

National Cancer Strategy 2006: a Strategy for Cancer Control in Ireland

Evaluation Panel Report

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Executive Summary

An Overview

The evaluation panel was very impressed with the excellent progress in the cancer control system in Ireland since the publication of “A Strategy for Cancer Control in Ireland” in 2006.

Major improvements have been made across the whole spectrum of the patient journey from Prevention to End-of-Life care. A major achievement of the National Cancer Control Programme (NCCP) is that cancer services are now centralized in 8 designated Cancer Centers established in 4 networks. This has led to major (and positive) changes in how cancer treatment is delivered with high volume multidisciplinary cancer services in diagnostics, surgery, radiation oncology and medical oncology. National Tumour Groups have been developed and produced comprehensive, succinct and evidence based guidelines for the management of many clinical conditions.

The various policies and strategies around cancer prevention developed during the past 7 years are excellent and these should be continued and incorporated into the next cancer strategy. The evaluation panel was impressed with the national screening programmes for breast, cervical and bowel cancer and also noted that there appears to be excellent integration with diagnostic and surgical services.

There has been significant progress in the area of early cancer diagnosis with the development of rapid access clinics, with electronic GP referral, in breast, lung and prostate and the implementation of three national screening programmes. National referral guidelines and pathways have been developed in multiple cancers. The evaluation panel was also very impressed by the progress to date of the National Quality Assurance Programmes in Histopathology, Endoscopy and Radiology.

Ongoing research is a key component of all high functioning cancer systems and the panel noted the breadth of clinical studies available to patients through ICORG and incremental progress made in terms of accrual to clinical trials.

The most significant factor that contributed to success in driving change in the cancer control system was the leadership of the NCCP. As pointed out by the World Health Organization, proficient management is needed to integrate these activities into a coherent programme:

“Key to competent management is the leadership of the programme, who should be facilitative, participatory and empowering in how vision and goals are carried out.”

Overall, the evaluation panel believes that the NCCP has done a magnificent job in driving positive change in the cancer system. Looking to the future, we would stress that we believe that the NCCP should continue in its current role overseeing the Irish cancer system.

This will be especially important as over the next decade there will be a major growth in incidence of cancer and demand for cancer services (27% projected increase in incidence from 2015 to 2025). Also, this is important in the context of acute hospital services being reorganized into hospital groups. With regionalization of acute care delivery, attention is needed to ensure the cancer control system evolves appropriately. We believe that the cancer system would continue to benefit from leadership at a national level.

Finally we would suggest the development of a publicly reported cancer system quality index based on the various components of Quality of Care, as described by the U.S. Institute of Medicine and contained in the National Standards for Safer Better Healthcare in Ireland. This is critical if the vision of the 2006 Cancer Control Strategy that “Ireland will have a system of cancer control which will reduce our cancer incidence, morbidity and mortality rates relative to other EU-15 countries” is to be achieved.

Despite the progress over the past 7 years we believe there are a number of key areas that require attention and these are outlined hereafter:

Key Areas that Require Attention

i. Legislative/Structural issues

- Mandatory notification of cancer diagnosis should be introduced.
- Introduction of a unique patient identifier (as planned in the Health Identification Act 2014).
- Information provided to hospital quality of care committees and other designated quality of care committees that deal with quality improvement should be shielded from disclosure in legal proceedings, as is done in many other jurisdictions. This legislative protection should be designed to encourage health professionals to share information and hold open discussions to improve patient care, without fear that the information will be used against them. Under such legislation, information that deals with quality improvement would be shielded from disclosure in legal proceedings. However, the legal protections for quality of care information should be designed so that it cannot be used as a shield to prevent the disclosure to the patient of the facts of any adverse medical event.
- The mandate of the Health Information and Quality Authority (HIQA) should be extended to the private sector.
 - 30% of cancer care occurs in the private sector.
 - All cancer patients (both public and private) should have their cases discussed at a multidisciplinary tumour board.
- Facilitation of data collection in screening programmes from those who decline participation, to allow full evaluation of the impact of these programmes.

ii. Infrastructure

- Inadequate IT infrastructure throughout the health care system, including multiple stand-alone Electronic Medical Records (EMRs) throughout the country is a major issue.

