolling programme of targeted multi-media based public awareness and education campaigns, aimed at the early detection of specific cancers and with particular focus on at-risk populations.

**Lead: NCCP  
HSE/Voluntary Sector**



### 7.3.2 Expanding the role of primary care and general practice

While GPs treat thousands of patients every year, each GP will, on average, only have eight patients in their practice who are diagnosed with cancer each year. However, symptoms which may suggest cancer such as lumps, bleeding and weight loss are common and require thorough investigation, even if non-cancerous causes are the most common diagnosis. Around 85% of all cancers present with symptoms, and primary care plays a critical role in assessment of these symptoms.

In the UK, the National Institute for Health and Care Excellence (NICE) GP Cancer Referral Guidelines [NG12] highlight the critical role of GPs in early diagnosis. Public health nurses also have an important role to play in this regard. The guidelines recommend that patients should be referred for investigation if they have specific symptoms that evidence suggests have a 3% chance of being cancer. The threshold is lower for children. Ultimately 97% of such patients who are investigated will be reassured that they do not have cancer.

In Ireland there are significant deficiencies in access to diagnostics and specialist opinion in the public health system. There are fewer GPs in deprived areas, GP access to diagnostics in the public system is variable and there are long waits for some specialist services. The resulting protracted patient pathway contributes to late diagnosis. Urgent attention must be paid to resolving these problems, particularly as the requirement for testing, referral and specialist investigations is predicted to increase substantially over the next ten years. This is particularly challenging, given the current shortage of diagnostic specialists and other health and social care professionals such as radiographers and ultrasonographers.

Service developments required to meet this growing need include:

- Better integration between primary care and specialist care;
- An expanded role for GPs in cancer care, with significantly increased direct access to appropriate diagnostic services; and
- Urgent referral criteria, protocols and timelines for direct GP access to cancer diagnostics or specialist opinion.

The role that other health and social care professionals can play in alerting patients to early warning signs of a developing cancer is also vital. For example, dentists have an important role to play in the prevention and early detection of mouth, head and neck cancer. They see many patients on a regular basis for routine dental check-ups, where the oral cavity is fully examined. This form of case finding is important in the early detection of mouth cancer. Co-operation between doctors, nurses, dentists and other health and social care professionals will be promoted to allow for diagnosis at an earlier stage, leading to better outcomes for the patient.

DIAGNOSING CANCER  
**EARLIER**  
 HELPS TO  
**IMPROVE**  
**SURVIVAL**





## 7.4. GP Referral Guidelines and Referral Processes

A **Strategy for Cancer Control in Ireland** (2006) recommended that the HSE should develop specific programmes that promote the early detection of cancer. In response, the NCCP set up the Community Oncology Division and established a partnership between the NCCP and the Irish College of General Practitioners (ICGP). GP e-learning programmes in cancer were developed by the ICGP with the support of NCCP and specialist cancer teams. GP referral guidelines and standardised referral processes were developed for common cancers. Rapid access clinics were set up in designated cancer centres for breast, lung and prostate referrals.

Performance in these Rapid Access Clinics is measured on a monthly basis. Key Performance Indicators (KPIs) have been developed which set out the target time within which patients should be seen in the clinic. The HSE and the Department of Health will continue to work together to ensure that patients who are referred to these Rapid Access Clinics are seen in a timely manner and that these KPIs are adhered to (KPI no. 5).

Further improvements in early diagnosis, including the provision of additional Rapid Access Clinics for other tumour types, more extensive referral guidelines for patients suspected of having cancer and additional educational modules, are required. In the future, guidelines on cancer care developed as part the NCEC's guideline development process should include, as appropriate, recommendations in relation to the establishment of Rapid Access clinics.

*I found a lump  
in my breast,  
went to my GP,  
was referred to  
the symptomatic  
breast disease  
clinic and had  
surgery all in less  
than a month,  
which was great.*

RESPONDENT, PUBLIC CONSULTATION

**PUBLIC AND  
HEALTH PROFESSIONAL  
AWARENESS  
OF WARNING  
SIGNS IS KEY**

## Recommendation

- 8 The NCCP, working with the ICGP and the National Clinical Effectiveness Committee, will develop a three year plan to enhance the care pathways between primary and secondary care for specific cancers. The plan will set out criteria for referral to diagnostics and incorporate the requirements for additional Rapid Access Clinics

Lead: NCCP  
NCEC/ICGP

Electronic referral processes have been implemented in collaboration with the GP IT Group and a broad range of stakeholders. This followed research that identified several barriers in the referral pathway, including delays in patient presentation, unequal access and communication difficulties (KPI no. 3).

## Recommendation

- 9 The HSE will ensure that cancer referrals from a GP into a hospital will be made electronically. Each Hospital Group will facilitate the phasing in of e-referral. This will be completed by the end of 2022.

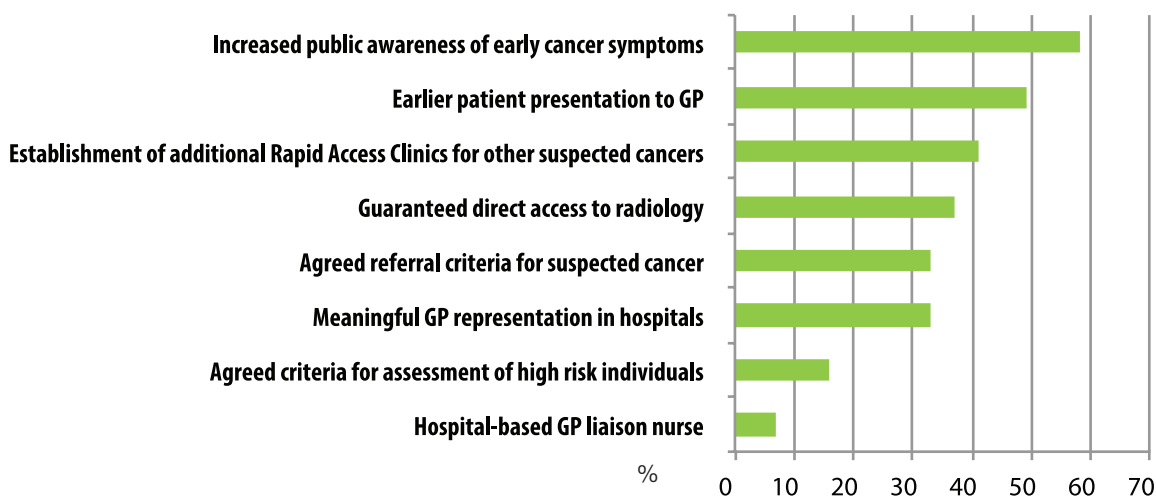
Lead: HSE  
NCCP/GPs

Patients who are diagnosed in Emergency Departments (EDs) are more likely to have later stage cancers and consequently have poorer outcomes. The extent to which these patients interact with primary care is not well understood, although they are more likely to come from a deprived background and they may frequently use the ED as a source of primary healthcare. The achievement of a reduction in the proportion of cancers diagnosed through the ED is one of the key performance indicators that will be measured over the course of this Strategy (KPI no. 7).

### 7.5. Initiatives to Assist in the Early Diagnosis of Cancer

In 2015 the ICGP undertook a survey of its members to document their experience of NCCP developments. Over 500 GPs responded. They identified a number of factors which they believe would help in the early detection of cancer, as outlined in Figure 7.3 below.

Figure 7.3 Factors which would assist in the early detection of cancer in primary care (2015 GP survey)



A coordinated programme of public education and improved GP access to relevant diagnostics will be required to address the barriers which they have identified above. The formation of Hospital Groups, with unified management structures, should enable more efficient use of available diagnostic resources within each Group to facilitate timely GP access under agreed referral guidelines. A Lead Radiologist and a Lead Endoscopist, who will liaise with the NCCP, will be nominated in each Hospital Group to assist in delivering these goals and in auditing the outcomes. This will require coordination between the NCCP, ICGP and Clinical Diagnostic Leads in each Hospital Group (KPI no. 6).

There is also a requirement for increased capital and human resources to meet targets. In this context the small number of radiographers (35-40) graduating from Irish universities each year is a real concern. Such numbers are inadequate for the needs of the health service in general, and the implementation of this Strategy in particular, over the next decade. Timely recognition of the qualifications of trained health and social care professionals who completed their training overseas is also important. Ensuring that highly trained individuals can take up positions in Irish hospitals quickly and easily will help to encourage more people to return to Ireland to provide high-quality health services for patients.

## Recommendations

- 10** The Department of Health will liaise with the Health and Education authorities with a view to increasing places in Third Level Institutions for the training of radiographers and sonographers.

**Lead: DoH**

- 11** The NCCP, working with other Directorates in the HSE, will develop criteria by end-2018 for the referral of patients with suspected cancer, who fall outside of existing Rapid Access Clinics, for diagnostic tests. The NCCP will ensure, through these criteria, that GPs will have direct access to cancer diagnostics within agreed timelines.

**Lead: NCCP/HSE**



# SECTION C

## PROVISION OF OPTIMAL CARE

- 8 Providing an Integrated Model of Care
- 9 Getting the Diagnosis Right
- 10 Getting the Treatment Right
- 11 Safe, High Quality, Patient Centred Care

### OBJECTIVES

- Ensure effective and equitable treatment throughout the care pathway to improve outcomes for all patients
- Further develop treatment facilities and infrastructure
- Maintain a strong focus on patient safety and quality assurance
- Ensure that appropriate palliative care supports are in place



There are **eight** designated **cancer centres** in Ireland

**33,000** patients receive anti-cancer medicines **each year**



**20%** of **all cancers** are **rare cancers**

About **200** **children and adolescents** are diagnosed with cancer **each year**









# PROVIDING AN INTEGRATED MODEL OF CARE

## 8.1. Introduction

A broad objective of this Strategy is to have models of care in place that ensure that patients receive the required care, in a timely fashion, from an expert clinical team in the optimal location. The concept of a continuum of care underpins the approach to patient services, from prevention, early diagnosis, through evidence-based high quality patient-centred treatment, to appropriate follow-up and support. A number of elements can be set out as design attributes of a system that has this continuum approach to the model of care as follows:

- Multidisciplinary care should be the cornerstone of cancer care: patients should have their diagnosis confirmed and their treatment planned in designated cancer centres by multidisciplinary teams of doctors and other professionals appropriate to the cancer type;
- Cancer patients should have access to high quality care staffed by appropriate specialists. While this should be as close to home as possible, centralisation of specialist services into the designated cancer centres is required to optimise outcomes for patients;
- Optimal cancer care should be closely integrated with a cancer research programme, including clinical trials;
- Planning for service delivery should address future demand as well as current needs, and should encompass the full patient pathway;
- Decisions on services should be evidence-based, with clear provision and accountability for the implementation of clinical guidelines and audit;
- Designated cancer centres should be networked to other elements of the health system to ensure that cancer control programmes are comprehensive;
- The integration of services across and within primary, secondary and tertiary care should be a priority;
- Referral pathways should be timely, and promote the early and prompt diagnosis and treatment of cancer;
- Patients and their families should be active partners in their care pathway and patients should have an informed choice on the treatments available;
- Services should be of a high quality and aim to deliver improved outcomes for patients based on the implementation of clinical guidelines; and
- Outcomes should be measured and reported upon regularly.

## 8.2. The Current Model of Care

Cancer treatment is primarily centred on referrals from GPs and smaller hospitals to designated cancer centres for diagnosis and treatment, with some limited referral back to local hospitals and GPs for follow-on care. With the growth in incidence and prevalence, there is a need to further develop patient pathways to ensure that high quality treatment, care and follow-up is provided in a more efficient and effective manner.

The current model of care for cancer treatment is centred on eight designated cancer centres serving a defined population and geographic area<sup>26</sup>. Chemotherapy is currently delivered mainly on a hub and spoke basis under the planning and supervision of the eight designated cancer centres. Radiation oncology is provided in the public system in Dublin, Cork, and Galway. Public access to private facilities is available in Waterford and Limerick, as satellites of the Cork and Galway services. Also, arrangements are now in place for patients from the North West to be referred to Altnagelvin Area Hospital in Derry for radiation therapy.

The current model of care also encompasses the role of GPs in primary care settings referring patients for investigation or diagnosis to local/regional hospitals or to designated cancer centres.

Since its establishment in 2007, the NCCP has worked to ensure that the pathway for cancer patients contains the following elements:

- Promotion of early accurate diagnosis;
- Primary, secondary and tertiary care services working closely together to:
  - ▶ provide more cohesive and better care for patients with cancer;
  - ▶ optimise arrangements for better co-operation and greater efficiency;
  - ▶ share and collaborate actively to achieve goals;
  - ▶ ensure multidisciplinary team engagement; and
  - ▶ effect smooth and timely transition from one service to another; and
- Follow-on support after treatment.

## 8.3. Challenges for the Model of Care

### 8.3.1 Managing the expected growth in cancer cases

The projected growth in incidence and prevalence of cancer will present a challenge for the current model of cancer care. A model of care is required that will be capable of managing the increase in cancer workload – from referral and diagnostics through to treatment and follow-up care – in a manner that provides safe, high quality care in clinically appropriate locations.

### 8.3.2 The need for improved integration in cancer services

There is a need to ensure that patients, including patients with metastatic disease, receive prompt referral, diagnosis and treatment in an integrated manner in order to ensure that outcomes are optimised. Equally, all treatment and post-treatment care should be planned and coordinated to ensure that there is a seamless transfer for patients between different settings. This includes survivorship care, psycho-oncology care, palliative care and end of life care. The need for improved integration across primary care and hospital settings was one of the key points arising from both the Evaluation Group and the public consultation.

26 The eight designated cancer centres are Beaumont Hospital, Cork University Hospital, Mater Misericordiae University Hospital, St. James's Hospital, St. Vincent's University Hospital, University Hospital Waterford, University Hospital Limerick and University Hospital Galway (Letterkenny University Hospital acts as a satellite of UHG for breast cancer services).

Improved integration requires patient pathways based on the different stages of cancer diagnosis, treatment and follow-up care, and taking into account specific cancer types. Based on the needs arising at each stage of the patient pathway, services can be aligned with appropriate local, regional and national locations. The concept of a networked approach to cancer care is important to ensure that each element of the patient pathway operates in an integrated manner. Designated cancer centres should be networked to other elements of the health system to ensure that cancer control programmes are comprehensive. An integrated network approach, including the continued development of the nursing input, also facilitates the provision of services as close to patients' homes as is appropriate.

## Recommendation

**12** The NCCP will further develop the model of care for cancer to achieve integration between primary care and hospital settings at all stages of the cancer continuum, from diagnosis to post treatment care.

Lead: NCCP

### 8.3.3 Increasing the level of specialisation in cancer care

Evidence of the positive relationship between higher case volume and better outcomes for patients has been demonstrated for many cancers and the Evaluation Group pointed to a need for further centralisation of cancer care.

Cancer care is becoming increasingly complex with the improved understanding of the genetic basis of some cancers and the development of more targeted treatments. This is driving increased specialisation, with requirements for greater levels of clinical and scientific expertise.

The required focus on rare cancers will also increase the need for specialisation, given the relatively small number of cases, the complexity of treatments and the need for nominated clinicians to link with rare cancer networks overseas.

### 8.3.4 The role of patients in improving the model of care

The experience of patients can inform improvements in the model of care. Mechanisms will be developed to facilitate patient involvement in the design and review of services, including through the establishment of a Cancer Patient Advisory Committee. With the establishment of hospital groups, the potential exists for the better utilisation of hospital resources to provide services at clinically appropriate locations, governed by agreed patient protocols and pathways.

### 8.3.5 Towards an improved model of care

Designated cancer centres will play a key role in providing accurate diagnoses and in directing treatment pathways, as well as in the provision of tertiary cancer services. The establishment of these centres was a key outcome from the **Strategy for Cancer Control in Ireland (2006)** and the performance of the centres will continue to be monitored by the NCCP with a view to maximising throughput and outcomes.

The model of care being developed should also facilitate the use of local or regional hospitals for routine or less complex diagnostics, as well as for the provision of systemic therapy services (medical oncology and haematology) where clinically appropriate. However, where the diagnosis indicates a requirement for more specialised treatment, typically with multi-disciplinary input, the pathway will be directly to the designated cancer centres.

The term quaternary care is sometimes used to describe services that are particularly specialised or carried out in only a very small number of locations. This model is currently applied where services for rare cancers are concentrated in a small number of designated cancer centres. The trend towards centralisation in a smaller number of designated cancer centres will continue for rare cancers and for common cancers where case volume, multidisciplinary working or infrastructural requirements are important determinants for patient outcomes.



*I couldn't fault the services; the clinical care is excellent. The flaws lie mainly in availability. There is not enough staff, and appointments for physiotherapy etc. are hard to get*

RESPONDENT, PUBLIC CONSULTATION

**Multidisciplinary** team working is internationally recognised as **best practice**.

## 8.4. Requirements to Improve the Model of Cancer Care

### 8.4.1 Develop the multidisciplinary care model in designated cancer centres

#### A Strategy for Cancer Control in Ireland (2006)

recommended that patients should have their diagnosis established and their treatment planned by Multidisciplinary Teams (MDTs). MDT working is an essential cornerstone of cancer care internationally. Key personnel from the various disciplines meet on a regular basis in a structured fashion to review and discuss newly diagnosed patients to plan their management and care. The care of individual patients is also discussed at other critical points in their care pathway, e.g. post-surgery or at relapse.

Significant progress has been made in establishing such teams in the cancer centres. MDT working has led to improved decision-making, more co-ordinated patient care and improvements in the overall quality of care. The treatment of patients whose cases are discussed at MDT meetings is more likely to be in accordance with clinical guidelines, and there is strong consensus that outcomes are likely to be better (KPI no. 12).

However, there is variation in the functioning of MDTs, with some more structured and better supported than others. To achieve equitable patient benefit from the process, the NCCP should review current MDT working to ensure that appropriate composition, resourcing, structures and procedures are in place, as well as reporting mechanisms to collect and analyse outcomes. In the future, guidelines on cancer care developed by the NCCP and endorsed through the NCEC's guideline development process should include, where appropriate, recommendations on the establishment and composition of MDTs.

## Recommendations

**13** Patients diagnosed with cancer will have their case formally discussed at a multi-disciplinary team meeting. The NCCP, working with the Hospital Groups, will oversee and support MDT composition, processes and reporting of outcomes.

Lead: NCCP

**14** The NCCP, working with other Directorates in the HSE and with the Department of Health, will develop a rolling capital investment plan, to be reviewed annually, with the aim of ensuring that cancer facilities meet requirements.

Lead: NCCP

### 8.4.2 Providing the capital infrastructure to support the model of care

While cancer care is provided in a variety of locations, the majority of patients receive their care in the designated cancer centres. Many of our cancer centres have significant deficits in capacity and infrastructure. For example, not all cancer centres have facilities for the 24/7 emergency evaluation of patients with cancer who are receiving treatment (KPI nos. 13 and 14), and many in-patient and day treatment facilities are at capacity. The Evaluation Group noted the need for upgrades in day-care centres, to improve patient experience, expand capacity and improve pharmacy facilities. Along with the need for investment in personnel and services that will be required to implement this Strategy, a rolling plan of capital investment will be required to ensure that high quality facilities are available for patients and staff, that the potential for on-going improvements in outcomes is maximised and that our health personnel can progress in line with developments in cancer worldwide. Such an investment plan would cover capital intensive infrastructure such as new radiation oncology facilities and on-going replacement of linear accelerators, as well as the necessary improvements to diagnostic equipment in local/regional hospitals and in designated cancer centres. The capital investment plan will also include the optimal provision of ambulatory and day care facilities, including medical oncology units at hospitals closer to patients' homes.

### 8.4.3 Develop Comprehensive cancer centres

There is a case for the establishment of a limited number of comprehensive cancer centres to more fully integrate high quality cancer care, combined with research and education. Such services would most likely be located on the site of existing designated cancer centres. Decisions on the establishment of at least one comprehensive cancer centre during the Strategy period will be made by the Department of Health, in consultation with the NCCP, and in the light of available resources and developments in the best performing centres worldwide.

The most effective cancer centres worldwide have been developed to integrate high quality clinical cancer care with teaching, as well as with basic, translational and clinical research focused on cancer. Comprehensive Cancer Centres provide a structural focus to facilitate leaders in cancer medicine and research, cancer doctors, nurses and health and social care professionals across all disciplines to work

together with the common goal of improving outcomes for patients. Cancer centres are usually located within, or adjacent to, major tertiary academic hospitals with strong University links and are frequently a local, regional and national resource for the development and promotion of cancer education and prevention. While the size, complexity and design of these centres vary, they share some key features:

- A focus on cancer clinical care, education and scientific endeavour;
- Breadth and depth of experienced high quality staff across all disciplines;
- High volume multidisciplinary cancer services in diagnostics, surgery, radiation oncology, medical oncology and haematology;
- Dedicated resources within a designated building usually linked with an associated University Hospital;
- Dedicated modern clinical facilities, including outpatient, day care, inpatient and associated interdisciplinary shared resources;
- Clinical and other research facilities, with programmatic support for clinical cancer research;
- Integration with scientific institutions to perform translational and basic cancer research, and to develop clinical and public health intervention strategies from basic and other scientific discoveries; and
- Recognition of the Comprehensive Cancer Centre as a formal organisational structure.

Internationally the integration of cancer services within a functioning Comprehensive Cancer Centre is the most successful model of care delivery. It must be our goal to ultimately have one or more such centres in Ireland. Eight hospitals have already been designated cancer centres. While this represents a major step forward, in many cases they are made up of a range of services, that themselves have a wider scope than cancer alone, located in different parts of a hospital. They are not comprehensive cancer centres when compared to some of the most advanced centres in countries such as the USA and Canada, where many of our cancer specialists worked and trained.

Transforming some of our facilities into functioning cancer centres with research commitment, scientific collaboration and breadth of facilities would consolidate current achievements and facilitate improved cancer services and outcomes. The planning and implementation of infrastructural and programmatic initiatives by the NCCP should ideally lead to at least one of our cancer centres meeting the criteria for Comprehensive Cancer Centres by the end of the Strategy period.

## Recommendation

- 15** The Department of Health will ensure that investment in infrastructure, facilities, personnel and programmes in the designated cancer centres will have a goal of ultimately developing at least one comprehensive cancer care centre that will optimise cancer prevention, treatment, education and research during the Strategy period.

Lead: DoH



# GETTING THE DIAGNOSIS RIGHT

## 9.1. Introduction

As outlined in Chapter 7 on Early Diagnosis, diagnosing cancer at the earliest possible stage is a critical first step in improving survival rates. Cancer diagnosis is a complex process and it is essential that the systems, structures and clinicians are in place to deliver the required services. It is important that specialists in radiology, endoscopy and pathology are involved in multidisciplinary team meetings, so that confirmation of diagnosis can be made. The aim of this strategy is to strengthen the various processes for cancer diagnosis so that it continues to play a key element of the multi-disciplinary model of care.

Quality assurance (QA) plays an important role in improving practice and the quality of care. National Quality Assurance Programmes are now in place for radiology, endoscopy and histopathology. These QA programmes aim to ensure patient safety and accurate diagnosis through the provision of timely, complete reports on the results of diagnostic tests.

## 9.2. Radiology

Along with surgical pathology, accurate, timely and high-quality diagnostic radiology services are a critical requirement for effective multidisciplinary management of cancer patients. Radiology services are capital intensive and there are substantial deficiencies in access to such services. This is affecting access to diagnostics for patients suspected of having cancer, as well as timely staging and evaluation of patients with documented disease.

Imaging capacity, particularly for MRI, CT and PET scanning, will need to be increased in all cancer centres. This will require additional equipment and staff. Ideally, cancer imaging should be mainly done in an outpatient setting, separate from inpatient and emergency services. Dedicated imaging centres should be included in future cancer centre design.

The current equipment base in our cancer centres needs to be expanded and modernised, and the on-going capital provision for replacement and new investment significantly enhanced. Planning and management of capital provision needs to be improved, and there may be scope for the exploration by the HSE of other models of equipment provision, such as managed equipment and services contracts.

Reference has already been made to the critical shortage of radiographers in Ireland even before any expansion to increase capacity. Too few are trained and it can be difficult to retain staff in the public workforce. Accordingly, the number of radiography training places at undergraduate and post graduate level needs to be increased.

As should be the case with other disciplines (e.g. pathology, haematology and medical oncology), proper sub-speciality radiology services must be provided in the cancer centres. Cancer services should be planned around having integral radiology services on site relevant to the area of expertise of the centre. In particular, cancer centres have an absolute requirement for dedicated interventional radiology services to assist in therapy. This will require capital and staff provision. With expansion of existing services, or the development of new services, radiology appointments to facilitate such improvements must be made conjointly with other appointments, such as those of surgeons and medical oncologists.

The NCCP must set, resource and enforce simple KPIs for all aspects of cancer imaging. All cancer centres must be connected to the National Integrated Medical Imaging System (NIMIS) as a matter of priority.

### 9.3. Endoscopy

A high quality national endoscopy service is essential for the timely diagnosis and management of the vast majority of gastrointestinal (GI) malignancies. GI endoscopy also has a significant role in facilitating therapy and in managing complications of many non-GI cancers. Most importantly, through appropriate surveillance and screening programmes, endoscopy has the potential to facilitate both prevention and early identification of cancers that could have fatal prognoses.

Diagnostic endoscopy, provided for the most part by gastroenterologists and GI surgeons, comprises the majority of the national endoscopy workload. Projected increases in endoscopy demands will give rise to a requirement for increased staff resources at physician, surgeon and nursing levels, with an associated need for the expansion of current training programmes.

At an institutional level, major determinants of ability to deliver high quality endoscopy services include infrastructure and access to quality equipment. Significant capital expenditure is necessary to bring endoscopy services in several cancer centres up to minimum international standards. Furthermore, a rolling programme of equipment replacement is required to maintain modern, safe endoscopy stock and to allow the decommissioning of obsolete equipment.

The national colorectal cancer screening service, BowelScreen, has demonstrated a clear benefit for the 60 to 69 year old cohort involved. However, difficulties are arising in meeting the demand for colonoscopies that arise from it. Such colonoscopies are considered to be urgent

and should be done within the current KPI period of 20 working days. Significant investment and comprehensive planning will be required to achieve the recommendation on the extension of BowelScreen to all aged 55 to 74.

Therapeutic endoscopy is a relatively new subspecialty. While some aspects of this have been practiced for many years in Ireland, other procedures are recent additions, or have yet to be established here. All are important in diagnosing and treating GI cancer according to the highest international standards. Such services require high levels of training, as well as ready access to ancillary services such as general anaesthesia.

### 9.4. Histopathology

Histopathology plays a key role in the multidisciplinary approach to cancer care, underpinning diagnosis and guiding treatment. It is crucial, therefore, that histopathology services at designated cancer centres are adequately resourced, both in terms of staffing and equipment.

Best practice dictates that these services are delivered by a minimum of two consultant histopathologists subspecialised in each of the subspecialty areas catered for at the cancer centre. Particular attention should be paid to ensuring that appropriate subspecialty expertise is available in areas such as haematopathology and skin pathology. Only about 80% of the required number of histopathologists are currently in post in Ireland, and some cancer centres have had difficulty in filling key posts.

As new services are developed, and existing ones expand, consultant appointments in histopathology must be made contemporaneously with those of oncological surgeons and physicians. Supportive laboratory and ancillary staff required to run new and expanding services must also be appointed in this way.

Consultant pathologists are overqualified for some of the tasks that they currently perform and this work could be safely delegated to appropriately up-skilled biomedical scientists. This would free up pathologist time for more highly skilled tasks. Developing extended roles for biomedical scientists in areas such as macroscopic dissection should be promoted to ensure optimal use of highly trained personnel.

Diagnostic laboratory equipment must be budgeted for replacement and upgrading in a rolling programme to facilitate modern practice and to meet the demands of increasingly sophisticated oncological practice. A national laboratory information management system (MedLIS) is now being developed. In some centres the current information systems are over 20 years old and are near obsolete. Priority should be given to rolling out the MedLIS programme as soon as possible.

cancer. The term molecular cancer diagnostics essentially refers to any such test which evaluates the status of tumour cells. The recent rapid expansion in knowledge of the human genome has led to the need for nucleic acid based testing in a wide variety of clinical situations including cancer. Such molecular testing in oncology has the potential to fulfil many roles, including risk assessment, disease diagnosis, classification and prognosis, prediction and monitoring of response to therapy, toxicity prediction and dose determination. Such tests already have routine daily application in a variety of common malignancies, including breast, colon, lung, melanoma, haematological malignancies and paediatric cancers. In a rapidly advancing field, scores of novel therapeutics are being developed for a variety of cancers with defined molecular targets. These molecular targets will need to be assessed to ensure therapeutic effectiveness for the patient and cost effectiveness for the health system.

## Recommendation

**16** The NCCP will ensure that consultant appointments for radiology, endoscopy and histopathology, where necessary, are made in conjunction with appointments in other disciplines such as surgery and medical oncology.

Lead: NCCP

## 9.5. Molecular Cancer Diagnostics

An accurate pathologic diagnosis is at the core of multidisciplinary management of any patient diagnosed with cancer. Over the past two decades a scientific revolution has taken place in understanding the molecular basis for cancer and the genetic alterations that underlie the development, growth, spread and persistence of

### 9.5.1 Molecular diagnostics: current situation

Molecular cancer diagnostic services for solid tumours in Ireland are poorly organised and fragmented. Solid tumour molecular testing throughout the country has evolved in a reactive, ad-hoc manner with various molecular tests being performed by a variety of methodologies in different laboratories. At present the NCCP partially funds testing at two hospitals operating under a collaborative Memorandum of Understanding for solid tumour (oncology) diagnostics. Limited testing takes place at other sites and some hospitals use external commercial service providers. While statistics are not available, it is unlikely that we are meeting patient needs in this area.

There is a lack of strategic direction in regard to molecular cancer diagnostics in solid tumours in Ireland. A mechanism is required to determine how well current tests are being done, how effective the service is for patients and clinicians, where the tests should be done, how they should be paid for, when they should be replaced and when new tests

should be considered. The goal of this Strategy must be to ensure that all patients who need a particular molecular test will have that test performed at the appropriate time and on the appropriate tissue.

### 9.5.2 Main challenges

It is essential to establish a national implementation framework, informed by experience internationally, such that molecular testing is carried out in a co-ordinated and standardised way within accredited laboratories, working through a networked programme. There is no justification for multiple laboratories reporting small numbers of cases each year. Overview at a national level, and networking in terms of service delivery, is needed to ensure the delivery of established tests, the on-going assessment of new tests, the commissioning of such tests, the validation of all new tests and the on-going assessment of the validity of current test repertoires so that those no longer clinically relevant are discontinued in a uniform and co-ordinated way.

This approach will facilitate the commencement of target validation for new drugs ahead of time to ensure that Irish patients with cancer can be offered novel therapeutics, if appropriate, as soon as approval is given and acceptable pricing levels have been agreed.

It is important to note that, not only is this a rapidly evolving field in terms of test type, but it is also a rapidly evolving field in terms of technology and test methodologies. The move towards massively parallel sequencing (next generation sequencing - NGS) provides a good example of a testing platform that not only has high throughput capacity but that will potentially produce an extensive range of genetic information. A clear strategy for dealing with patient information obtained from genetic testing will need to be developed.

A further major challenge is to ensure that the education and training of all those involved in this area keep pace with the scientific and technical developments. Engagement with the relevant stakeholders, particularly the Faculty of Pathology of the Royal College of Physicians

of Ireland, will be required to ensure the appropriate incorporation of molecular diagnostics into the curriculum for trainee pathologists and trainee laboratory medical scientists.

In order to address the challenges in this area, the NCCP will appoint a National Lead for Cancer Molecular Diagnostics. The Lead will chair a Steering Group to oversee the organisation, location and delivery of cancer molecular diagnostic services in Ireland. This Group will include representatives from pathology, haematology, genetics, laboratory science and oncology.

## Recommendations

**17** The NCCP will appoint a National Lead for Cancer Molecular Diagnostics for solid and liquid malignancies.

**Lead:** NCCP

**18** The NCCP will establish a Steering Group for Cancer Molecular Diagnostics, chaired by the National Lead. This Steering Group will set out the framework for the organisation, location and delivery of cancer molecular diagnostic services.

**Lead:** NCCP

## 9.6. Genetics in Cancer Care

Genetics is the study of how particular diseases or features are inherited through genes passed down from one generation to the next. The incorporation of genetics into mainstream cancer care began in the early 1990s with the discovery of the BRCA1 and BRCA2 genes. However, it is now clear that in most cases it is not a mutation in a single gene that determines whether cancer develops but more likely a combination of multiple mutations in different genes that work together to allow the aberrant proliferation of cells. Genomics allows for the examination of mutations in cancer cells on a genome-wide basis and can provide insights into interactions between genes which can result in cancer.

Much technological progress has been made in this field and it will continue to advance rapidly. These innovations will improve people's health by making treatment more precise, and it will increasingly transition healthcare towards risk assessment, surveillance and prevention. Internationally, oncology is leading the translation of genetics into healthcare and, over the lifespan of this Strategy, we face the challenge of progressing cancer genetics to maintain top quality oncology services by international standards. This will involve significant investment. At the same time, the pace of innovation provides an opportunity for Ireland to rapidly move towards the current international standard of cancer genetics, and even to become a leading example of how to incorporate genetics into healthcare. This Strategy aims to create a national framework for the delivery of genetics-based cancer care that can be adopted by other medical specialities.

In recent years the core business of genetics in cancer care has changed from being focused on prevention. Genome-wide association studies can identify mutations and can allow for a more thorough understanding of the cancer and more precise and effective diagnosis and treatment. Treatment decision-making based on timely genetic test results in a minority of patients with an inherited predisposition is rapidly becoming an international standard

of care. Genetic test results guide surgical decisions and direct choice of medication. Targeting medication according to genetic test results (pharmacogenetics) is at the forefront of precision medicine.

### 9.6.1 Cancer genetics in Ireland

At present cancer genetics services in Ireland are underdeveloped and underfunded. The NCCP established a Hereditary Cancer Programme in 2012, in response to advances in diagnostics and increasing demand for services. This programme operates in collaboration with the Department of Clinical Genetics at Our Lady's Children's Hospital Crumlin (OLCHC) and aims to improve access to assessment and genetic testing for those patients and their families whose cancer may have a genetic component. The NCCP recently appointed a National Clinical Lead for Cancer Genetics (St James's Hospital) who is charged with developing the national cancer genetics service.

A genetics service is currently offered in OLCHC, St James's Hospital and the Mater Misericordiae University Hospital, though none of these are in a position to provide comprehensive national quaternary care. Approximately 1,800 new patients avail of the cancer genetics service each year. Increased patient and doctor awareness has resulted in an exponential growth in cancer genetics referrals in recent years. The majority of these referrals are healthy individuals concerned about their genetic predisposition to cancer. Waiting lists in the three hospitals are extensive, and patients often have prolonged waits for their results. Thus, results with therapeutic relevance for patients undergoing treatment are delayed and healthy individuals are not being informed of their inherited cancer risk in a timely way.

It is likely that many new patients diagnosed with breast, colorectal, ovarian and endometrial cancers will soon benefit from genetic testing. Other patients, such as those with prostate, thyroid, gastrointestinal stromal tumours and pheochromocytomas will also require testing in the future. Clinical cancer genetics in Ireland requires a strategic approach that will include increased infrastructural and financial support.



As science continues to advance, it is important to ensure that the introduction of new tests and phasing out of others is informed by specific guidelines, and that this will be audited. Audits will ensure that equitable access is available irrespective of patients' age, geographic location and socioeconomic status.

## Recommendation

- 19** The NCCP will further develop the Programme for Hereditary Cancers to ensure that evaluation, counselling, testing and risk reduction interventions are available as appropriate, and that services are available to patients on the basis of need.

Lead: NCCP

### 9.6.2 Development of the Irish cancer genetics service over the next ten years

#### Amalgamation of services

The new children's hospital offers an opportunity to merge the existing cancer genetics services into one National Cancer Genetics Service. This would facilitate the development of a national quaternary referral clinical service for children and adults, operating closely with a national molecular laboratory and delivering translational bench to bedside care.

## Recommendation

- 20** The HSE will ensure that the existing cancer genetics services are amalgamated into one National Cancer Genetics Service and will identify the most appropriate site for its location.

Lead: HSE

#### New consultant, nursing/genetic counselling appointments

Oncology care in all designated cancer centres will require input from the Clinical Cancer Genetics Service. Oncologists with subspecialty genetics training, and/or geneticists with a subspecialty interest in cancer genetics, will be required to lead this service. Individuals with such training are in short supply and a directed effort to train Irish oncology graduates in genetics will be required. To meet present demand, additional full-time consultant appointments will be required in the National Cancer Genetics Service to facilitate the delivery of a high quality service, using a hub and spoke model involving the active participation of surgeons and/or physicians in individual cancer centres to generate a deeper engagement with cancer genetics at a local level.

Regular multidisciplinary clinics should be established for less common cancer predisposition syndromes to ensure appropriate care for patients with these disorders, as well as to facilitate Ireland's participation in international efforts to develop a unified approach for such cases.

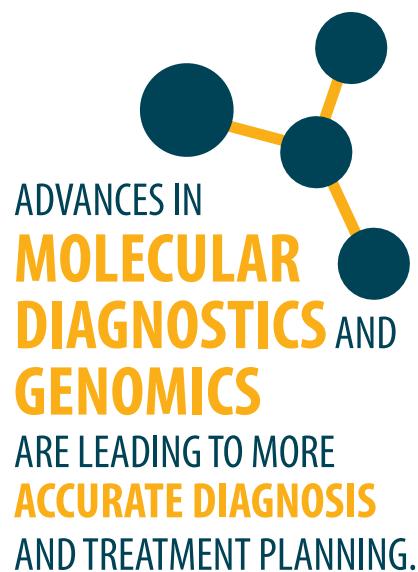
We have an opportunity now to develop an integrated cancer genetics service, which will provide an infrastructure for a time when genetics-based clinical care is commonplace, by appointing at least one cancer genetics nurse specialist/counsellor in each designated cancer centre. National management protocols for common predisposition syndromes will enable decentralisation of care for common genetic disorders, and facilitate nurse/counsellor-led clinics in cancer centres nationally, backed up by appropriate consultant-led clinical governance.

### 9.6.3 Genetics in general practice

Direct to consumer genetic testing is now a reality. Well individuals are coming to their GPs with genetic test results that predict their future risk of disease. These people, and others who have not had genetic testing but are worried about their family history, are being referred to the Cancer Genetics Service. The evolution of cancer genetics in Ireland should include an assessment service for GP referrals.

### 9.6.4 Infrastructure

Other issues include the need for a coordinated national recording of genetic test results and an associated method of communication. This could be incorporated into a National Electronic Health Record utilising the new Individual Health Identifier. Telemedicine services between hospitals will facilitate the delivery of genetics counselling. There is also a need for a comprehensive biobanking<sup>27</sup> programme.



<sup>27</sup> A cancer biobank stores blood and other human tissue samples donated by patients for research into cancer. It also requires the informatics capabilities to store and analyse vast quantities of data



# GETTING THE TREATMENT RIGHT

## 10.1. Introduction

Three major treatment modalities are used to treat solid tumours. These are surgery, radiation oncology and medical oncology. As discussed in Chapter 8, the development of a fully integrated model of care requires cooperation and communication between many different facets of the health service. This is particularly important for cancer treatment. Some patients can require surgery, chemotherapy and radiation therapy. It is important that these disciplines share information and work in a coordinated way to ensure optimum outcomes for the patient. It is an aim of each cancer centre to have designated beds to meet the needs of patients with cancer.

Certain patient cohorts, such as those with rare cancers, older patients and children and adolescents/young adults with cancer, require a specific focus to be placed on their care. This can involve centralisation of services, specialist training for healthcare professionals and the development of protocols to ensure the efficient, timely transfer of care between settings.



## 10.2. Surgical Oncology

Surgery plays a pivotal role in the management of non-haematological cancer and is curative as the sole treatment in a high percentage of cases. As one of the major pillars of cancer care and control, it can be preventive, diagnostic, curative, supportive, palliative and/or reconstructive. While the primary benefit of successful surgery is improved survival and quality of life, it also leads to reduced costs of on-going treatment in many cases.

Arising from **A Strategy for Cancer Control in Ireland (2006)**, an implementation group was established that recommended:

- the designation of eight cancer centres (with one satellite centre of University Hospital Galway in Letterkenny University Hospital for breast cancer); and
- the centralisation of initial diagnosis, treatment planning and primary surgery for many cancers.

While there has been considerable progress in implementing these recommendations, the work is not complete. The rationale for the reorganisation of services was based on clear evidence that patients who are operated on by surgeons who carry out higher volumes of surgery in specialist centres, that themselves have high volumes, achieve better outcomes. The centralisation of services, and the establishment of the NCCP as part of an overall programmatic approach to cancer control, is in line with international best practice and has led to significant improvements in the treatment of patients. Designation of hospitals for cancer surgery on a site specific basis is centred on patient needs and the volume of surgery involved per hospital, taking best international evidence into consideration and subject to review as new evidence becomes available.

Advances in surgical techniques and centralisation of complex surgery have led to improvements in the quality of cancer treatment. More operations are being carried out by specialist surgeons with particular expertise, resulting in less invasive procedures, shorter recovery times and better outcomes for patients. There is broad consensus that surgical services should be configured in a way that results in patients receiving the highest standard of multidisciplinary care.

Progress has been made towards the centralisation of cancer surgery in line with proposals drawn up in 2007 - e.g. all breast cancer surgery now takes place in the eight designated cancer centres (with LUH acting as a satellite of UHG). However, significant centralisation remains to be attained. The following will be achieved:

- All cancer surgery will be carried out in a designated cancer centre<sup>28</sup>. This will be achieved during the period of this Strategy (KPI no. 11);
- The centralisation of surgical services for various cancer sites will be broadly in line with the 2007 proposals, revised in the light of the review of current evidence and new treatment modalities; and

- Surgery for the majority of tumour types will be delivered in a maximum of four designated centres.

The NCCP will draw up a plan for the prompt completion of the centralisation programme, to be agreed with the Department of Health. Meanwhile, the NCCP will continue to work with the Hospital Groups to ensure that all cancer patients receive their surgery in an appropriate setting.

## Recommendation

**21** The NCCP will draw up a plan setting out the number/location of designated cancer centres in which surgery will take place for the various tumour types. Timescales for the implementation of the plan will be included for each tumour type.

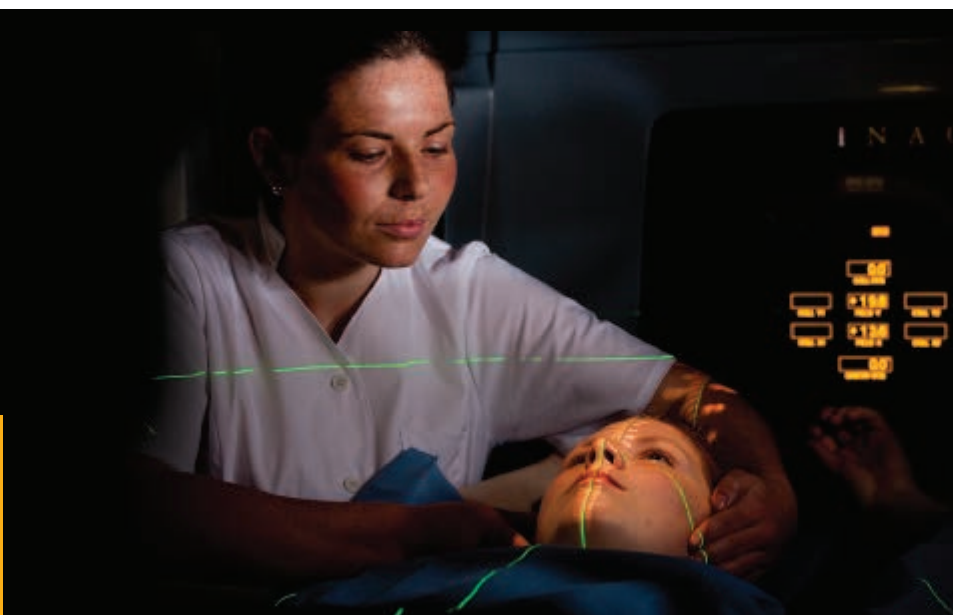
**Lead: NCCP**

This further centralisation of cancer surgery will require leadership from the NCCP, collaboration with Hospital Groups, flexibility from clinicians and, in some cases, further investment in personnel and infrastructure.

Further innovations in surgery, such as laparoscopic and robotic surgical techniques, will be monitored in the coming years with a view to introducing innovative approaches as appropriate, following the outcome of health technology assessments. Such technologies require particular expertise and would involve substantial investment.

<sup>28</sup> With the addition of LUH for breast surgery.





**60%** of  
all patients with  
cancer will require  
radiation therapy

### 10.3. Radiation Oncology

Radiation oncology (or radiotherapy) is a primary curative modality in a number of cancers (prostate, cervix, head and neck and early lung) and increases cancer survival as an adjunctive therapy in others (e.g. breast cancer). Radiation oncology is also a highly effective palliative treatment. Modern radiation oncology is more accurate in the delivery of radiation dose, thus sparing more normal tissue, reducing side effects and leading to improvements in patient outcome. It is delivered through external beam teletherapy (90% of treatments) or through brachytherapy.

Currently, radiation oncology treatment is available in five public hospitals in Ireland: St. James's Hospital, Beaumont Hospital and St. Luke's Hospital (which three together form the St. Luke's Radiation Oncology Network - SLRON), Cork University Hospital and University Hospital Galway. Public sector radiation oncology services are provided in two private facilities in Waterford and Limerick. Radiation oncology services are available to patients from the Republic of Ireland at the North West Cancer Centre in Altnagelvin Area Hospital, Derry.

The following issues arise in relation to radiation oncology services:

- Demand for radiation oncology is expected to increase in line with increases in cancer incidence;
- The NCCP expects that up to 60% of patients will require radiation oncology for primary treatment and palliative care;
- Additional radiation oncology facilities are required in Dublin, Cork and Galway to meet increasing service need, as well as the planned replacement of current equipment; and
- A lead-in time of up to four years is required to plan, build and commission new radiation oncology facilities

The **National Plan for Radiation Oncology** (NPRO) envisions the further development of radiation oncology facilities in Dublin, Cork and Galway. It is critical that the NPRO be progressed to ensure that the required facilities for radiation oncology are available over the period of this Strategy. For the greater Dublin region, new linear accelerators (linacs) are being installed in St. Luke's Hospital, pending the provision of additional capacity for the region

## Recommendation

# 22

In line with the National Plan for Radiation Oncology, public sector radiation oncology facilities in Dublin, Cork and Galway will be expanded to meet patient demand and a planned National Programme of Equipment Refreshment and Replacement will be implemented across the Strategy period.

Lead: NCCP

in Beaumont Hospital. Additional facilities at St. James's Hospital are also required. New facilities with increased capacity in Cork and Galway are planned and will be required during the first half of the Strategy period.

Matched to this infrastructural development, the NCCP will continue to manage the recruitment of appropriate levels of specialised staff for this treatment modality. In addition to ensuring the provision of adequate capacity in the public network, a health technology function to assess new treatment options as they become available will be developed.

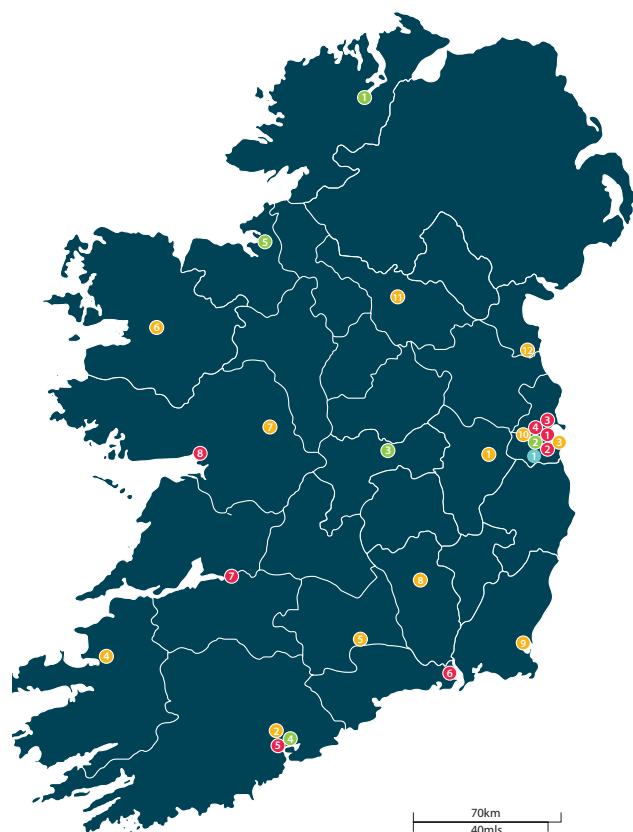
In addition to the provision of adequate radiotherapy facilities to meet demand, it is also important that patients who require radiation therapy are provided with adequate multi-disciplinary care pre- and post-treatment (e.g. pre-radiation dental assessment and treatment).



## 10.4. Medical Oncology

Medical oncology involves the treatment of cancer with medicine, chemotherapy in particular, and is now commonly referred to as Systemic Anti-Cancer Therapy (SACT). The use of SACT has increased markedly over the last ten years, with a variety of new and effective therapeutics becoming available that has led to improved cure rates and long-term remission rates, better quality of life and longer survival. Chemotherapy and other systemic therapies are estimated to contribute to around one in ten cancer cures in their own right. They also play a crucial role in combination with other treatment modalities such as surgery or radiotherapy. Systemic therapy services are currently provided at 26 public hospitals (Figure 10.1).

Figure 10.1 Publicly-funded hospitals currently providing SACT



#### Designated Cancer Centres

- 1 Mater Misericordiae University Hospital
- 2 St. Vincent's University Hospital
- 3 Beaumont Hospital
- 4 St. James's Hospital
- 5 Cork University Hospital
- 6 Waterford University Hospital
- 7 University Hospital Limerick
- 8 University Hospital Galway

#### Centres with Medical Oncology/Haematology Consultants

- 1 Letterkenny University Hospital
- 2 Adelaide and Meath Hospital, Tallaght
- 3 Midlands Regional Hospital, Tullamore
- 4 Mercy University Hospital, Cork
- 5 Sligo University Hospital

#### Centres with visiting or part time Medical Oncologist/Haematology Consultants

- 1 Naas General Hospital
- 2 South Infirmary/Victoria University Hospital
- 3 St. Luke's Hospital, Dublin
- 4 University Hospital Kerry
- 5 South Tipperary General, Clonmel
- 6 Mayo University Hospital
- 7 Portiuncula Hospital, Ballinasloe
- 8 St. Luke's Hospital, Kilkenny
- 9 Wexford General Hospital
- 10 Connolly Hospital, Blanchardstown
- 11 Cavan General Hospital
- 12 Our Lady of Lourdes Hospital, Drogheda

#### Paediatric hospital

- 1 Our Lady's Children's Hospital Crumlin

Approximately 33,000 people receive treatment with cancer drugs each year. This involves oral anti-cancer medicines largely taken at home and parenteral<sup>29</sup> drugs administered in hospital, with all patients assessed, supported and followed through their treatment in specialised oncology or haematology day units. The NCR has predicted that the number of new patients receiving chemotherapy will increase by between 42% and 48% in the period 2010 to 2025. The last ten years have already witnessed a huge increase in the complexity and volume of chemotherapy administered. The growth in both the incidence of cancer, and the prevalence of patients on active treatment with new drugs, is giving rise to a significant increase in the volume and complexity of medical oncology work.

Given the current low number of medical oncologists in Ireland against international standards, as identified in the Evaluation Report on **A Strategy for Cancer Control in Ireland (2006)**, as well as the increasing patient numbers and the increasing complexity of these therapies requiring a higher level of site specialisation among oncologists, a significant increase in the number of consultant medical oncologists, specialist nurses and hospital pharmacists will be required. The NCCP will address this shortfall on an incremental basis, with the aim of meeting international standards over the next five years. The number of health and social care professionals supporting patients under SACT care needs to be expanded.

SACT services operate on a hub and spoke model, with

29 Parenteral chemotherapy is chemotherapy administered as an injection or infusion.

oncologists and haematologists based in designated cancer centres travelling to provide agreed services to satellite centres. In many cases, patients have their treatment planning done initially in the cancer centre hub hospital and may have at least some of their treatment closer to home. More complex chemotherapy and associated services are provided at designated cancer centres. Access to in-patient beds is required where complex haemato-oncology services are provided. The NCCP has established national programmes for medical oncology and haemato-oncology. They have also established a multidisciplinary group to develop a model of care for systemic cancer treatment. The aim is to produce a comprehensive model of care that will form a roadmap for the planning of SACT services for the ten year strategy period.

Oral Anti-cancer Medicines (OAMs), while prescribed in hospitals by specialists, are mainly dispensed in community pharmacies and administered in the patient's home. OAMs have the same potential for risk as parenteral SACT in terms of treatment-related toxicities and potential for serious medication errors leading to patient harm. Patients receiving OAMs, including oral chemotherapy and newer targeted therapies, should have access to trained specialist oncology doctors, nurses and support staff, appropriate to their needs in an oncology unit, regardless of where the oral therapies are dispensed. Also, some OAMs are significantly more toxic than others and patients receiving such drugs require careful monitoring in oncology day units.

The first dispensing of these drugs provides an important opportunity for in-depth counselling and consultation in the hospital setting. All patients receiving these complex medicines should have access at the outset to trained, specialist pharmacists, in a hospital setting, who can advise them on how to take their medication correctly, the implications for misuse of the medication and an awareness of possible side effects. These specialist pharmacists should be utilised effectively throughout the new hospital group structure to ensure that all patients can benefit from their expertise.

In addition to providing patients with access to specialist pharmacists in hospitals, it is important to ensure that community pharmacists are adequately trained to dispense OAMs and to counsel their patients. The development of dispensing protocols and training programmes for community pharmacists will aim to ensure that these medications are dispensed in a consistent, effective manner. Processes for information sharing, clinical handover and shared protocols for dispensing and checking prescriptions can ensure a common approach and standardise care between hospital and community settings.

Overall, the objective is to ensure that OAMs are dispensed safely and effectively to patients and that the optimum balance between hospital and community dispensing is achieved.

A national Medical Oncology Clinical Information System (MOCIS) to deliver an Electronic Patient Record (EPR) for medical oncology and haemato-oncology services is planned for implementation from 2017. MOCIS will provide a complete overview of each patient's treatment history (including care delivered in different locations) and will support the safe and efficient delivery of SACT.

## Recommendation

**23** The NCCP will examine the model of care for patients receiving oral anti-cancer medicines and recommend steps to ensure that all patients receive such medicines in a safe and effective manner, with appropriate and proportionate supports, both in the hospital and community setting.

**Lead: NCCP**

New-to-market cancer therapeutics are exceedingly expensive. The NCCP Technology Review Committee appraises the clinical effectiveness of new cancer drugs with input from the relevant healthcare professionals and consideration of peer-reviewed research and guideline publications. This approach is underpinned by clinical evidence and health technology assessment techniques. The National Centre for Pharmacoeconomics (NCPE) produces both rapid review and pharmacoeconomic assessments for new drugs. Drug treatment may also be included in NCEC National Clinical Guidelines as relevant. A defined structure and pathway is in place to approve new anticancer drugs, assessing the overall value of a new drug both in terms of the benefit of the drug to defined patient groups and the cost of providing the treatment. While overall the current system is working effectively to provide new drugs to patients in Ireland, the approach needs to be kept under on-going review to ensure that the balance between patient care and value for money is optimised against a background of competing needs.

## 10.5. Haematological Malignancies/ Lymphoma

### 10.5.1 Introduction

Treatments for haematological malignancies<sup>30</sup> can vary significantly in intensity from surveillance, through outpatient chemotherapy and immunotherapy, to complex inpatient therapy up to the level of allogeneic stem cell transplantation. Administration of the most intensive curative treatments is influenced by the age of the patient and the co-morbidities involved. Diagnostics and therapeutics have developed hugely over the past five years resulting in improved outcomes for patients. However, haematology services in Ireland are now faced with severe challenges in coping with complex treatment programmes and increased patient numbers.

### 10.5.2 Organisation of clinical services

Haematology services have been provided using a hub and spoke configuration for many years. Current referral routes reflect functional relationships built over time. They may not always be aligned to hospital groups or to cancer centres. Haematologists have a presence in smaller hospitals because of the need to provide clinical consultation and laboratory services. This presence has been leveraged to provide local care with links to larger cancer centres.

Acute haematological malignancies require complex treatment and are resource intensive. Such treatment should be delivered in a limited number of centres.

### 10.5.3 Haematological malignancies: outcome-focused groupings

Haematological malignancies span a wide range of neoplasms, with varying levels of complexity and prognosis. They can be roughly divided into three outcome-focused groups. These are:

- haematological malignancies treated with curative intent requiring complex inpatient care;
- Hodgkin Lymphoma and other aggressive non-Hodgkin lymphomas; and
- lower grade chronic haematological malignancies.

These cohorts should be considered separately when organising services, as patients will require different facilities depending on the type and aggressiveness of their cancer and the expected outcome.

Some haematological malignancies (such as acute leukaemias in patients aged less than 65-70 years and some aggressive non-Hodgkin lymphomas) require comprehensive multidisciplinary team availability at all times, single high-efficiency particulate air-filtered (HEPA) rooms and day unit and admission facilities that are separate from the general hospital emergency department. The NCCP will examine the data available relating to patient outcomes for acute

<sup>30</sup> Haematological malignancies are cancers that begin in blood forming tissues (such as bone marrow) or in the cells of the immune system and include acute leukaemia, lymphomas, multiple myeloma, myelodysplastic syndromes, myeloproliferative and lymphoproliferative disorders.

leukaemias/Burkitt/CNS lymphoma and, by end-2017, recommend a designated number of centres to deal with such patients. These centres will be capable of accepting patients on transfer within 24 hours of diagnosis.

Other haematological malignancies (such as Hodgkin lymphoma and other aggressive non-Hodgkin lymphomas) also require MDT discussion and planning but receive less complex treatment that can be delivered in haematology/oncology day units. The NCCP will, by end-2017, designate a limited number of centres for the treatment of patients with potentially curable high grade non-Hodgkin lymphomas and Hodgkin lymphoma. These patients will have their treatment directed by an MDT.

Lower grade chronic haematological malignancies have median survivals of five to 20 years. Most of these patients will have the majority of their care in hospitals where chemotherapy is administered in haematology/oncology

day units, and will require access to complex integrated diagnostic and surveillance expertise. The NCCP will ensure that patients with chronic and low grade malignant haematological disorders are managed in cancer hospitals where chemotherapy is administered. This treatment will be planned and conducted in collaboration with an MDT in a cancer centre.

Given the wide range of treatment modalities that are required for haematological malignancies, centralisation of these services is required. Arising from **A Strategy for Cancer Control in Ireland (2006)**, it was recommended that haematology services be provided in four of the eight cancer centres. The NCCP will examine the data available relating to outcomes for each of the three patient cohorts and designate an appropriate number of centres to provide comprehensive care for all patients with haematological malignancies.

## Recommendation

**24** The NCCP will develop appropriate MDT, centralisation and treatment arrangements to meet the diverse needs of patients with haematological cancers.

Lead: NCCP





#### 10.5.4 Haematological malignancies: services for adolescents/young adults (AYA)

The development of the treatment of AYA patients with haematological malignancies will require strong working relationships and effective co-operation between the new children's hospital and adult haematology services in designated cancer centres so that patients can be treated in a shared care context where appropriate (see Section 10.7).

#### 10.5.5 Haematological malignancies/lymphomas: diagnostic services

Haematological malignancy diagnoses are complex and require integration of morphology, immunophenotyping, cytogenetics and molecular diagnostics to make an accurate diagnosis that will direct optimal therapy. The development of a national laboratory information system (MedLIS) will make integrated reporting more feasible and will aim to ensure that complex immunophenotyping and molecular diagnostics (even if performed centrally) will be uniformly available for all treating centres. Information on all elements of haematology diagnosis should ultimately be available through MedLIS.

The National Clinical Lead for Molecular Diagnostics (when appointed, see Section 9.5) should examine the centralisation of acute leukaemia immunophenotyping to ensure adequate throughput and expertise and to facilitate the management of minimal residual disease (MRD) monitoring. Such a service must focus on equitable provision of quality controlled critical results to treating centres in a timely, sustainable, auditable and resilient fashion. The potential to combine/develop haematological cytogenetics (currently based at OLCHC) with malignant haematological molecular diagnostic services should be evaluated. As with other areas of cancer molecular diagnostics, the economic model elaborated must provide a sustainable funding stream to develop molecular assays which direct therapy. Specialist haematopathology review, particularly for patients with lymphomas, must be timely and integrated early into MDT planning. This may require the appointment of new staff as well as the more widespread use of telemedicine, virtual pathology and hub and spoke arrangements.

## Recommendation

**25** The NCCP will develop a systematic, evidence-based mechanism to prioritise the establishment of MDTs for further rare cancers. The centralisation of diagnosis, treatment planning and surgical services for these cancers will be organised in line with best international practice.

Lead: NCCP  
HSE/DoH

*Lack of information about rarer cancers can lead to patients and families feeling more isolation and distress*

RESPONDENT, PUBLIC CONSULTATION

## 10.6. Rare Cancers

There are many less common cancers where a focus on coordination of care in an expert setting is equally as important as for the more common cancers. Rare cancers are defined as those with an annual incidence of less than six per 100,000 per year and approximately 5,200 new cases are diagnosed annually in Ireland. However, although they collectively comprise about 20% of all cancers, individually each rare cancer affects a relatively small number of patients every year. Improving awareness of rare cancers among both the public and healthcare practitioners is important as they can be difficult to diagnose and can require complex treatment. As a result, there is a need for clear care pathways for the diagnosis and treatment of patients, with particular emphasis on timely treatment planning at national MDT level, involving subspecialty expertise in diagnosis and treatment and with linkages to international centres of excellence for specialist advice and intervention.

National MDTs have already been established for several rare cancers. These include soft tissue sarcomas and neuroendocrine tumours. The NCCP will ensure that all patients diagnosed with these cancers have their cases presented at these MDTs. For other rare cancers, while informal processes may be in place (the informal network to care for patients with high risk germ cell tumours is an example), there is a need to develop a formalised national model of care.

The NCCP will promote the assessment of all patients who present with rare tumours at specialised MDTs. The establishment of further national MDTs for rare cancers should be informed by evidence. Surveillance data from the National Cancer Registry, combined with international best practice, will facilitate the assessment process. International links are vital in this area, with a view to learning from advances made in other countries and to sharing our experiences with others. An EU Joint Action on Rare Cancers has now commenced. This initiative will inform progress in relation to rare cancers in Ireland during the Strategy period.

## 10.7. Child and Adolescent/Young Adult Cancers

### 10.7.1 Introduction

There is a need to develop a uniform service specification that ensures that all children with cancer have equitable access to an appropriate range of clinical and laboratory services for diagnosis, treatment planning and follow-up. International recommendations suggest that adequately trained and experienced staff in a wide range of specialties and services should be available within a cancer centre to provide an acceptable standard of care for children.

### 10.7.2 National Paediatric Haematology and Oncology Centre

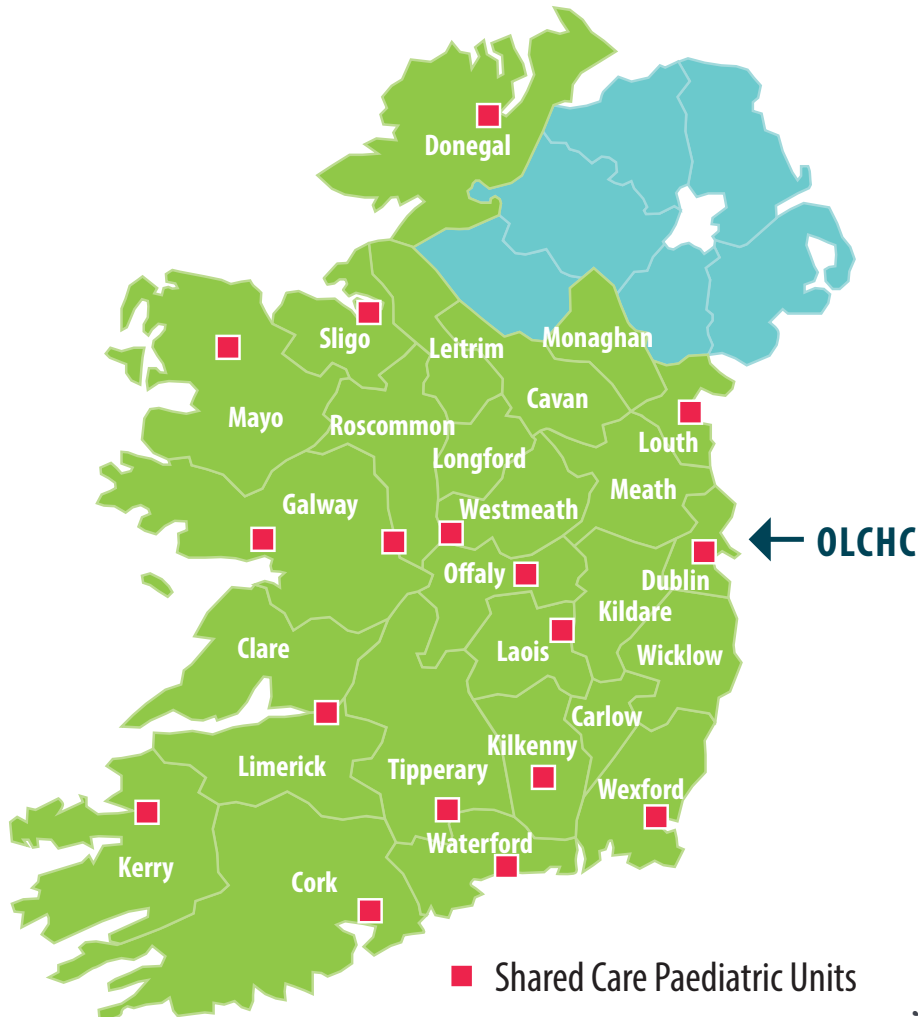
The National Paediatric Haematology and Oncology Centre (NPHOC) at Our Lady's Children's Hospital Crumlin (OLCHC) was established in 2002. Approximately 200 children and young adolescents (0-16 years of age) are diagnosed with cancer in the Republic of Ireland every year. All of these children are referred to NPHOC to have their diagnosis established, treatment planned and follow-up mapped out. The comprehensive cancer care model for children and young adolescents delivered by NPHOC includes:

- co-ordination of the delivery of services (both in the hospital and in the community), while liaising with affiliated regional centres and appropriate community agencies;
- a 24-hour advisory and response service for regional centres, GPs, hospital doctors, patients and families;
- participation in international clinical trials;
- a diagnostic and reference laboratory service;
- specialist follow-up and intervention (post original treatment);
- counselling, palliative care and bereavement services; and
- a range of research, development and educational programmes.

### 10.7.3 The NPHOC shared care network

As 60% of patients live outside the Dublin catchment area, the NPHOC Programme is supported by 16 shared care paediatric units across Ireland (Figure 10.2). These shared care hospitals provide essential supportive care and components of treatment locally under the supervision of the NPHOC and in accordance with the NPHOC Programme Supportive Care Guidelines. The model of shared care also extends to primary care, allowing the family involved to have access to three tiers of healthcare, combining the survival benefits of specialist care with the comforts of a more local service.

Figure 10.2 Shared Care Paediatric Units in Ireland



*Children with cancer often need to visit their local hospital for infections, platelets, bloods, etc. and often are not treated [by] the same knowledgeable staff that Crumlin have*

RESPONDENT, PUBLIC CONSULTATION

To ensure that a high standard of care for children and adolescents with cancer continues, NPHOC at Our Lady’s Children’s Hospital Crumlin will be recognised as a designated cancer centre.

**10.7.4 NPHOC at the new children’s hospital**

Child and young adolescent cancer services will be further developed in the new children’s hospital. The schedule of accommodation of the new haematology and oncology unit in that hospital will significantly increase the capacity to deliver more comprehensive cancer care. This could include treatment of specific clinically-driven conditions for adolescents/young adults (AYA) who have paediatric-centric tumours and are aged between 16-20 years inclusive. The aim is to ensure that patients are treated in the centre (adult or paediatric) most appropriate to their needs.

## Recommendation

**26** The HSE will ensure that an age appropriate facility is designated for adolescents and young adults with cancer within the new children's hospital.

Lead: HSE

### 10.7.5 Service delivery for adolescent/young adult patients

Care for cancer patients in the AYA group poses a significant health challenge. While paediatric cancers continue to be seen in this population, some patients in this age group will have cancers (e.g. germ cell tumours, Hodgkin lymphoma) that require treatment in an adult cancer centre. In recent years AYA has been recognised as a distinct population within the oncology community. While recent studies show that child and young adolescent cancers have seen a large increase in survival rates, the same cannot be said for AYA patients with solid tumour cancers.

It is now widely accepted internationally that traditional models of cancer care do not adequately meet the needs of the AYA population. A more tailored comprehensive multidisciplinary approach to the specific service needs of this population, who are undergoing intensive physiological and psychosocial change during their cancer journey, needs to be developed. To achieve this in Ireland, a joint integrated programme will be developed involving paediatric and adult haematologists/medical oncologists, in partnership with the patients and their families.

An AYA Cancer Service Network, involving the designated cancer centres, will be established. This will function on a hub and spoke model, with the NPHOC/the new children's hospital as the hub, but with strong input from dedicated adult haematologists/ oncologists. The creation of AYA Units in up to four of the eight designated cancer centres will be considered.

## Recommendation

**27** The HSE will develop closer links, on a hub and spoke model, between the National Centre for Child and Adolescent Cancer and the other designated cancer centres to provide appropriate and flexible transition arrangements for adolescents/ young adults. This will include the joint appointment of adolescent/ young adult oncologists and haemato-oncologists and the provision of age-appropriate psycho-social support for these patients

Lead: HSE  
NCCP

### 10.7.6 Psychosocial care

A challenge for healthcare professionals is to support the normal development process throughout the complex cancer journey. For AYA during this crucial stage of development, a cancer diagnosis creates many unique challenges that persist beyond the cancer diagnosis and treatment. Numerous studies have identified a significant unmet psychosocial need in the AYA population. Various guidelines<sup>31</sup> have been published highlighting the essential elements for multidisciplinary care of AYA with cancer. Such guidelines will inform the basis for the provision of care to the AYA cohort in collaboration with the National Clinical Lead for Psycho-oncology (See Section 10.9).

31 European Society for Paediatric Oncology (SIOPE), European Standards of Care for Children with Cancer (2009); National Institute for Health and Care Excellence (NICE), Improving Outcomes in Children and Young People with Cancer (2005); and Teenage Cancer Trust, A Blueprint of Care for Teenagers and Young Adults with Cancer (2012)

### 10.7.7 Survivorship

The cure rate among the AYA cancer population exceeds 80% and hence there are a growing number of survivors. AYA cancer survivors can experience a wide range of long-term treatment-related toxicity which results in an increased risk of later health effects in this population. The unique medical needs of AYA cancer survivors will be recognised within the proposed survivorship programmes (See Chapter 13: Survivorship).

## 10.8. Cancer in Older Patients

### 10.8.1 Introduction

The ageing population is a significant driver of increased cancer incidence and prevalence in Ireland (See Chapter 2: Cancer in Ireland). In addition, older patients (generally those over 75 years) with cancer pose their own unique challenges. Older patients are less likely to have tumour directed treatment. For some cancers they tend to present at a later stage and are often more commonly diagnosed after an emergency presentation. For these and other reasons, older patients have poorer outcomes than the general population with cancer, with a decline in survival from cancer with increasing age. Older patients are significantly more likely to have non-cancer comorbidities. They can also lack social support and so it can be more difficult for them to access, or to tolerate, what would be optimal cancer treatment for others.

Multidisciplinary care of older patients with cancer requires a focused and coordinated approach, informed by the emerging discipline of geriatric oncology. Formalised geriatric input needs to be built into the multidisciplinary assessment of the care of older patients with solid and haematological malignancies. For many patients this can be performed by oncology and haematology nurse specialists, while for others frailty assessments, or sometimes comprehensive geriatric and/or palliative needs assessments, may be required.

To determine the degree to which such services may be required, the age, morbidity and socio-economic profiles of patients with cancer treated in the eight cancer centres should be assessed by the NCCP. To coordinate the elaboration of such an approach, the NCCP will appoint a National Clinical Lead for Geriatric Oncology. This person will coordinate education and training in geriatric oncology (both for medical and nursing oncology specialists) in collaboration with national training bodies; work with cancer centres to improve care of older patients; and utilise programmes (such as the Irish Longitudinal Study on Aging (TILDA) research consortium) to advise the NCCP on developing care pathways for older patients.

### 10.8.2 Key requirements

#### Education

There is an urgent need to improve health care providers' knowledge of geriatric oncology. Steps should be taken to include geriatric oncology in the core undergraduate nursing and medicine curricula. Geriatric oncology should be included in the teaching modules for both geriatric and oncology specialist trainees, national workshops jointly for oncology and geriatric trainees should be established and opportunities for participation in international fora should be promoted. The National Geriatric Oncology Conference, held for the first time in 2015, will provide an opportunity to deepen co-operation in the coming years. National oncogeriatric training, as part of on-going continual professional development, should also be formulated.

#### Clinical Practice

Broadly speaking, the goal of geriatric oncology is to improve the quality of prevention measures, diagnosis, treatment and follow-up of older patients with cancer. Geriatric evaluation must be incorporated into oncology decision-making, in line with the core recommendation of the International Society of Geriatric Oncology. In this context, collaboration between oncologic and geriatric disciplines is essential, ultimately leading to the establishment of interdisciplinary geriatric oncology clinics/MDTs, with lead physicians, appropriate nurse specialists and health and social care personnel identified.





### Research

Improving research in the field of geriatric oncology will inform and encourage excellence in clinical practice. This is an area on which organisations such as Cancer Trials Ireland (formerly ICORG) and the Irish Cancer Society might place more focus in the coming years.

### Recommendation

**28** Links between cancer services and geriatric services will be strengthened, facilitated by the appointment of a National Clinical Lead in Geriatric Oncology in the NCCP.

Lead: NCCP

## 10.9. Psycho-Oncology Services

### 10.9.1 Introduction

Psycho-oncology is concerned with the psychological, social, behavioural and ethical aspects of cancer. It addresses the two major psychological dimensions of cancer: the psychological responses of patients to cancer at all stages of the disease (and that of their families and carer); and the psychological, behavioural and social factors that may influence the disease process.

Access to appropriate psycho-oncology services within cancer centres has not developed as envisaged in A **Strategy for Cancer Control in Ireland (2006)**, an issue highlighted in the report of the Evaluation Group. Only two of the eight designated cancer centres have a dedicated psycho-oncology service, and one of these is part-time. This needs to be addressed, particularly given the predicted growth in incidence of cancer and demand for cancer services.

*The hospital I attended was fantastic and the **care was superb**, but the effects of treatment were gruelling...I raised my **mental health concerns** with my consultant and she advised that really there were **only ad hoc services available***

RESPONDENT, PUBLIC CONSULTATION

In addition, other issues highlighted in the Evaluation Report will impact upon psycho-oncology and psychosocial service requirements in the coming years. These include the deployment of new models of care, as well as hereditary cancer and survivorship initiatives that have the potential to place additional demands on already insufficient psycho-oncology and psycho-social care service providers.

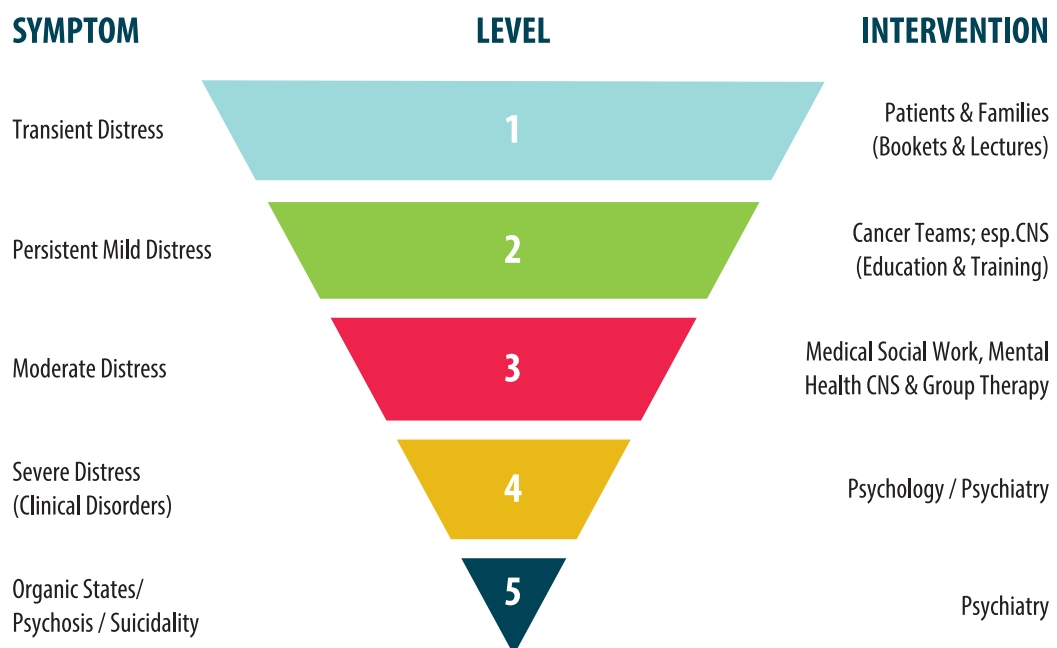
Two essential issues need to be considered when planning psycho-oncology and psycho-social support services:

- The appropriate level of expertise and intervention required relative to patients’ needs; and
- The development of a model for psycho-oncology that has the capacity to cross the voluntary, primary and acute services.

**10.9.2 Proposed model of hospital-community psycho-oncology and psycho-social care**

The term ‘distress’ is the preferred term to describe the psychological challenges that patients with cancer experience. Cancer related distress is best conceptualised as existing on a continuum of severity ranging from mild (adaptive, ‘normal’ levels of sadness and fear) to severe (disabling symptoms such as clinical depression, anxiety, panic disorder, body image problems or relationship and family breakdown). The degree of severity experienced by the cancer patient will dictate the level of intervention and expertise required. The model presented below (Figure 10.3) is based on this understanding and has a range of specific psychological interventions, matching each level of intervention with the level of distress or morbidity experienced by the patient with cancer. As a stepped care approach to service provision, this model is flexible to meet the needs of all patients with the intervention selected according to the type and severity of psychological morbidity. As such, it ensures the most efficient use of resources, while also ensuring that interventions received are appropriate to the level of distress.

**Figure 10.3** Proposed Model of Hospital-Community Psycho-oncology and Psycho-social Care<sup>32</sup>



<sup>32</sup> Model adapted from O’Dwyer and Collier, St. James’s Hospital, 2003

## LEVEL ONE

Level 1 care is provided to patients and families, supported by public lectures and information leaflets/booklets produced by the cancer centres and the voluntary sector.

## LEVEL TWO

Level 2 care is for patients with more significant morbidity who can be managed in cancer centres by cancer clinical nurse specialists or in primary care by staff such as GPs, community mental health nurses and health promotion officers. Services should provide care to both patients and their families. The staff involved in providing the support should receive appropriate training from psycho-oncology services based in the cancer centres. In some cases cancer support services in the community will provide programmes at this level, bridging between hospital services and community care.

## LEVEL THREE

Level 3 care is for patients with moderate degrees of distress and should be managed by trained mental health practitioners in hospitals and in the community (including cancer support centres). This includes clinical/counselling psychologists, cognitive behavioural therapists, clinical cancer nurse specialists and social workers.

## LEVEL FOUR & FIVE

Level 4 and 5 care is for patients with severe and pervasive distress and requires more intensive input from senior specialist mental health professionals, such as principal psychologists and consultant psychiatrists. It will be necessary for patients at this end of the continuum to attend psycho-oncology services in a cancer centre where specific expertise in cancer-related morbidity, including steroid-induced psychosis, severe cancer-related fatigue or body image disorder, will be available in a manner similar to services for physical treatments in cancer.

The establishment of multi-disciplinary psycho-oncology teams in each of the cancer centres is required. These teams will deliver a comprehensive hospital-based clinical service and will also provide a community support function into community cancer support groups. This model will also facilitate the provision of psycho-oncology support to centres where patients are being treated in a hub and spoke model. The teams will comprise psychologists, psychiatrists, clinical nurse specialists (CNSs) and social workers.

The Evaluation Report of **A Strategy for Cancer Control in Ireland (2006)** suggests the need for a co-ordinated approach to the education of all cancer care workers in the psychosocial support needs of patients, including the sensitive management of communication around diagnosis and prognosis. The psycho-oncology MDT (at levels 3 - 5) will provide such education and training.

To develop psycho-oncology services nationally, the NCCP will appoint a National Clinical Lead for Psycho-oncology. She/he will ensure the delivery of the networked services outlined above, with a view to achieving a significant beneficial impact on the quality of life for patients and their families.

## Recommendations

**29** The NCCP will appoint a National Clinical Lead for Psycho-oncology to drive the delivery of networked services.

Lead: NCCP

**30** Each designated cancer centre will establish a dedicated service to address the psycho-social needs of patients with cancer and their families. This will operate through a hub and spoke model, utilising the MDT approach, to provide equitable patient access.

Lead: NCCP

### 10.10. Palliative Care

Palliative care is defined as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care services are organised into specialist and generalist services that operate in partnership, as part of an integrated network of providers.

Traditionally, many people think of palliative care as care provided at the last stage of life - around the time of death. However, in the last twenty years the scope of palliative care has broadened to providing care at an earlier stage in the disease trajectory. In this model of integrated palliative care provision, such care is not dependent on prognosis. Instead it is provided on the basis of need, and may be delivered at the same time as curative treatment.

Palliative care in Ireland is recognised as a core component of healthcare provision and services are structured in three levels of ascending specialisation:

- **Level 1** – Palliative Care Approach: All health care professionals appropriately apply palliative care principles;
- **Level 2** – General Palliative Care: Health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care;
- **Level 3** – Specialist Palliative Care: This involves services whose core activity is the provision of palliative care.

The role of generalist palliative care (levels 1 and 2) is fundamental to the provision of high quality care for children and adults with cancer. Indeed, generalist palliative care providers can appropriately and effectively meet the needs of many people with cancer. GPs and broader Primary Care providers can play a key role in providing such palliative care.

However, should an individual experience uncontrolled symptoms, or problems of high intensity, complexity and/or frequency as a consequence of their illness, then input from specialist palliative care services is needed to ensure best possible outcomes. The aim is that cancer services, specialist palliative care services and community care services will work in an integrated way to ensure that all cancer patients with palliative care needs receive that care in a timely manner and in the appropriate location. Symptom control is an integral component of this care. The Palliative Care Clinical Programme has led two NCEC National Clinical Guidelines which were published in 2015 and which offer evidence based guidance for the management of patients with cancer pain and constipation.

Palliative care may be provided in a variety of locations - at home, in a primary care setting, in hospital or in a hospice. It may be provided for varying periods of time - days, weeks, months or, for some, episodically over a number of years.

Systems of care should be sufficiently flexible to ensure that specialist services remain aligned to the changes in level of need, respond promptly and collaborate effectively with generalist providers. It is important that generalist staff receive the necessary training and education to ensure that they are competent in their appropriate level of palliative care provision. It is recommended that guidance be developed in order to ensure safe transition, including clinical handover, between settings and to promote continuity of care. Staff in the community, such as GPs, community nurses, occupational therapists, physiotherapists and pharmacists should also be offered training to ensure that they have the appropriate skillset to address the palliative care needs of patients outside of the hospital setting.

The NCCP and the National Clinical Programme for Palliative Care will work together, with particular focus on the coordination of organisational, clinical and information systems, to progress the further integration of cancer and specialist palliative care services.

## Recommendations

**31** Designated cancer centres will have a sufficient complement of specialist palliative care professionals, including psycho-oncologists, to meet the needs of patients and families (such services will be developed on a phased basis to be available over seven days a week).

**Lead: HSE**  
**Designated Cancer Centres**

**32** Oncology staff will have the training and education to ensure competence in the identification, assessment and management of patients with palliative care needs and all patients with cancer will have regular, standardised assessment of their needs.

**Lead: HSE**

## Recommendation

**33** The HSE will oversee the further development of children's palliative care to ensure that services are available to all children with a life limiting cancer.

Lead: HSE

At present, the majority of specialist palliative care in Ireland is provided by voluntary hospices, which are funded both through service level agreements with the HSE and through their own fundraising activities. Currently in the region of 80% of the patients seen by specialist palliative care providers have a cancer diagnosis, though this proportion is decreasing. However, for the foreseeable future, patients with cancer will continue to comprise the majority of palliative care patients (KPI no's. 18 and 19).

While Ireland's commitment to the provision of palliative care has been recognised internationally, limitations in service availability remain. It is therefore necessary to continue to develop our national services in order to ensure that all people with cancer, who have palliative care needs, including a small cohort of children, can readily access appropriate services.



# SAFE, HIGH QUALITY, PATIENT CENTRED CARE

## 11.1. Introduction

The primary aim of all cancer services is to provide effective, safe, high quality and patient-centred care. Systems are required across the health service so that technologies and treatments are designed for efficacy and efficiency. The overall aim is to ensure that informed decisions are made on the provision of high quality and equitable health care.

Safety is fundamental to quality healthcare and cancer services must be enabled to deliver safe care, while balancing competing pressures and demands. Assurance of patient safety requires active leadership, governance and clinical commitment to quality at all levels. Each cancer service will have a defined patient safety and quality operating framework to address service user advocacy, complaints, incident management and response, learning systems and service improvement, and to foster a patient safety culture.

A National Patient Safety Office (NPSO) has been established within the Department of Health. This Office leads a programme of patient safety measures. This patient safety programme involves new legislation and centres on initiatives such as the establishment of a national patient advocacy service, measurement of patient experience, introduction of a patient safety surveillance system, extending the clinical effectiveness agenda and setting up a National Advisory Council for Patient Safety

## 11.2. Improving Evidence Based Practice

Cancer diagnostics and treatments are advancing at a rapid pace. Cancer policies and services will need to be both responsive and anticipative over the lifetime of this Strategy in order to ensure the provision of high quality and equitable cancer services with the aim of optimising patient outcomes.

The opportunity to improve cancer outcomes and survival rates should be grasped in an equitable manner across the Irish health system. Scientific advances have created opportunities for individual patients to have access to new therapies, including the development of personalised treatments and more accurate diagnostic techniques. Policy decisions for cancer care must endeavour to achieve a balance between creating opportunities for individuals and the provision of population-based equitable care. A process that supports and guides policy in prioritisation and decision making in a cost effective manner is required.

The use of economic evaluations and health technology assessments should underpin the models for cancer service delivery across prevention, screening, diagnostics and treatment. This approach will ensure that an enhanced analytic approach to evaluating the clinical effectiveness, costs and health consequences of alternative courses of action becomes the norm. The aim is to provide a coherent, equitable and transparent prioritisation process for planning for cancer service delivery for our population over the lifetime of this Strategy.

### 11.3. Health Technology Assessments

Health technology assessments (HTAs) are increasingly being utilised internationally to judge value for money. A HTA is a form of research that generates information about the clinical and cost-effectiveness of health technologies. These technologies can include drugs, medical devices, diagnostic techniques, surgical procedures and public health programmes (e.g. cancer screening programmes). They are relevant to the assessment of both new and existing technologies. A HTA may also look at the social, ethical, medico-legal and organisational aspects associated with use of a technology, including its resource implications and budget impacts. The information provided by the HTA is used to inform health policy decisions regarding investment/disinvestment.

Advances in cancer care have led to questions of the sustainability of the cost of new treatments and how these new treatments can be assessed, trialled and integrated into mainstream care. The process by which existing treatments are assessed and potentially discontinued is also important.

While in Ireland HTAs are often performed by HIQA, other areas of the health services also conduct HTAs and economic assessments. Examples include the HSE National Centre for Pharmacoeconomics (NCEPE), which examines the efficacy and cost effectiveness of new drugs. HTAs and Budget Impact Assessments form part of the development of National Clinical Guidelines for approval by the NCEC. Less formal assessments of new and existing technologies and therapeutics are also carried out.

### 11.4. National Standards

Standards help to set public, provider and professional expectations and they enable those involved in cancer services, and all involved in healthcare, to play a vital part in safeguarding patients and in delivering continuous improvement in the quality of care provided. The HIQA **National Standards for Safer Better Healthcare (2012)** provide a strategic approach to improving safety, quality and reliability across health services.

### 11.5. National Patient Advocacy Services and Measurement of Patients' Experience

Patient advocacy is well developed in relation to cancer services in Ireland. The Irish Cancer Society plays a primary role in this regard, with many other organisations also focusing on cancer patients. This was recognised with the establishment of a Cancer Patient Forum to represent the views of patients and patient groups in the development of this Strategy, and through the public consultation process (see Chapter 12).

Advocacy activities in regard to healthcare occur at an individual level and at a macro level. Increasingly, patient advocacy services are assisting cancer patients to navigate the health system, as well as helping them to cope with psychological and social effects of illness. At the macro level patient advocates give patients a voice in public fora. Work on a new national model for patient advocacy has commenced. The NPSO will define the core components for the national advocacy model.

The patient's voice is essential to inform and evaluate the care given, and to guide quality improvement initiatives at all levels. A joint partnership between HIQA, the Department of Health and the HSE is progressing a plan for the measurement of patient experience across in-patient acute care. This will facilitate a comparison between Irish and international patient experiences.

## 11.6. National Patient Safety Surveillance

The NPSO will establish a National Patient Safety Surveillance System which will provide the evidence to inform patient safety policy decisions. This system will produce patient safety profiles by bringing together data from various health information resources. For cancer services, such a surveillance system is likely to include, but is not limited to, elements on clinical activity, safe structures, optimal workforce, supportive culture, appropriate behaviour, notifications to the Health Products Regulatory Authority (HPRA), the Hospital Patient Safety Statement, information from the Coroner, State Claims Agency data and temporal issues. The surveillance of patient safety profiles for service and clinical cohorts will form part of a cyclical quality improvement process.

## 11.7. National Healthcare Quality Reporting System

The Department of Health is committed to public reporting of indicators that reflect the quality and safety of healthcare, including cancer care, through the National Healthcare Quality Reporting System (NHQRS). The NHQRS framework sets out five domains against which quality is delivered<sup>33</sup>. Such public reporting helps to drive improvements in the quality of care provided to patients. The Department of Health published the third NHQRS Annual Report in June 2017. The following were included in respect of cancer services:

### Cancer Screening Rates

Percentage uptake of breast screening

Percentage uptake of cervical screening

### Cancer Survival Rates

Five year relative survival rate for breast cancer

Five year relative survival rate for cervical cancer

Five year relative survival rate for colorectal cancer

### Cancer Surgery

Breast cancer surgical activity

Colon cancer surgical activity

Rectal cancer surgical activity

## Recommendations

**34** The NCCP will ensure that each hospital has a clearly defined framework for cancer patient safety and quality.

Lead: NCCP

**35** The NCCP will define focused cancer patient experience surveys to incorporate treatment and survivorship in line with HIQA's standard approach for the National In-Patient Acute Care Patient Experience Survey.

Lead: NCCP  
HIQA

<sup>33</sup> Helping people to stay healthy and well; supporting people with long term conditions; helping people when they are being treated and cared for in our health services; supporting people to have positive experiences of health care; treating and caring for people in a safe environment.

The Department of Health will develop further indicators as appropriate under the NHQRS to assess progress in achieving the objectives of this Strategy.

### 11.8. Adverse Events, the National Incident Management System and Open Disclosure

The further development and rationalisation of cancer care, as proposed in this Strategy is intended to enhance the quality of care to patients. However, the delivery of healthcare is inherently risky, and its scale and complexity is without parallel in other sectors and businesses. It is essential that we are always vigilant with regard to quality and that we have a strong patient safety culture.

The reporting of adverse events is one indicator of a strong patient safety culture. Healthcare services covered by the Clinical Indemnity Scheme are legally obliged to report all adverse events, including Serious Reportable Events (SREs), on the National Incident Management System (NIMS) to the State Claims Agency. Legislation is being progressed which will require providers to report SREs to the State Claims Agency, HIQA and the Mental Health Commission. Cancer services will report adverse events and will support open disclosure with patients and their families in parallel with other services in the health system.

### 11.9. Clinical Effectiveness

The National Clinical Effectiveness Committee (NCEC) is charged with prioritising and quality assuring, to the level of international methodological standards, a suite of National Clinical Guidelines and National Clinical Audit for the Irish health system. Clinical guidelines are internationally recognised methods for defining healthcare interventions, improving the effectiveness of care and treatment and reducing variation in care delivery. Policies, procedures, protocols and guidelines are also a source of robust, quality information for patients. Development of these Guidelines is informed by the NCEC Standards for Clinical Practice Guidance (2015) to promote consistency of approach. Within cancer services, the most appropriate

## Recommendation

# 36

The NCCP will develop, publish and monitor a programme of national quality healthcare indicators for cancer care, involving both process and outcome measures, in line with international standards.

Lead: NCCP



clinical practice guidance should be prioritised in a systematic manner, in line with the service need and the methodological rigour required.

NCEC National Clinical Guidelines and National Clinical Audit endorsed by the Minister for Health are mandated for implementation in the Irish health system and their implementation will be monitored through HSE Performance Assurance Reports, compliance with the National Standards for Safer Better Healthcare and increased alignment with the Clinical Indemnity Scheme. There should be a focus on guideline implementation and audit performance, and on ensuring that the resources and clinical leadership to support the development and implementation of prioritised guidelines and audit are available. Where appropriate, high quality international guidelines should be formally adapted for the Irish healthcare setting.

Fourteen NCEC National Clinical Guidelines have been published to date. A number of these relate directly to cancer services as outlined below. Further guidelines in relation to lung, colon, rectal, pancreatic and oesophageal cancer are being developed by the NCCP.

#### National Clinical Guidelines Relating to Cancer and Palliative Care

|            |   |
|------------|---|
| NCG No. 7  | Diagnosis, Staging and Treatment of Patients with Breast Cancer, June 2015                    |
| NCG No. 8  | Diagnosis, Staging and Treatment of Patients with Prostate Cancer, June 2015                  |
| NCG No. 9  | Pharmacological Management of Cancer Pain in Adults, Nov 2015                                 |
| NCG No. 10 | Management of Constipation in Adult Patients receiving Palliative Care, Nov 2015              |
| NCG No. 13 | Diagnosis, Staging and Treatment of Patients with Gestational Trophoblastic Disease, Nov 2015 |

Future National Clinical Guidelines relating to cancer should include where appropriate recommendations on MDT location and composition, and on centralisation of services, as well as descriptions of how care should be structured at a community, regional and national level. Where necessary, these guidelines should also include recommendations relating to the establishment of Rapid Access Clinics.

## Recommendation

**37** The NCCP will develop further guidelines for cancer care in line with National Clinical Effectiveness Committee (NCEC) Standards. Audits will also be developed in accordance with the NCEC Framework for National Clinical Audit.

Lead: NCCP/NCEC

### 11.10. Leadership in Safe, High Quality Cancer Care

Leadership, governance, clinical commitment and clinical effectiveness approaches are required to deliver safe, high quality cancer care at national, regional and local level. There is a need for investment in capacity development for quality and patient safety in our cancer services. This requires that each service/hospital has a dedicated patient safety and quality leadership and oversight function, which encompasses both cancer patient safety elements (e.g. complaints procedures, advocacy, and management of risk and adverse events) and cancer quality elements such as standards, clinical effectiveness guidelines, audit and key performance indicators.







# SECTION D

## MAXIMISE PATIENT INVOLVEMENT AND QUALITY OF LIFE

- 12 Involving Patients in their Cancer Care
- 13 Survivorship

### OBJECTIVES

- Strengthen the role of patients in the delivery of cancer care, including through the establishment of structures for patient involvement
- Develop and implement survivorship care programmes



**150,000**  
cancer survivors  
in Ireland

**50%** of all  
cancer survivors have  
had breast cancer or  
prostate cancer



**1 in 4**  
cancer survivors  
have physical/  
psychological  
consequences  
following treatment

**Survivorship**  
begins at the **time of**  
**diagnosis** and continues  
until **end of life**

By **2020**,  
**1 in 20**  
will be a cancer  
**survivor**



# INVOLVING PATIENTS IN THEIR CANCER CARE

## 12.1. Introduction

It is recognised internationally that patient involvement should be an integral part of both cancer care and service development. Patients who are fully informed about their care are patients who are empowered, active participants in their treatment. Additionally, cancer patients are in a position to provide a unique perspective on the development of cancer services at a local, regional and national level. This Strategy aims to put structures in place to allow for increased patient involvement into the development of cancer services in Ireland.

## 12.2. Patient Advocacy

Patients with cancer and their families and friends have long been to the fore in advocating for the needs of cancer patients locally and nationally and there is a recognition that patient advocacy needs to be developed and enabled in a more structured way. Elements of advocacy relate to patient rights, matters of privacy, confidentiality and informed consent, patient representation, awareness building and support and education of patients and their carers. Advocacy services can also assist cancer patients to navigate the healthcare system. At national level, advocacy provides a patient voice at public fora.

This approach is being developed more broadly across health services and the National Patient Safety Office in the Department of Health will define the core components for the national advocacy model and oversee its introduction (See Chapter 11).

## 12.3. Providing for a Structured Engagement with Cancer Patients

The development process for this Strategy saw the establishment of a Cancer Patient Forum, to provide a strong patient input and to consider how patient input into cancer services can be facilitated more broadly. The Cancer Patient Forum was represented on the Cancer Strategy Steering Group to enable it to make a direct contribution to the development of this Strategy. In implementing this Strategy, it is proposed to establish a Cancer Patient Advisory Committee to facilitate continued patient input into cancer control measures.

Service providers, including hospital groups, designated cancer centres and community healthcare organisations (CHOs) are encouraged to develop structures to facilitate patient and public input into cancer services. Some hospitals already have patient councils or similar programmes for involving patients. In some cases, patients will not be in a position to take on a representative role until their course of treatment has finished. It is intended that patient representation at local level will be expanded over the lifetime of this Strategy.

## Recommendations

**38** The Department of Health will ensure that patient representatives are involved in policy making, planning, practice and oversight of cancer services at local, regional and national levels.

Lead: DoH

**39** The Department of Health will establish a Cancer Patient Advisory Committee to provide input into the development of programmes for patients with cancer. Membership of this committee will reflect the diverse nature of patients living with the effects of cancer, and will ensure that the needs of patients living in more remote areas are represented

Lead: DoH

**40** All hospitals will offer patients a Patient Treatment Summary and Care Plan as part of their support. These plans will allow patients to store information about their cancer, their cancer treatment and their follow up care. The plans will also inform future healthcare providers.

Lead: NCCP/HSE  
Designated Cancer Centres/  
Primary Care settings

## 12.4. Patient Information

A central principle of cancer care is that patients should be involved in decisions on their condition and their treatment. Cancer is a complex collection of diseases and the number of available treatments is expanding. While much of this information will be made available to patients as part of their diagnosis, treatment and follow up, views expressed in the public consultation included that the provision of information should go beyond the *handing out of leaflets*.<sup>34</sup> Clinicians and providers of services to cancer patients must ensure that information is available to patients and their carers in a manner that is appropriate, accessible and understood. Specialist oncology and haematology nurses have an important role to play in the provision of such information to patients. The development of Patient Treatment Summary and Care Plans, as outlined below, will provide information and empowerment to patients.

The voluntary sector also provides much information to cancer patients through cancer support centres, through ICS Daffodil Centres in hospitals and through the work of many charitable organisations.

## 12.5. Treatment Summary and Care Plans for Cancer Survivors

Care plans, consisting of a treatment summary and follow-up care plan, are useful tools to communicate and coordinate survivorship care. These plans were strongly recommended by the Cancer Patient Forum as a vital resource for patients. A number of templates and frameworks have been developed internationally to advance the use of such plans. Also, a number of barriers have been identified to the use of care plans, ranging from time constraints, multi-modal treatment records, a lack of role clarity and a paucity of data linking care planning and patient outcomes. The trend towards electronic patient records and individual health identifiers will facilitate the implementation of care planning initiatives. Patient Treatment Summary and Care Plans should include information about the patient's cancer, the treatments they had and their follow-up care (KPI no. 17).

<sup>34</sup> Comment from public consultation.

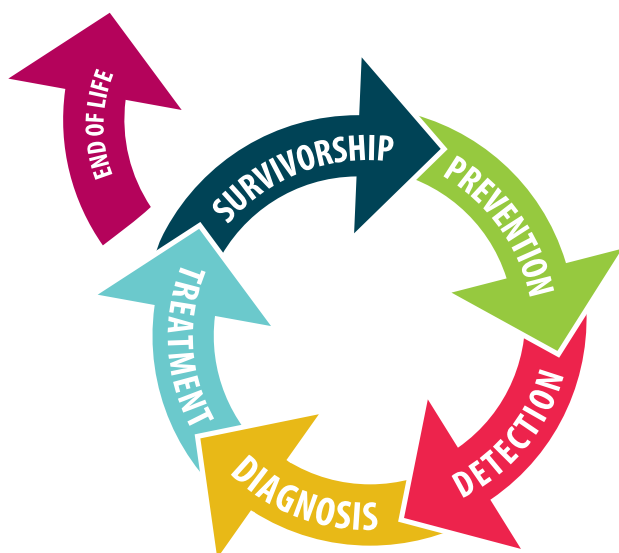
# SURVIVORSHIP

## 13.1. Introduction

Cancer survivorship begins at the time of diagnosis and continues until end of life. There are currently more than 150,000 cancer survivors in Ireland.<sup>35</sup> Survival for some common cancers has greatly improved in recent years - breast cancer five year survival is now over 80%, while the rates for testis, thyroid and prostate cancers are over 90%. The increased number of survivors underscores the importance of addressing survivor health and care needs.

Internationally, survivorship care has been developing rapidly in recent years. There has been increasing awareness of cancer survivorship as a distinct period in the continuum of cancer care which includes prevention, diagnosis, treatment and post treatment care and life beyond cancer (Figure 13.1).

Figure 13.1: The Continuum of Cancer Care



While caregivers and family members are often seen as cancer survivors too, the focus of this Strategy is on people who have, or who have had, cancer. For those who have metastatic cancer the 'survivor' label may not always be considered appropriate as these people continue to live with cancer every day. Also, since many forms of cancer are chronic yet highly survivable, the definition of successful treatment can be seen to have shifted toward maximising the quality of life of individuals diagnosed with cancer for as long as they live. In short, it is not a question of "just surviving" - the aim is to maximise quality of life.

The need to develop and promote effective survivorship care pathways for patients was highlighted both in the public consultation and in the deliberations of the Cancer Patient Forum.

Two main themes emerged:

- The need for a continuum of care so that people would have a means of access back to their treatment providers as required. Some spoke of being 'on their own' once they exit the hospital system and the link is partly needed for reassurance and psychological support, rather than for renewal of treatment; and
- The realisation of a life beyond cancer in the sense of optimising the quality of life. This could range from achieving a level of pain-free contentment to assimilation back into the workforce.

<sup>35</sup> Data collected from 1994 onwards.



Much of the focus of care for cancer survivors is on services, information and resources for patients after curative treatment is complete, or for those on maintenance and prophylactic therapy. The number of male and female survivors is similar and approximately half of all survivors comprise women with breast cancer and men with prostate cancer. In a significant number of cases, a greater emphasis on long term surveillance will be required in view of the increased risk of likely health complications, including the development of second cancers. With the increasing overall numbers involved, this is likely to require considerable effort on the part of healthcare professionals and is likely to have an increasing impact on overall resources.

A focus on high quality survivorship can empower patients to achieve their best possible health outcomes while living with and beyond a diagnosis of cancer. The goal for many cancer survivors will be to return to as normal a life as possible, including return to work in many cases. Employers should endeavour to support the successful transition of cancer survivors back to work. As survivor numbers continue to rise, and as treatment improves, the overall beneficial economic impact of people returning to work will be substantial.<sup>36</sup> To ensure a coordinated national approach to addressing the multiple issues that arise, the NCCP will undertake a Cancer Survivorship Needs Assessment with the aim of developing an appropriate model of survivorship healthcare for Ireland.

## Recommendation

**41** The NCCP, in conjunction with the ICGP, cancer centres, the Irish Cancer Society and cancer support centres, will conduct a Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare. The Needs Assessment will be completed by the end of 2018.

Lead: NCCP

## 13.2. Elements of Survivorship Care

Survivorship care involves the delivery of health care services specifically designed for cancer survivors, including patients who are living with cancer until the end of life. Figure 13.2 below describes the main components of survivorship care.

Figure 13.2: Elements of Survivorship Care

- Prevention and detection of new cancers and surveillance for recurrent cancer
- Monitoring and interventions for long term and late effects of cancer and its therapies
- Coordination between specialists and primary care providers to ensure that survivors' needs are met and providing referral as needed
- Monitoring and intervention as needed for psychological and social effects
- Encouragement of self-management with support
- Information and health education
- Familial genetic risk assessment, if deemed necessary

<sup>36</sup> OECD, Health at a Glance 2015 (2015).

### 13.3. Quality in Survivorship Care

Cancer survivors can require life-long, evidenced-based health care, both preventive and general medical, as well as psychosocial care and care specific to the cancer diagnosis. The patient pathway is complex and requires co-ordination across the health service. In particular it requires coordination between specialist and primary care to provide safe, high quality and effective responses. Follow-up and surveillance should be standardised and delivered close to the patient in an evidence-based manner with facilitated re-entry to specialist care as required. Survivorship care should address the general health needs of patients with respect to chronic disease management and co-morbidities. Programmes of information, advice and engagement, that highlight the importance of lifestyle and cancer prevention, should be provided.

#### Recommendation

**42** The NCCP, in conjunction with the cancer centres, will develop shared care protocols for patients with cancer following treatment. These protocols will span the hospital and primary care settings.

Lead: NCCP

While the majority of cancer survivors live well and do not have significant on-going needs, some survivors face distinct and serious health care issues. It is estimated that 25% of cancer survivors will have one or more physical or psychological consequences of their cancer treatment that affects their life to a greater or lesser degree in the long-term. Those who are poor, isolated, living alone or elderly are likely to have the greatest need.

### 13.4. Survivorship and Lifestyle

Although research into the lifestyle benefits (e.g. from good nutrition or physical exercise) for cancer survivors is at an early stage, there is emerging evidence that appropriately modified lifestyle behaviours can reduce recurrence rates for certain cancers. Evidence in breast, prostate and colorectal cancer, in particular, suggests the possibility of decreased mortality with physical activity for cancer survivors. Physical activity improves heart health and may also counteract long-term effects of cancer treatments such as chronic fatigue and cardiotoxicity. The evidence on smoking cessation for cancer survivors is incontrovertible and, where necessary, smokers should be given appropriate smoking cessation supports as part of their treatment regime and care planning. Generally cancer survivors will be encouraged to follow the same guidance for reducing cancer risk as the general population.

### 13.5. Late and Chronic Effects of Cancer Treatment

*Coming through a cancer diagnosis brings many new physical, mental and emotional challenges. We need to concentrate on creating strong supports for these areas so as to allow people to integrate back into family and society so that they can contribute competently and rebuild themselves strongly*

RESPONDENT, PUBLIC CONSULTATION

Cancer and its treatment can have a wide range of adverse effects, including physical, psychosocial, social and financial, on patients and their families. Exacerbations of pre-existing conditions may also develop. Effective management of these effects is central to good survivorship care. Adverse effects that are not addressed in the first year post completion of acute treatment are significantly more likely to become chronic requiring greater levels of on-going care.

Some side effects from cancer treatment are inevitable given the nature of that treatment. The effect on quality of life varies with the cancer type, treatment and stage at diagnosis. Although some treatment effects can be short-term, for a substantial minority of patients problems following treatment can persist and become long-term. These can include urinary and sexual dysfunction, lymphoedema and reduced fertility. Late effects of cancer treatments, such as osteoporosis, heart disease and the development of second cancers, may not arise for many months or years after treatment. This highlights the need for information on late and chronic effects to form part of appropriate treatment summaries and care plans for all patients.

Childhood and adolescent/young adult cancer survivors require specific late effects support as they can experience a wide range of treatment related toxicities that, in some cases, result in serious health complications. In developing survivorship programmes, particular attention will be required to address the needs of this group.

### 13.6. The Role of Primary Care

Primary care services are the appropriate setting for a greater proportion of protocol-driven survivorship care. Currently much survivorship care is delivered in follow-up clinics in hospitals. Primary care must be supported to increase its involvement in follow-up care through the provision of appropriate guidelines, with educational support and through clear lines of communication, while maintaining easy access back to the hospital setting as required.

Patients often garner considerable reassurance from follow-up care delivered in hospital clinics. Evaluation of alternative models of care has found that both primary care services, and nurse-led care, are equally effective for detecting recurrence. Patients need to be encouraged to realise the benefits of convenience, familiarity, physician knowledge of family circumstances and the treatment of co-morbidities that general practice can deliver. This is particularly important given that many older cancer survivors have complex health conditions such as diabetes and coronary artery disease. Primary care services will be supported by hospital-based care with specialist oncology nurse-led clinics, using remote follow up where appropriate.

### 13.7. Self-care for Cancer Survivors

A key goal of survivorship care is to empower patients to achieve their best possible health. This involves providing knowledge, guidance and support to survivors and families in relation to healthy lifestyle, disease prevention and disease control so as to aim for a good quality of life and prolonged survival. Patients should be educated to recognise the warning signs of potential recurrence or new cancers. Supported self-management can improve general physical health, including preventing and managing co-morbidities. Programmes should be developed to encourage survivors to take responsibility for their follow-up care and their general health and services should offer self-management support.

*Drop in centres...provide the security blanket and get you to take baby steps to get you back living and managing and taking responsibility for your own health*

RESPONDENT, PUBLIC CONSULTATION

## VOLUNTARY ORGANISATIONS PLAY A HUGE ROLE IN SUPPORTING SURVIVORS



### 13.8. Psychosocial Care for Cancer Survivors

Dedicated psycho-oncology services and strengthened psycho-social support are essential across the patient pathway. Approximately 20% to 30% of patients with cancer will develop some form of psychological disorder across their cancer trajectory, including in the survivorship phase. Development and delivery of comprehensive psycho-oncology services, from diagnosis into the survivorship phase, is a major focus of this Strategy (See Section 10.9). Such support can greatly impact on the patient experience of cancer care. Furthermore, available evidence indicates that patients with cancer who have their psychosocial needs addressed have better outcomes and superior quality of life.

### 13.9. The Role of the Voluntary Sector

#### **A Strategy for Cancer Control in Ireland (2006)**

recognised the need for the organisation of voluntary sector psychosocial support services in Ireland. In response to this, the ICS developed a programme of activities aimed at supporting good practice and governance in cancer support centres throughout Ireland. This programme includes good practice guidelines and policy templates that cancer support centres can use/adapt for their services. This approach has facilitated the development of broadly standardised high quality services that provide much needed support to patients outside of the acute care setting. While not every cancer support centre is affiliated to this process, almost all centres adhere to standards that ensure equity of access that is free of charge.



While cancer support centres in the community are a valuable resource, many patients are not aware of the existence of these services, and there are no structured referral pathways between hospitals and support centres. Development and implementation of dedicated survivorship programmes, as envisaged in this Strategy, could have a profound impact on the quality of life of many who are living with the effects of a cancer diagnosis. Such programmes will address both the physical and psychosocial aspects of survivorship, and will include the provision of practical support in areas such as lifestyle and financial advice.

*The patient is pointed to charity support units and this is not easily accessed by all, it is location dependent. Support is dependent on local funding*

MEMBER, PATIENT FORUM

## Recommendation

**43** Designated cancer centres working with the NCCP, the ICGP, primary care services, patients and voluntary organisations will develop and implement survivorship programmes. These programmes will emphasise physical, psychological and social factors that affect health and wellbeing, while being adaptable to patients with specific survivorship needs following their treatment.

**Lead:** NCCP  
Designated Cancer Centres



# SECTION E

## ENABLING AND ASSURING CHANGE

### OBJECTIVES

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- Strengthen the role of the NCCP in the oversight of cancer control and in implementing the recommendations of the Strategy
- Ensure on-going workforce planning to fulfil changing needs
- Utilise technology, research and data to create a sustainable, high quality and accountable cancer service
- Build better systems and processes to ensure evidence-based prioritisation and service delivery



**20%**  
of HRB-Funded  
Research spend is on  
**cancer  
research**

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**3%** of  
**cancer patients**  
are taking part  
in a **clinical trial**

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**ALL**  
**hospitals** now  
accept **electronic**  
referrals

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# GOVERNANCE AND MANAGEMENT OF CANCER SERVICES AND THE ROLE OF THE NATIONAL CANCER CONTROL PROGRAMME

## 14.1. Introduction

Strong governance is highlighted by the WHO, the OECD and the European Union as a key requirement of cancer control systems. Effective governance structures, together with a comprehensive approach to the prevention, detection and treatment of cancer, are necessary to ensure that the objectives of this cancer strategy will be implemented. A well designed system will provide for effective cancer control policies and plans across the full spectrum of cancer services and across all elements of the patient pathway, encompassing prevention, screening, early diagnosis, treatment and survivorship.

The Evaluation Report on the implementation of **A Strategy for Cancer Control in Ireland (2006)** stated that the most significant factor that has contributed to driving changes in the system was the establishment of the National Cancer Control Programme (NCCP) in the HSE in 2007. The Evaluation Report emphasised that the NCCP should continue overseeing the development of the Irish cancer care system.

## 14.2. Strengthening the Role of the NCCP

The adoption of a programmatic approach to cancer control is recommended internationally in order to harness the necessary policy responses, ensure equity of access to services and ultimately deliver improved outcomes for patients. The NCCP works with the Department of Health, the Health & Wellbeing Directorate of the HSE, Hospital Groups, community healthcare organisations and training, accreditation and professional bodies to achieve these aims.

The NCCP provides leadership across the continuum of cancer care. It promotes the provision of high quality evidence-based care to optimise outcomes and patient experience. The functions, work areas and achievements of the NCCP since its establishment have been documented in its seven year report, published in 2014. The overall strategic input and impact of the NCCP will continue to be in the following areas:

- Leading on the implementation of cancer policy and on the development of cancer services including in the areas of prevention and survivorship;
- Defining evidence-based guidelines and practice in cancer care;
- Commissioning and monitoring service provision;
- Leading on the implementation of capital projects to ensure optimum patient access to diagnostics and treatment; and
- Developing programmes to promote best practice in cancer care, including workforce planning and education/training programmes.

The attainment of the vision, goals and objectives of this Strategy requires a continued commitment to the population based approach to cancer control through an improved model of care with leadership from the NCCP.

#### 14.2.1 Leadership and direction

The NCCP, including through its role on the HSE Leadership Team, will continue to provide leadership and direction to the cancer system to ensure that service priorities are aligned with desired outcomes. The NCCP will work closely with Hospital Groups and community healthcare organisations to lead service reorganisation and to ensure that integrated care pathways are provided for those affected by cancer. The NCCP will be the lead actor in the HSE in the implementation of this cancer strategy and will work to ensure that the objectives of the Strategy underpin decisions on cancer care across the health services.

#### 14.2.2 Funding and commissioning

The NCCP is actively engaged in the funding and commissioning of cancer services. It currently coordinates funding for new cancer developments, including oncology drugs. The NCCP's role in the commissioning of services is supported by its membership on the Consultants Applications Advisory Committee which allows it to influence the appointment and location of new consultant posts.

In order to strengthen its leadership of the cancer services and to drive service improvements, the NCCP will take on an enhanced role in the funding and commissioning of cancer services, including through Service Level Agreements (SLAs) aligned to the implementation of Activity Based Funding (ABF). This will include the linking of funding with strategic priorities and performance monitoring. The NCCP will retain responsibility for all new HSE funding for cancer services and related posts in the annual national service planning process. The enhanced funding role envisaged for the NCCP will extend to the use of existing funding and will not be confined to additional funding. This approach will involve rewarding good performance and reviewing the continued provision of funding to hospitals not providing

the high quality services mandated by the NCCP including adherence to National Standards and NCEC National Clinical Guidelines as appropriate. ABF will facilitate the promotion of high quality cancer services.

The NCCP currently plays a central role in the development of new radiation oncology facilities in the public sector. In the future, it must play a more central role in the planning and commissioning of new and replacement of all health infrastructures with a cancer component.

#### 14.2.3 Oversight and performance review

The NCCP will continue its strong oversight of cancer services, including monitoring the provision of services against agreed performance criteria as set out in the HSE Performance and Accountability Framework. SLAs will be entered into with the Hospital Groups. Implementation of these services will be audited with a focus on achieving agreed outputs and outcomes. Findings will be published annually. This process will be supported by the cancer intelligence function within the NCCP and will also build on other data sources such as the National Cancer Registry. The audit mechanism is essential to support the evidence base for the provision of services, including the provision of specialist services in designated cancer centres. The NCCP will support best practice and the SLAs with the hospital groups will provide a mechanism to address suboptimal performance issues.

The NCCP has significant authority over cancer control services in the public sector in order to ensure that they are in line with national policies and international best practice. This includes the authority to direct the discontinuation of any services that are not in line with agreed policy, or that do not meet required standards. Where clinical and performance targets are not being met, the NCCP will be in a position to move specific services and related resources to other designated cancer centres. There may also be scope to define details of the indemnity cover provided for HSE funded hospitals on the basis of specific surgical oncology procedures.

#### 14.2.4 Developing a mechanism for prioritising new developments in cancer care

New developments in cancer care are emerging rapidly. It is essential that a robust, evidence-based mechanism for assessing, evaluating and prioritising the implementation of these new developments is put in place. The NCCP will develop such a mechanism and ensure that it is used to evaluate new developments in a manner that takes into account the potential benefit to patients in terms of quality of life and outcomes and also ensures that it makes the best possible use of available resources.

#### 14.2.5 Leading service improvements

The NCCP will lead on the development and introduction of service improvements through an on-going review of cancer control measures in Ireland and internationally. This will be based on an assessment of best practice and, where appropriate, may involve the use of economic evaluations and HTAs. The main area of focus will of necessity continue to be on the diagnosis and treatment of cancer. However, other areas in which the NCCP can play a significant role include prevention, screening and survivorship. The development of the NCCP's cancer intelligence function to collate and interrogate the multiple sources of cancer data currently available, and coming on stream, should also be a priority. This latter function will inform a further area of significant need - the provision and implementation of a coherent and comprehensive cancer workforce plan.

The NCCP will continue to develop standards for cancer care in Ireland through its National Guideline Development Groups.

#### 14.2.6 The role of the NCCP with regard to cancer care in the private sector

A significant proportion of cancer care is provided in the private sector. However, the NCCP has no statutory role in the supervision or regulation of cancer care in such settings. In order to ensure optimum patient care in all sectors of cancer care, the NCCP and private sector providers should work together to achieve voluntary participation in data collection, audit, compliance with guidelines and

### Recommendation

- 44** The central role of the NCCP in ensuring that the National Cancer Strategy 2017-2026 is implemented across the health service will be strengthened, including through the use of Service Level Agreements, and through a direct role in financial allocations to Hospital Groups under Activity Based Funding.

Lead: NCCP



**STRONG**  
GOVERNANCE IS A **KEY**  
**REQUIREMENT**  
OF A CANCER CONTROL SYSTEM



reporting of outcomes. Such a programme should be designed to offer reassurance to patients, many of whom move between the public and private sector care on the patient pathway, and funders concerning the standards being achieved in the private sector. The forthcoming Patient Safety (Licensing of Healthcare Facilities) Bill, which includes provisions on hospital licensing, will aim to ensure that cancer treatment only takes place in hospitals, public or private, that meet criteria set out in relation to data collection, audit, compliance with guidelines and reporting of outcomes.

## Recommendation

**45** The NCCP will work with the private sector providers to achieve voluntary participation in cancer data collection, audit, compliance with guidelines and reporting of outcomes.

**Lead:** NCCP

# RESEARCH

## 15.1. Introduction

The positive impact of research activity, including clinical trials, on the care of patients is universally accepted. The development of a culture in the cancer care system that values research to the benefit of patients, and is supportive of those who engage in it, is an aim of this Strategy.

Cancer research supports the recruitment, retention and motivation of clinical staff who will drive the development of quality services. Research is multi-disciplinary and engages professionals from a variety of backgrounds, from basic science through to translational, clinical and health services research. It requires infrastructure and supports appropriate to these different environments, as well as a healthcare system that is supportive. Also, academic and clinical researchers are a major skill base asset for the pharmaceutical sector, which is itself a major contributor to the Irish economy.

National state funding for cancer research is estimated to be in the region of €25m- €30m per annum. This represents approximately 20% of the overall health research spend, a similar percentage to that applying in the UK, though the overall funding for health research in Ireland relative to the size of the healthcare budget is significantly lower than in the UK.

## 15.2. The Environment for Cancer Research

Cancer research is carried out across all the designated cancer centres, Universities and in many other settings. The breadth of research ranges from the discovery and validation of biomarkers for diagnosis, to nutritional studies, psychological and social supports for patients with cancer and survivors, clinical trials of new interventions and research on the sustainable configuration of cancer services. The cancer research community is represented by the Irish Association for Cancer Research (IACR), a non-profit organisation focused on bringing multidisciplinary researchers together to generate a world-class research environment in Ireland. Where access to patients, their samples or their data is needed for research, the HPRA and the recognised Research Ethics Committees (RECs) play a key role in overseeing and regulating research.

The National Cancer Registry (NCR) collects, collates and analyses data on cancer incidence, staging, treatment and survival. Mortality data is collected and published by the Central Statistics Office. The NCR also contributes to the majority of epidemiological and statistical research in this field. The National Centre for Pharmacoeconomics (NCPE) carries out HTAs for cancer drugs. For clinical research, infrastructure supports such as the Health Research Board (HRB) Clinical Research Facilities and the HRB Trials Methodology Research Network are synergistic. Although they are not disease-specific, these infrastructures support high quality cancer research. University-based research is supported by a variety of departments including medicine, nursing, health and social care, psychology, health economics, mathematics, business schools and engineering. In addition, HIQA provides guidance for conducting HTAs and a HTA service for assessment of appropriate technologies.

The largest collaborative cancer research infrastructure in Ireland is Cancer Trials Ireland. Cancer Trials Ireland, which has almost 500 members, is a network encompassing a central office in Dublin (hub) supporting clinical cancer trials units in the cancer centres (spokes). Virtually all oncologists and haematologists in Ireland are active participants, as well as research specialists such as research nurses and translational researchers. In 2014, Cancer Trials Ireland had almost 8,800 patients on active studies. They are funded by the HRB, the Irish Cancer Society (ICS) and by industry. Some pharmaceutical and clinical diagnostics companies have a clinical cancer research base in Ireland and they work closely with Cancer Trials Ireland, and cancer treating hospitals, to evaluate the impact, relevance and utility of emerging diagnostic and treatment approaches. Arising from this, Irish patients have often had unique access to vital new therapeutic advances. In 2014 approximately 3% of all patients with cancer in Ireland were taking part in a clinical trial, and another 6% were involved in a non-interventional study (KPI no. 20).

### 15.3. Funding for Cancer Research

Cancer research in Ireland is funded from a variety of sources. The HRB's investment in such research over the last decade has accounted for 20% of its budget, a significant portion of which has gone to support the work of Cancer Trials Ireland. Since its foundation in 2000, Science Foundation Ireland (SFI) has invested approximately €100m in cancer research. This includes the recent establishment of a Blood Cancer Clinical Trial Network jointly funded with the ICS. Cancer research is also funded by some charities, principally the ICS which has invested over €25m in research over the last decade. From a background of funding individual Fellows and projects, the ICS has moved to funding larger, co-operative awards. (e.g. funding of €7.5m for Breast Predict as a large inter-institutional collaboration across disciplines).

### 15.4. Planning and Coordination

To significantly increase the beneficial impact of clinical, laboratory, translational and population research on outcomes for patients in Ireland, a number of steps need to be taken over the coming years. A key challenge is the absence of an overarching national framework for cancer research in Ireland. There is potential for better coordination between different initiatives and research entities, as well as between Governmental and private agencies. Also, research investment across different cancers may not reflect their relative incidence, emerging patient needs or the national burden of disease.

Research priorities, linked to this Strategy, should be defined within the first year of the Strategy's publication. The NCCP will establish a National Cancer Research Group:

- to monitor and influence national investment in cancer research;
- to foster and promote a supportive environment for cancer research; and
- to improve co-ordination of cancer research, aligned to this Strategy and to the priorities identified by the NCCP over the lifetime of the Strategy.

It is envisaged that the HRB will be represented on this Group, and that the newly appointed HSE lead for research will also be included.

#### Recommendation

46

The NCCP will establish a National Cancer Research Group by end-2017 to improve the coordination of cancer research, to foster a supportive environment for research within the health service and the universities, to set research priorities in line with the overall cancer strategy, to seek to ensure that funding allocation is linked to these priorities and to work to achieve continuity of funding.

Lead: NCCP

## 15.5. People and Leadership

The absence of recognition, stable funding and defined paths of career progression for research staff represent significant impediments to the progress of cancer research in Ireland. There is a lack of appreciation within the health service that research is a relevant, vital and critical activity. Cancer clinical trials should be a core activity of cancer centres. The current funding mechanism for staff in cancer clinical trials units is via recurrent iterations of HRB grants. This has resulted in the proliferation of temporary positions in these units that are unattractive to highly trained staff and, thus, are difficult to fill. The National Cancer Research Group should work to address this problem. This Group should also examine the stability of funding of Cancer Trials Ireland, with a view to enabling it to support longer-term multi-annual commitments and to complete research of critical national importance.

Finally, the NCCP and the National Cancer Research Group should examine mechanisms to ensure that newly appointed consultant cancer specialists have truly protected time to pursue research interests in their new posts.

## Recommendations

**47** The HSE will ensure that clinical cancer research, and the staff who deliver it, become a fully integrated component of cancer care delivery.

**Lead:** HSE

**48** The NCCP and the National Cancer Research Group will examine mechanisms to ensure that newly appointed cancer consultants and Advanced Nurse Practitioners have protected time to pursue research interests in their new posts.

**Lead:** NCCP/National Cancer Research Group



## 15.6. Cancer Research Infrastructure

Ireland has made significant progress with the development of infrastructure for cancer research, including Cancer Trials Ireland, the NCR and a network of Clinical Research Facilities/Clinical Research Centres. It is most important that we grow and support integrated translational and clinical trial infrastructure. Enrolling 6% of patients with cancer on therapeutic trials annually is a goal of this Strategy (see KPIs in Chapter 17). This will result in a doubling of the current figure of 3% described above.

The National Cancer Research Group should also develop proposals for a coherent and integrated approach to cancer biobanking, in line with broader national developments on biobanking, and with a focus on standards, quality and access, to achieve an internationally compliant biobanking resource within the lifetime of the Strategy.

Effective ethical supervision is critical to the successful conduct of clinical trials. Under the EU Directive and the Clinical Trials Regulations 2004 for medicinal products, studies evaluating investigational new drugs only require approval from one Recognised Ethics Committee. However, for other studies, such as translational, epidemiological or biomarker studies, Ethics Committees supervising each individual research site require separate approvals. It is envisaged that the research ethics approval process for such studies will in future be streamlined under the proposed Health Information and Patient Safety Bill. Under this legislation, it is proposed that a single ethical approval will be involved for national or regional human health research. Among the other measures proposed in the Bill is the nomination of HIQA, as the supervisory body for Approved Research Ethics Committees.

## 15.7. Patient Engagement in Research

Patient involvement in cancer research improves the relevance of research questions, the quality, acceptability and feasibility of research conduct and the likelihood of uptake of research outputs. The National Cancer Research Group will look at ways to optimise patient input to cancer research.



# WORKFORCE PLANNING

## 16.1. Introduction

Cancer care, like many other areas of health care, is resource intensive. Staffing is a key part of this resource and is the major contributor to both processes and outcomes in cancer care. Without highly trained and educated staff, the significant improvements in cancer care seen in the past decade would not have occurred. A key aim of this Strategy is to ensure that the appropriate workforce is in place to deliver on its goals and recommendations. This implies an adequate number of staff, with core competencies in cancer care, working at the top of their scope of practice. This will include addressing immediate workforce gaps in areas such as medical oncology, urology and nursing. The provision of additional staff across all disciplines will require a coordinated effort by the NCCP, other Directorates in the HSE, the Department of Health, the education sector and regulatory authorities.

It is difficult to quantify the number of staff involved in cancer care in Ireland. Many health professionals, such as general practitioners, for example, play a significant role in the early assessment and referral of patients and are also involved in the follow up of patients after treatment. Similarly, in our hospitals, many staff in departments such as radiology, dermatology, pathology, physiotherapy, surgery, haematology and gastroenterology are involved in the care of patients with benign and malignant conditions. The increased cancer workload, and increased complexity of therapy, will have significant implications for workforce planning in several of these specialities where cancer forms a major component of day to day working. Examples include the core diagnostic specialities of radiology and pathology, as well as dermatology, where the implications of the increased burden of skin cancers for workforce planning are clear.

Of course many health professionals are wholly, or predominantly, involved in cancer care, such as specialist oncology nurses, radiation therapists and consultant radiation and medical oncologists. Other staff who may work exclusively in cancer care include data managers, MDT coordinators and cancer research staff.

## 16.2. Evaluation Group Assessment of the Current Workforce

In its report on **A Strategy for Cancer Control in Ireland (2006)**, the Evaluation Group made a number of findings and recommendations in relation to the cancer workforce. The Group believed that there are significant opportunities for the deployment of new models of care. They recommended the establishment of comprehensive multidisciplinary oncology teams, underpinned by service specifications that embrace a major and increased role for clinical nurse specialists (CNS), advanced nurse practitioners (ANP) and health and social care professionals (HSCP) in patient assessment, delivery of treatment, survivorship and end-of-life care.

The Evaluation Group recommended that acute staffing shortages in all areas of cancer care in Ireland, including medical, nursing, health and social care professions be addressed as soon as possible. They made particular reference to nursing shortages in chemotherapy units, the lack of ANPs, the widespread use of agency nurses, a severe shortage in health and social care disciplines, including pharmacists and dieticians, and a lack of rehabilitation staff. They were of the opinion that the number of medical oncologists in the country was just over half that which international standards would suggest as appropriate. They also pointed to a shortage of urologists leading to regional variations in access to rapid access prostate cancer clinics.

A clear model of care is the starting point for the development of a workforce plan in any area of the health service. A number of the HSE clinical programmes have recently developed models of care, which have informed their workforce plans (e.g. orthopaedic surgery and paediatrics). Experience gained in developing these plans should be useful in the development of a workforce plan for oncology services.

### 16.3. Areas that Require Investment

While it is not possible at this point to make definitive assessments of the changing or additional needs for the cancer workforce over a ten year period, the following are areas which require urgent attention:

#### 16.3.1 Surgical oncology services

Surgical staff are a critical part of the cancer MDT workforce but, unlike some other specialists, most surgeons work on both cancer and benign disease. This makes it more difficult to predict workforce needs for cancer separate to overall requirements. The Evaluation Report highlighted consultant staff requirements in urology, in particular, as requiring urgent attention. Other staff clearly required to support surgical oncology programmes include specialist nurses, physiotherapists, speech and language therapists and dieticians, with the specific skills mix required being dependent on site specialisation and the completion of the programme for centralisation of cancer surgery.

#### 16.3.2 Radiation oncology services

These services have expanded in line with increased demand and developments in technology. Along with this, radiation oncology therapy has become increasingly tumour-site specialised. There is, therefore, a need for consultant staffing to take account of specialisation within the profession, while maintaining the requirements for comprehensive cover at each centre. In addition, there is a need to increase the number of advanced practice roles for radiation therapists and nurses to manage patients both through the acute phase of their radiotherapy and in follow-up care.

#### 16.3.3 Medical oncology services

As referenced in the Evaluation Report, there is a pressing need to increase staffing in medical oncology units. This involves an immediate need to address existing deficits for consultant medical oncologists and also to plan for the additional requirements resulting from the forecasted increase in cancer incidence, as well as the increasing complexity of medical oncology therapies. Staffing of haematology services also needs to be addressed. Additional medical oncology nursing resources (including CNSs and ANPs) are also required, not only to manage the increasing numbers of patients on therapy, but also to develop nurse-led follow-up programmes. There is also a need for more pharmacists and other health and social care professionals, as well as liaison psychiatry, in medical oncology units.

#### 16.3.4 Oncology and haematology nursing

Nurses comprise one third of the total healthcare workforce and are ideally placed to play a variety of essential roles in cancer care, some in highly specialised posts and others contributing to multiple phases of the patient pathway. There is a growing body of international evidence outlining the beneficial impact of emerging nursing roles in the delivery of care. In the cancer setting, these include generalist nurses, specialist oncology and haematology nurses, CNSs and ANPs.

There is very significant scope and need to expand the number and roles of CNSs and ANPs in our cancer services, in areas such as nurse-led clinics for new patient assessment, oral chemotherapy, follow-up support and survivorship. The immediate expansion of such nursing roles will be a priority for workforce planning by the NCCP.

The provision of additional specialist cancer nurses will require a coordinated effort by the NCCP, the HSE more broadly, the Department of Health, nursing regulatory authorities, hospitals and universities. At present there are significant impediments to the training, recruitment and retention of specialist oncology nurses that need to be addressed. Various issues, such as support for postgraduate education, will need to be reviewed. Specialist nurses will

require administrative support to enable them to effectively fulfil their clinical roles.

The long and complicated pathway to advanced nursing practice has acted as an impediment to the recruitment to, and development of, such roles. A new developmental pathway for graduate, specialist and advanced practice nurses is being established. This will include tackling the barriers that discourage nurses from pursuing higher qualifications, reducing the time involved in developing the skills, knowledge and experience to take up advanced nursing practice positions and breaking the individual nurse/advanced nursing post link to better facilitate continuity of high level services. To drive these changes in the cancer area, and to maximise their impact on cancer nursing services to the benefit of patients, the NCCP will appoint a national clinical lead for cancer nursing.

### 16.3.5 Health and social care professionals

Health and social care professionals (HSCPs) comprise a wide range of grades and professions that are involved at many stages of the cancer care pathway, including radiographers, sonographers, pharmacists, physicists and medical scientists, medical social workers, psychologists, dentists and the therapy professions. Speech and language therapists, occupational therapists and physiotherapists, for example, are vital for patient recovery from surgery and radiation therapists and physicists are an essential part of radiation oncology services. Pharmacists play an important role in the treatment of cancer patients, both in the hospital and the community, and greater support for community pharmacists is required to allow them to provide oral anti-cancer medicines and to counsel patients in a safe and effective manner. Our cancer services in general suffer from a lack of these vitally important staff and this will need to be addressed on a phased basis focusing initially on areas of most critical need. The number of HSCPs graduating from Irish Universities, particularly in the area of radiography, is also a concern, and this will need to be addressed over the course of the Strategy.

### 16.3.6 Research

As outlined in Chapter 15, there is a need to review the career structure of research staff to align the research and clinical needs of organisations conducting research, including cancer clinical trial units. Such staff should integrate fully into the mainstream of cancer care.

### 16.3.7 Leadership

Additional leadership roles for clinicians and non-clinicians will need to be developed to support the implementation of the Strategy. In addition, clinical leads to develop specific areas outlined in the Strategy are required in, geriatric oncology, molecular cancer diagnostics and psycho-oncology. An oncology nursing leadership development programme should also be considered, as recommended by the Strategy Evaluation Group. There is also a need to ensure that the leadership role of the NCCP, across all disciplines, is supported.

## Recommendation

**49** The NCCP will appoint a National Clinical Lead for Cancer Nursing. This person will work with other Directorates in the HSE and with the Department of Health to determine an integrated nursing leadership infrastructure for cancer nursing services at national, regional and local levels to support practice and research.

**Lead:** NCCP

## Recommendation

50

The NCCP, aided by a cross-sector group, will draw up a comprehensive workforce plan for cancer services. This will include an interim assessment of staffing needs at medical, nursing and health & social care professional levels by mid-2018.

Lead: NCCP

### 16.3.8 Other cancer staff

A number of service developments outlined in this Strategy will have workforce planning implications. There have been rapid developments in several clinical areas, largely driven by technological advances and increased specialisation, that will require additional resources. These include cancer genetics, molecular diagnostics, geriatric oncology and psycho-oncology.

Data managers, MDT co-ordinators and other staff should be in place at designated cancer centres to facilitate the efficient operation of the entire cancer care system. Some additional staff will also be required in the NCCP to reflect their responsibilities arising from this Strategy.

## 16.4. A Workforce Planning Framework for Cancer Care

The Department of Health is working on the development and implementation of a national integrated strategic framework for health workforce planning. The framework is intended to support the optimisation of the existing workforce, recruitment and retention, and the optimum mix of skills and competences for the future, across the health system. Once the framework is in place, it is expected that a collaborative multi-disciplinary approach to health workforce planning will be adopted, informed by policy, strategy and the agreed model of care.

In the context of the national integrated strategic framework, the NCCP will develop a comprehensive workforce planning model for cancer in consultation with the Department of Health and other key stakeholders. As a first step an interim assessment of staffing needs at medical, nursing and all health and social care professional levels will be carried out by mid-2018. This process will take account of evidence-based workforce methodologies and will be informed by developments internationally.

# DELIVERING RESULTS: MEASURING PERFORMANCE, QUALITY AND OUTCOMES

## 17.1. Introduction

Measuring the performance and quality of cancer care services and programmes is essential to ensure that the objectives of this Strategy are being met. Provision of accurate and timely information is a central requirement of any effective strategy of cancer control. Such information underpins evidence-based and informed decision making by policy makers, researchers, health professionals and patients.

## 17.2. Cancer Data

The lack of an integrated information system across the entire health service is the major obstacle in providing accessible and shareable management information to measure performance and to inform future policy.

The health system currently captures a large amount of data in a myriad of electronic and manual formats. Some of the information can be used to measure cancer trends, record cancer system activity, improve system performance and, to an extent, shape policies to improve cancer control. Qualitative and quantitative data are available on some population and lifestyle issues, and there are limited data on patient experience of treatment and palliative care. Further data can be captured by surveys and research projects.

The multiplicity of data collection sources do not, in general, collect data in a uniform manner with agreed datasets, shared definitions or standardised coding and classification. In addition, while much data are available from sources such as the NCR or HIPE, it is not evident that these are being systematically, serially and consistently interrogated to generate information that can drive policy. In the context of an overall approach to management of information and information technology across the HSE, it must be a priority to improve collaboration between the collectors and the users of cancer data, such as the NCR, the NCCP, the NSS, individual hospitals and Hospital Groups, the Department of Health and researchers. It will also be essential to have a clear legal and administrative framework for the collection, sharing and reporting of cancer data.

## Recommendations

### 51

The HSE will ensure that all hospitals provide the National Cancer Registry with data related to cancer in an appropriate timeframe to allow for sufficient surveillance of cancer rates and outcomes in Ireland.

**Lead:** HSE

### 52

The Department of Health will review the scope of the National Cancer Registry with a view to increasing and optimising the use of available data to drive improvements in cancer care for patients.

**Lead:** DoH  
NCCP/NCR



### 17.3. eHealth and Cancer Data

The introduction of the Individual Health Identifier (IHI) will greatly facilitate the more efficient collection of cancer data and the resultant reporting of outcome measures.

The **eHealth Strategy for Ireland** outlines how e-health has the potential to transform the delivery of healthcare into safer, higher quality, more efficient and easier to access systems. It will include integration of financial, human resource and clinical systems, facilitating the linkage of resource utilisation to individual patients and outcomes. The implementation of eHealth Ireland will lead to enhanced care for patients, while facilitating aggregation of data for multiple uses.

The introduction of an Electronic Health Record (EHR) is the cornerstone of the eHealth Strategy. A national EHR will support the creation and sharing of key patient information and will consist of core operational solutions (such as ePrescribing and Case Management) along with the ability to aggregate data into a comprehensive national record accessible to health and social care professionals, as well as to patients, service users and carers.

eHealth Ireland, working with the NCCP, created a Cancer Care IT plan which facilitated the procurement of a new Medical Oncology Clinical Information System (MOCIS, Section 10.4) which will be integrated into other national solutions such as the Individual Health Identifier and the Electronic Health Record. Systems such as MOCIS must form part of a larger electronic information network which will plot and report on the entire course of care and follow up for patients with cancer.

### 17.4. Reporting Structures

An annual report will be published by the Department of Health, with input from other stakeholders, on the implementation of this Strategy, with particular focus on the implementation of the recommendations and

the degree to which Key Performance Indicators (set out below) are being met.

Regular monitoring of cancer services will be carried out by the Department of Health, the NCCP and the NSS. The NCCP will engage with the Hospital Groups, the CHOs and Primary Care on a regular basis to ensure that cancer services are provided at all levels of the health service.

The recommendations of the Strategy will be reviewed towards the end of 2021 to ensure that the aims and direction continue to be appropriate to deliver optimum outcomes for patients.

### 17.5. Key Performance Indicators

Key Performance Indicators (KPIs) are required to measure how the health system is delivering on the objectives for improvements in cancer care outlined in this Strategy. They are essential to monitor the impact of the various elements of cancer control across the patient pathway.

The KPIs include internationally comparable clinical outcome measures, as these are the ultimate test of whether the system has performed for patients. Other indicators, such as those focused on process and activity, are required to provide signals in areas such as system performance and capacity.

KPIs will also be used to focus attention on variations in performance, e.g. against the targets or between organisations, regions and populations. The information arising can inform decision making in areas such as policy and resource allocation. Therefore, the KPIs outlined in this Strategy must be collected, collated and reported by the NCCP not only on a national level, but also at geographic or institutional level where relevant.

The KPIs to be captured are set out below. Some refinement of the KPIs over the lifetime of the Strategy is to be anticipated.

Table 17.1 Key Performance Indicators

| KPI No.  | Objective/Action   | Performance Indicator  | Target  | Target date  |
|--|--|--|---|--|
| <b>Objective: Reduce the number of preventable cancers</b> |  |  |   |  |
| 1  | Reduce the proportion of adults in the population who smoke                              | Percentage of adults (aged 15+) in population smoking daily                                  | 5%  | 2025 (Interim measure 17% by 2018)                           |
| <b>Objective: Improve the Early Detection of Cancer</b>    |  |  |   |  |
| 2  | Introduce cancer awareness campaigns for specific diseases (e.g. lung cancer)            | Percentage of lung cancers diagnosed at stage I and II one year following awareness campaign | 15% relative increase                           | One year after awareness campaign. To be reviewed thereafter |
| 3  | Expand electronic referrals for all General Practice cancer referrals                    | Percentage of GP referrals received electronically   | 95%   | End 2022 (Interim Target of 75% for end-2019)                |
| 4  | Increase proportion of cancers diagnosed early   | Percentage of colorectal, breast, and lung cancers diagnosed at stage I and II               | Combined 10% relative increase over 2013 figure | 2020   |
| 5  | Ensure that Rapid Access Clinic and Symptomatic Breast Disease Clinic targets are met    | Percentage of new patients attending RAC or SBD clinic within the recommended timeframe      | 95%   | 2017   |
| 6  | Ensure that GPs have direct access to diagnostics for patients meeting referral criteria | Percentage of patients accessing Imaging/ Diagnostics/ Endoscopy within agreed timelines     | 90%   | 2020   |
| 7  | Reduce the proportion of cancers detected in Emergency Departments                       | Percentage of cancers diagnosed in Emergency Departments                                     | 50% relative decrease over 2013 figure          | 2026   |
| 8  | Maintain target uptake rate for BreastCheck  | Percentage uptake rate for BreastCheck screening population                                  | 70%   | 2017-2026  |

| KPI No. | Objective/Action                               | Performance Indicator  | Target | Target date                               |
|---------|--|--|--------|---|
| 9       | Achieve target coverage rate for CervicalCheck | Percentage five year rolling coverage of CervicalCheck in screening population | 80%    | 2017-2026                                 |
| 10      | Achieve target uptake rate for BowelScreen     | Percentage uptake rate for BowelScreen screening population                    | 60%    | 2020 (Interim measure of 45% by end 2018) |

### Objective: Improve the Treatment of Cancer

|    |  |   |               |                              |
|----|--|---|---------------|------------------------------|
| 11 | Complete centralisation of cancer surgical services  | Percentage of surgeries conducted in approved centres   | 95%           | Various target dates to 2020 |
| 12 | Ensure that patients have their case discussed at an MDT meeting                               | Percentage of patients diagnosed with invasive cancers formally discussed at MDT meetings   | 95%           | End 2020                     |
| 13 | Ensure that patients on active treatment receive appropriate admission in emergency situations | Percentage of patients on active cancer treatment admitted to hospital for cancer treatment that are admitted through Emergency Departments | Less than 20% | 2018                         |
| 14 | Ensure patients with cancer are admitted to cancer units                                       | Percentage of patients requiring active treatment for their cancer admitted to dedicated cancer units in hospitals                          | 80%           | 2020                         |
| 15 | Reduce waiting times for surgery   | Percentage of patients seen within NCCP target surgery timeframes for defined cancers   | 90%           | 2017                         |
| 16 | Achieve the radiotherapy treatment target  | Percentage of patients commencing treatment within 15 working days of being deemed ready to treat   | 90%           | 2017                         |

### Objective: Improve Survivorship Programmes

|    |  |  |     |                                  |
|----|--|--|-----|----------------------------------|
| 17 | Offer patients with cancer a Treatment Summary and Care Plan | Percentage of patients receiving a Treatment Summary and Care Plan | 95% | 2020; Interim target 50% by 2018 |
|----|--|--|-----|----------------------------------|

| KPI No.   | Objective/Action   | Performance Indicator  | Target                            | Target date |
|---|--|--|-----------------------------------|-------------|
| <b>Objective: Improve End of Life Care</b>                                    |  |  |                                   |             |
| 18  | Avoid chemotherapy in patients with advanced cancer who are unlikely to benefit as they are in the terminal phase of their disease | Percentage of patients with metastatic cancer given chemotherapy in last month of life                     | Less than 25%                     | 2019        |
| <b>Objective: Improve Palliative Care Services</b>                            |  |  |                                   |             |
| 19  | Increase proportion of patients receiving specialist palliative care   | Percentage of patients with cancer with stage IV disease receiving a specialist palliative care assessment | 90%                               | 2019        |
| <b>Objective: Support Research and Clinical Trials</b>                        |  |  |                                   |             |
| 20  | Increase patient participation in clinical trials  | Percentage of patients on cancer therapeutic clinical trials   | 6%                                | 2020        |
| <b>Overarching Objective: Improve Incidence and Survival Rates in Ireland</b> |  |  |                                   |             |
| 21  | Improve Ireland's cancer ranking among EU member states  | Ireland to be in top quartile for five year survival among EU member states                                | Top quartile for overall survival | 2026        |
| 22  | Reduce inequalities in age standardised cancer incidence for all malignant neoplasms (excl. NMSC)                                  | Comparison between bottom 20% deprivation vs. top 20%  | Difference no greater than 3%     | 2026        |
| 23  | Reduce inequalities in five year survival for:<br>-all cancers combined (excl. NMSC);<br>-colorectal;<br>-lung; and<br>-breast.    | Comparison between bottom 20% deprivation vs. top 20%  | Difference no greater than 3%     | 2026        |

# RECOMMENDATIONS

| Recommendation  | Lead Agency                        |
|---|------------------------------------|
| 1. The Department of Health will ensure that policies under the <i>Healthy Ireland</i> framework are implemented in full and that opportunities to address cancer prevention measures under those policies are maximised. In particular, measures aimed at further reducing smoking levels will be pursued.                                 | Lead: DoH                          |
| 2. The NCCP will develop a cancer prevention function, working in conjunction with the broader <i>Healthy Ireland</i> initiative, and will lead in relation to the development and implementation of policies and programmes focused on cancer prevention.  | Lead: NCCP                         |
| 3. The Department of Health will develop a national skin cancer prevention plan and oversee its implementation as a priority. The plan will prioritise children, outdoor workers, sunbed users and those who pursue outdoor leisure activities.   | Lead: DoH                          |
| 4. The NCCP will develop a systematic, evidence-based mechanism to ascertain the potential benefits and the cost-effectiveness of various initiatives (including chemoprevention) which will inform future cancer prevention programmes.  | Lead: NCCP                         |
| 5. The HSE will ensure that the appropriate endoscopy capacity is provided in hospitals to allow for the expansion of BowelScreen to all aged 55-74 by end-2021.  | Lead: HSE                          |
| 6. The NCCP will draw up a plan by end-2017 for the development of an integrated cancer control and surveillance service for defined population subgroups with an inherited familial predisposition to cancer (e.g. breast, ovarian and colorectal).  | Lead: NCCP                         |
| 7. The NCCP and the HSE Health & Wellbeing Directorate, in partnership with the voluntary sector, will develop a rolling programme of targeted multi-media based public awareness and education campaigns, aimed at the early detection of specific cancers and with particular focus on at-risk populations.                               | Lead: NCCP<br>HSE/Voluntary Sector |
| 8. The NCCP, working with the ICGP and the National Clinical Effectiveness Committee, will develop a three year plan to enhance the care pathways between primary and secondary care for specific cancers. The plan will set out criteria for referral to diagnostics and incorporate the requirements for additional Rapid Access Clinics. | Lead: NCCP<br>NCEC/ICGP            |
| 9. The HSE will ensure that cancer referrals from a GP into a hospital will be made electronically. Each Hospital Group will facilitate the phasing in of e-referral. This will be completed by the end of 2022.  | Lead: HSE<br>NCCP/GPs              |
| 10. The Department of Health will liaise with the Health and Education authorities with a view to increasing places in Third Level Institutions for the training of radiographers and sonographers.   | Lead: DoH                          |



| Recommendation  | Lead Agency        |
|---|--------------------|
| 11. The NCCP, working with the other Directorates in the HSE, will develop criteria by end-2018 for the referral of patients with suspected cancer, who fall outside of existing Rapid Access Clinics, for diagnostic tests. The NCCP will ensure, through these criteria, that GPs will have direct access to cancer diagnostics within agreed timelines | Lead: NCCP/<br>HSE |
| 12. The NCCP will further develop the model of care for cancer to achieve integration between primary care and hospital settings at all stages of the cancer continuum, from diagnosis to post treatment care.  | Lead: NCCP         |
| 13. Patients diagnosed with cancer will have their case formally discussed at a multi-disciplinary team meeting. The NCCP, working with the Hospital Groups, will oversee and support MDT composition, processes and reporting of outcomes.   | Lead: NCCP         |
| 14. The NCCP, working with the other Directorates in the HSE and with the Department of Health, will develop a rolling capital investment plan, to be reviewed annually, with the aim of ensuring that cancer facilities meet requirements.   | Lead: NCCP         |
| 15. The Department of Health will ensure that investment in infrastructure, facilities, personnel and programmes in the designated cancer centres will have a goal of ultimately developing at least one comprehensive cancer care centre that will optimise cancer prevention, treatment, education and research during the Strategy period.             | Lead: DoH          |
| 16. The NCCP will ensure that consultant appointments for radiology, endoscopy and histopathology, where necessary, are made in conjunction with appointments in other disciplines such as surgery and medical oncology.  | Lead: NCCP         |
| 17. The NCCP will appoint a National Lead for Cancer Molecular Diagnostics for solid and liquid malignancies.   | Lead: NCCP         |
| 18. The NCCP will establish a Steering Group for Cancer Molecular Diagnostics, chaired by the National Lead. This Steering Group will set out the framework for the organisation, location and delivery of cancer molecular diagnostic services.  | Lead: NCCP         |
| 19. The NCCP will further develop the Programme for Hereditary Cancers to ensure that evaluation, counselling, testing and risk reduction interventions are available as appropriate, and that services are available to patients on the basis of need.   | Lead: NCCP         |
| 20. The HSE will ensure that the existing cancer genetics services are amalgamated into one National Cancer Genetics Service and will identify the most appropriate site for its location.  | Lead: HSE          |
| 21. The NCCP will draw up a plan setting out the number/location of designated cancer centres in which surgery will take place for the various tumour types. Timescales for the implementation of the plan will be included for each tumour type.   | Lead: NCCP         |

| Recommendation  | Lead Agency                               |
|---|---|
| 22. In line with the National Plan for Radiation Oncology, public sector radiation oncology facilities in Dublin, Cork and Galway will be expanded to meet patient demand and a planned National Programme of Equipment Refreshment and Replacement will be implemented across the Strategy period.   | Lead NCCP                                 |
| 23. The NCCP will examine the model of care for patients receiving oral anti-cancer medicines and recommend steps to ensure that all patients receive such medicines in a safe and effective manner, with appropriate and proportionate supports, both in the hospital and community setting.   | Lead: NCCP                                |
| 24. The NCCP will develop appropriate MDT, centralisation and treatment arrangements to meet the diverse needs of patients with haematological cancers.   | Lead: NCCP                                |
| 25. The NCCP will develop a systematic, evidence-based mechanism to prioritise the establishment of MDTs for further rare cancers. The centralisation of diagnosis, treatment planning and surgical services for these cancers will be organised in line with best international practice.  | Lead: NCCP<br>HSE/DoH                     |
| 26. The HSE will ensure that an age appropriate facility is designated for adolescents and young adults with cancer within the new children's hospital.   | Lead: HSE                                 |
| 27. The HSE will develop closer links, on a hub and spoke model, between the National Centre for Child and Adolescent Cancer and the other designated cancer centres to provide appropriate and flexible transition arrangements for adolescents/young adults. This will include the joint appointment of adolescent/young adult oncologists and haemato-oncologists and the provision of age-appropriate psycho-social support for these patients. | Lead: HSE<br>NCCP                         |
| 28. Links between cancer services and geriatric services will be strengthened, facilitated by the appointment of a National Clinical Lead in Geriatric Oncology in the NCCP.  | Lead: NCCP                                |
| 29. The NCCP will appoint a National Clinical Lead for Psycho-oncology to drive the delivery of networked services.   | Lead: NCCP                                |
| 30. Each designated cancer centre will establish a dedicated service to address the psycho-social needs of patients with cancer and their families. This will operate through a hub and spoke model, utilising the MDT approach, to provide equitable patient access.   | Lead: NCCP                                |
| 31. Designated cancer centres will have a sufficient complement of specialist palliative care professionals, including psycho-oncologists, to meet the needs of patients and families (such services will be developed on a phased basis to be available over seven days a week).   | Lead: HSE<br>Designated<br>Cancer Centres |
| 32. Oncology staff will have the training and education to ensure competence in the identification, assessment and management of patients with palliative care needs and all patients with cancer will have regular, standardised assessment of their needs.  | Lead: HSE                                 |

| Recommendation  | Lead Agency   |
|---|---|
| 33. The HSE will oversee the further development of children's palliative care to ensure that services are available to all children with a life limiting cancer.   | Lead: HSE   |
| 34. The NCCP will ensure that each hospital has a clearly defined framework for cancer patient safety and quality.  | Lead: NCCP  |
| 35. The NCCP will define focused cancer patient experience surveys to incorporate treatment and survivorship in line with HIQA's standard approach for the National In-Patient Acute Care Patient Experience Survey.  | Lead: NCCP<br>HIQA  |
| 36. The NCCP will develop, publish and monitor a programme of national quality healthcare indicators for cancer care, involving both process and outcome measures, in line with international standards.  | Lead: NCCP  |
| 37. The NCCP will develop further guidelines for cancer care in line with National Clinical Effectiveness Committee (NCEC) Standards. Audits will also be developed in accordance with the NCEC Framework for National Clinical Audit.  | Lead: NCCP<br>NCEC  |
| 38. The Department of Health will ensure that patient representatives are involved in policy making, planning, practice and oversight of cancer services at local, regional and national levels.  | Lead: DoH   |
| 39. The Department of Health will establish a Cancer Patient Advisory Committee to provide input into the development of programmes for patients with cancer. Membership of this committee will reflect the diverse nature of patients living with the effects of cancer, and will ensure that the needs of patients living in more remote areas are represented. | Lead: DoH   |
| 40. All hospitals will offer patients a Patient Treatment Summary and Care Plan as part of their support. These plans will allow patients to store information about their cancer, their cancer treatment and their follow-up care. The plans will also inform future healthcare providers.   | Lead: NCCP/<br>HSE<br>Designated<br>Cancer Centres/<br>Primary Care<br>settings |
| 41. The NCCP, in conjunction with the ICGP, cancer centres, the Irish Cancer Society and cancer support centres, will conduct a Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare. The Needs Assessment should be completed by the end of 2018.  | Lead: NCCP  |
| 42. The NCCP, in conjunction with the cancer centres, will develop shared care protocols for patients with cancer following treatment. These protocols will span the hospital and primary care settings.  | Lead: NCCP  |

| Recommendation  | Lead Agency                                   |
|---|---|
| 43. Designated cancer centres working with the NCCP, the ICGP, primary care services, patients and voluntary organisations will develop and implement survivorship programmes. These programmes will emphasise physical, psychological and social factors that affect health and wellbeing, while being adaptable to patients with specific survivorship needs following their treatment.                           | Lead: NCCP<br>Designated Cancer Centres       |
| 44. The central role of the NCCP in ensuring that the National Cancer Strategy 2017-2026 is implemented across the health service will be strengthened, including through the use of Service Level Agreements, and through a direct role in financial allocations to Hospital Groups under Activity Based Funding.  | Lead: NCCP                                    |
| 45. The NCCP will work with the private sector providers to achieve voluntary participation in cancer data collection, audit, compliance with guidelines and reporting of outcomes.   | Lead: NCCP                                    |
| 46. The NCCP will establish a National Cancer Research Group by end-2017 to improve the coordination of cancer research, to foster a supportive environment for research within the health service and the universities, to set research priorities in line with the overall cancer strategy, to seek to ensure that funding allocation is linked to these priorities and to work to achieve continuity of funding. | Lead: NCCP                                    |
| 47. The HSE will ensure that clinical cancer research, and the staff who deliver it, become a fully integrated component of cancer care delivery.   | Lead: HSE                                     |
| 48. The NCCP and the National Cancer Research Group will examine mechanisms to ensure that newly appointed cancer consultants and Advanced Nurse Practitioners have protected time to pursue research interests in their new posts.   | Lead: NCCP/<br>National Cancer Research Group |
| 49. The NCCP will appoint a National Clinical Lead for Cancer Nursing. This person will work with other Directorates in the HSE and with the Department of Health to determine an integrated nursing leadership infrastructure for cancer nursing services at national, regional and local levels to support practice and research.   | Lead: NCCP                                    |
| 50. The NCCP, aided by a cross-sector group, will draw up a comprehensive workforce plan for cancer services. This will include an interim assessment of staffing needs at medical, nursing and health & social care professional levels by mid-2018.   | Lead: NCCP                                    |
| 51. The HSE will ensure that all hospitals provide the National Cancer Registry with data related to cancer in an appropriate timeframe to allow for sufficient surveillance of cancer rates and outcomes in Ireland.   | Lead: HSE                                     |
| 52. The Department of Health will review the scope of the National Cancer Registry with a view to increasing and optimising the use of available data to drive improvements in cancer care for patients.  | Lead: DoH<br>NCCP/NCR                         |

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# APPENDICES

## APPENDIX A: MEMBERSHIP AND TERMS OF REFERENCE OF THE STEERING GROUP

|                                      |  |
|--------------------------------------|--|
| Professor M. John Kennedy (Chairman) | Consultant Medical Oncologist, St. James's and St. Luke's Hospitals          |
| Ms Majella Byrne                     | HSE Health and Wellbeing Directorate   |
| Mr Donal Buggy                       | Head of Services, Irish Cancer Society                                       |
| Mr Tony Carlin                       | Principal Medical Social Worker, St. Luke's Hospital                         |
| Dr Jerome Coffey                     | Director, National Cancer Control Programme                                  |
| Dr Harry Comber                      | Interim Director, National Cancer Registry                                   |
| Mr Michael Conroy                    | Cancer, Blood and Organs Policy Unit, DoH                                    |
| Ms Sharon Foley                      | CEO, Irish Hospice Foundation  |
| Professor Liam Grogan                | Chair, Irish Society of Medical Oncologists                                  |
| Professor John Hyland                | President, Royal College of Surgeons in Ireland                              |
| Dr Mary Hynes                        | Deputy Director, National Cancer Control Programme                           |
| Ms Anne Jacob                        | Clinical Lead Manager, Carers Association                                    |
| Ms Pauline Kehoe                     | President, Irish Association for Nurses in Oncology                          |
| Dr Marie Laffoy                      | Assistant National Director, National Cancer Control Programme               |
| Dr Graham Love                       | CEO, Health Research Board   |
| Dr Kathleen MacLellan                | Director of Patient Safety and Clinical Effectiveness, Department of Health  |
| Ms Mairéad Mangan                    | Cancer Patient Forum   |
| Dr Deirdre Mulholland                | Deputy Chief Medical Officer, Department of Health <sup>36</sup>             |
| Professor Fergus O'Kelly             | President, Irish College of General Practitioners                            |
| Dr Susan O'Reilly                    | CEO, Dublin Midlands Hospital Group  |
| Professor Joe O'Sullivan             | Clinical Director, Northern Ireland Cancer Centre                            |
| Dr Anne-Marie Ryan                   | Deputy Chief Nursing Officer, DoH  |
| Dr Karen Ryan                        | HSE Clinical Lead for Palliative Care  |
| Professor Owen Smith                 | Consultant Paediatric Haematologist, Our Lady's Children's Hospital, Crumlin |

*The terms of reference of the Steering Group are set out below:*

- To provide guidance and advice to the Department of Health in the development of a National Cancer Strategy;
- To review the report of the Evaluation Team on A Strategy for Cancer Control in Ireland 2006 and the NCCP's Report on the implementation of *A Strategy for Cancer Control in Ireland 2006*;
- To assess the impact of the prevalence of cancer, taking into account the projections of the National Cancer Registry, particularly in regard to providing a continuum of care for patients;
- To review the policy and operational effectiveness of the current approaches to dealing with cancer with a view to building on the progress achieved and addressing challenges over the coming 10 years; and
- To submit a draft Cancer Strategy for consideration by the Minister for Health.

<sup>36</sup> Dr Deirdre Mulholland was replaced by Dr Kathleen MacLellan

## APPENDIX B: MEMBERSHIP AND TERMS OF REFERENCE OF THE PATIENT FORUM

|                           |  |
|---------------------------|--|
| Mr Michael Conroy (Chair) | Department of Health                   |
| Ms Brigid Doherty         | Patient Focus                          |
| Ms Noelle Duddy           | Cooperating for Cancer Care North West |
| Dr Nicola Elmer           | Irish Cancer Society                   |
| Mr Patrick Flanagan       | Barretstown                            |
| Ms Helen Forristal        | Marie Keating Foundation               |
| Ms Evelyn Griffith        | CanTeen Ireland                        |
| Ms Betty Holmes           | Donegal Action for Cancer Care         |
| Ms Ellen Joyce            | Cork ARC Cancer Support House          |
| Ms Mairéad Mangan         | ARC Cancer Support Centres (Dublin)    |
| Mr William McDermott      | Men's Cancer Alliance                  |
| Ms Fiona McEntee          | Europa Donna Ireland                   |
| Ms Bernie McHugh          | Cancer Support Sanctuary LARCC         |
| Ms Teresa O'Brien         | Screening Participant                  |
| Ms Veronica O'Leary       | Purple House Cancer Support            |

*The terms of reference of the Cancer Patient Forum were as follows:*

- To facilitate a patient input to the development of a National Cancer Strategy;
- To inform the work of the Cancer Strategy Steering Group;
- To nominate one member of the Forum to sit as a member on the Steering Group; and
- To consider how the patient input into cancer services can be facilitated more broadly

## APPENDIX C: LIST OF ABBREVIATIONS

|       |  |        |  |
|-------|--|--------|--|
| ABF   | Activity Based Funding                         | IARC   | International Agency for Research on Cancer            |
| ANP   | Advanced Nurse Practitioner                    | ICGP   | Irish College of General Practitioners                 |
| AYA   | Adolescent and Young Adult                     | ICS    | Irish Cancer Society                                   |
| CHO   | Community Healthcare Organisations             | IHI    | Individual Health Identifier                           |
| CNS   | Clinical Nurse Specialist                      | KPIs   | Key Performance Indicators                             |
| CSO   | Central Statistics Office                      | MDT    | Multidisciplinary Team                                 |
| CT    | Computed Tomography                            | MedLIS | National Medical Laboratory Information System         |
| DoH   | Department of Health                           | MMUH   | Mater Misericordiae University Hospital                |
| ED    | Emergency Department                           | MOCIS  | Medical Oncology Clinical Information System           |
| EHR   | Electronic Health Record                       | MRI    | Magnetic Resonance Imagins                             |
| EMA   | European Medicines Agency                      | MRD    | Minimal Residual Disease                               |
| EPR   | Electronic Patient Record                      | NAEDI  | National Awareness and Early Diagnosis Initiative (UK) |
| EPAAC | European Partnership for Action Against Cancer | NCCP   | National Cancer Control Programme                      |
| EU    | European Union                                 | NCEC   | National Clinical Effectiveness Committee              |
| FIT   | Faecal Immunochemical Test                     | NCPE   | National Centre for Pharmacoeconomics                  |
| GI    | Gastrointestinal                               | NCR    | National Cancer Registry                               |
| GP    | General Practitioner                           | NGS    | Next Generation Sequencing                             |
| HEPA  | High-Efficiency Particulate Air                |        |  |
| HIPE  | Hospital Inpatient Enquiry                     | NHQRS  | National Healthcare Quality Reporting System           |
| HIQA  | Health Information and Quality Authority       | NHS    | National Health Service (UK)                           |
| HIV   | Human Immunodeficiency Virus                   | NICE   | National Institute for Health and Care Excellence (UK) |
| HPRA  | Health Products Regulatory Authority           | NIMIS  | National Integrated Medical Imaging System             |
| HPV   | Human Papilloma Virus                          | NIMS   | National Incident Management System                    |
| HRB   | Health Research Board                          | NMSC   | Non-melanoma skin cancer                               |
| HRT   | Hormone replacement therapy                    | NPHOC  | National Paediatric Haematology and Oncology Centre    |
| HSCP  | Health and Social Care Professionals           | NPRO   | National Plan for Radiation Oncology                   |
| HSE   | Health Service Executive                       | NPSO   | National Patient Safety Office                         |

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| HTA   | Health Technology Assessment                           | NSS   | National Screening Service             |
| IACR  | Irish Association for Cancer Research                  | OAM   | Oral Anti-Cancer Medicine              |
| OECD  | Organisation for Economic Co-Operation and Development | SJH   | St. James's Hospital                   |
| OLCHC | Our Lady's Children's Hospital, Crumlin                | SLA   | Service Level Agreement                |
| PET   | Positron Emission Tomography                           | SLRON | St. Luke's Radiation Oncology Network  |
| PSA   | Prostate-specific antigen                              | SREs  | Serious Reportable Events              |
| QA    | Quality Assurance                                      | TILDA | The Irish Longitudinal Study on Ageing |
| RAC   | Rapid Access Clinic                                    | UHG   | University Hospital Galway             |
| RECs  | Research Ethics Committees                             | UK    | United Kingdom                         |
| SACT  | Systemic Anti-Cancer Therapy                           | USA   | United States of America               |
| SBD   | Symptomatic Breast Disease                             | UVR   | Ultraviolet Radiation                  |
| SFI   | Science Foundation Ireland                             | WHO   | World Health Organisation              |



## APPENDIX D: GLOSSARY

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| Adjuvant Therapy      | Another treatment used together with the primary treatment. Its purpose is to assist the primary treatment. Also called adjunctive or adjunct therapy.   |
| Benign                | Not cancerous. Benign tumours may grow larger but do not spread to other parts of the body.  |
| Brachytherapy         | A type of radiation therapy where a radioactive source is placed in or near a cancerous tissue.  |
| Cancer                | A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.   |
| Cancer Incidence Rate | The number of new cancers of a specific site/type occurring in a specified population during a year, usually expressed as the number of cancers per 100,000 population.<br><br>Age standardised: The rates are calculated by applying the age-specific rates for the location being studied to a theoretical world-wide standard population, usually expressed per 100,000 persons per year. |
| Cancer Prevalence     | The number of people now living who have ever been diagnosed with cancer. It includes people diagnosed with cancer in the past as well those who were recently diagnosed.  |
| Cancer Screening      | Examinations to detect cancer before symptoms appear. This may involve blood tests, urine tests, other tests, or medical imaging. Screening is usually offered for all individuals in a defined population group based on criteria such as age or gender, also called Population Cancer Screening.   |
| Chemotherapy          | The use of drugs, singly or more usually in multiple combinations, to treat or cure cancer.  |
| Epidemiology          | The study of the distribution and determinants of health-related states or events (including disease), and the application of this study to the control of diseases and other health problems.   |
| Every Contact Counts  | A behaviour change programme which encourages professionals to use every contact with a member of the public to have a conversation to improve health.   |
| Genomics              | A discipline in genetics that applies recombinant DNA, DNA sequencing methods, and bioinformatics to sequence, assemble, and analyse the function and structure of genomes (the complete set of DNA within a single cell of an organism, )   |

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| Germline mutation     | A germline mutation is a gene change in a reproductive cell (egg or sperm) that is passed down from parent to offspring and are incorporated into the DNA of every cell in the body of the offspring. Germline mutations are also known as hereditary mutations.   |
| Invasive cancer       | Cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues.  |
| Malignant             | Cancerous. Malignant cells can invade and destroy nearby tissue and spread to other parts of the body.   |
| Metastatic Cancer     | The spread of cancer from the primary site to other places in the body.  |
| Molecular Diagnostics | A technique used to analyse biological markers in the individual's genetic code in order to diagnose and monitor disease, detect risk, and decide which therapies will work best for individual patients.  |
| Mortality rate        | The number of deaths occurring in a specified population during a year, usually expressed as the number of deaths per 100,000 population.  |
| Oncology              | Oncology is a branch of medicine that deals with the prevention, diagnosis and treatment of cancer. The three main divisions include: <ul style="list-style-type: none"> <li>• Medical oncology: focuses on treatment on cancer with chemotherapy, targeted therapy, immunotherapy and hormonal therapy</li> <li>• Surgical oncology: focuses on treatment of cancer with surgery.</li> <li>• Radiation oncology: focuses on treatment of cancer with ionising radiation.</li> </ul> |
| Secondary cancer      | A cancer which has spread from the site of the original cancer to another part of the body (see also metastatic cancer).   |
| Somatic Mutation      | A somatic mutation is an alteration in DNA that occurs after conception. Somatic mutations can occur in any cell of the body except for germ cells and therefore are not passed on to any offspring. These alterations can (but do not always) cause cancer or other diseases.   |
| Stage of presentation | The stage at presentation describes the severity of a person's cancer based on the size and/or extent of the primary tumour and whether or not cancer has spread in the body.  |
| Survival              | <b>Net:</b> The probability of surviving cancer in the absence of other causes of death.<br><b>Relative:</b> The ratio of the proportion of observed survivors (all causes of death) in a cohort of cancer patients to the proportion of expected survivors in a comparable cohort of cancer-free individuals.   |
| Survival rate         | The percentage of people in a study or treatment group who are alive for a given period of time after diagnosis.   |



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