- The development of an EMR for cancer patients which can be shared across all health care providers and “mined” for cancer data should be actively considered.
- The “minimum dataset” should be reviewed to ensure that all factors relevant to quality of care and cancer system performance are collected (to ensure Safe, Effective, Accessible, Responsive, Equitable, Integrated, Efficient care as per Institute of Medicine)
- Molecular diagnostic infrastructure needs to be developed as a priority to support advances in personalise medicine.
- Radiation Therapy:
 - Radiation facilities in St Luke’s should be consolidated onto the St James’s Hospital site, as planned.
 - A capital replacement plan for current radiation equipment should be developed.
- Systemic Therapy:
 - Design of chemotherapy day-care facilities should be re-evaluated with possible changes considered to improve pharmacy facilities, capacity, and patient experience. Particular attention should be given to facilitating assessment and management of acutely unwell patients requiring review.

iii. Prevention and Screening

There should be:

- A sustained emphasis on Primary Prevention and Screening.
- An independent evaluation of the impact of screening programmes at a national level to assess possible harms and benefits.
- The development of a workforce plan for endoscopy services.
 - The roll out of the colorectal screening programme is dependent on sufficient numbers of endoscopists (nurses and doctors) being available.

iv. Organisation of Care Services

The current model of service delivery needs to be re-examined and the establishment of “Comprehensive Multidisciplinary Oncology Teams” should be pursued. This should be underpinned by service specifications that embrace a major role for Clinical Nurse Specialists, Advanced Nurse Practitioners and Allied Health Professionals in patient assessment, delivery of treatment, survivorship and end-of-life care.

a. Continuity of Care:

A model of providing 24/7 care to cancer patients needs to be developed by the NCCP – the current default position, the panel noted, of whereby cancer patients with issues re-enter treatment through Emergency Departments is unacceptable.

b. Cancer Surgery:

- There seems to be considerable delays in diagnosis and treatment due to lack of beds due to admissions from Emergency Departments. Some method of ensuring that beds for cancer patients requiring surgery are available is necessary. We were informed that cancellation of planned cancer surgery occurs on a regular basis and this should not be allowed to continue.
- Continue the process of consolidation of surgical services.
 - In Gynaecological Oncology having 7 centres in a country of 4.5m people seems excessive.
 - Approximately 50% of lung cancer surgery is performed in one large centre:
 - Consider concept of Level I and Level II centres as has been done in other jurisdictions with Level I centres providing the full range of thoracic surgical care and level II centres providing basic thoracic surgery needs.

- Neurosurgery: The evaluation panel was concerned to hear that while local and regional referral pathways have evolved for treatment of patients with spinal metastases that a national or programmatic approach does not exist at this time— this would appear to be a potential major gap in patient care and should be addressed as soon as possible.

c. *Palliative Care:*

The planned review of Palliative Care strategies should include examination of the following:

- How to integrate palliative care across the whole patient journey
- Timing of intervention
 - Palliative Care appears, for the most part, only to be introduced to patients in the last few weeks of life and this is contrary to international best practice.

d. *Psycho-oncology and psychosocial support services:*

A comprehensive psycho-oncology and psychosocial support service plan should be developed as part of the next cancer strategy.

- This should be done in conjunction with the voluntary sector and should include a strategy to improve education of all health care workers in the psychosocial support needs of patients

e. *Role of Primary Care:*

- Role definition of GPs necessary to ensure a more consistent approach to patient management in partnership with specialist care. The evaluation panel noted that there was a significant disconnect between specialist care and primary care.
- Access of GPs to diagnostic tests should be standardised in line with patient diagnostic/referral pathways.

f. Patient and Family input:

A strategic approach to engaging patients and families at the national and local level should be developed.

v. Staffing Shortages:

While the development of new models of care is an urgent priority, dealing with acute staffing shortages in all areas including nursing, allied health and physicians must be undertaken as soon as possible.

- Nursing:
 - Nursing shortages in chemotherapy delivery units is a major concern as regards patient safety
 - Lack of Advanced Nurse Practitioners in this area was startling, compared to other jurisdictions
 - The widespread use of agency nurses on in-patient units (who are often unfamiliar with patient issues and with hospital processes) should be phased out
- Allied Health Professionals:
 - Severe shortage of in allied health disciplines including pharmacists
 - Rehabilitation services poor.
- Medical Oncology
 - Currently 34 Medical Oncologists in Ireland, international standards would suggest that the appropriate number of staff should be approximately 60 at a minimum.
- Urology
 - There is considerable regional variation in access to prostate rapid access clinics due to shortage of urologists.

vi. Oncology Nursing:

Nurses play a key role in all aspects of patient care along the cancer journey and we recommend that the NCCP and HSE appoint senior cancer nurses to all work streams, supported by a leadership development programme.

vii. Hereditary Cancer Programme:

A National Lead for the Hereditary Cancer Programme in the NCCP should be appointed and tasked with development of a National Cancer Genetics Policy as a matter of urgency. This programme requires considerable expansion to meet the needs of patients and their families.

viii. Cancer Survivorship:

A national strategy for cancer survivorship needs to be developed as part of the new national cancer strategy to meet the needs of the growing population of patients requiring follow up of their cancer and support for recovery

- Particular attention should be given to new service delivery models including the contribution of GPs and primary care

ix. Research:

The promotion and facilitation of clinical and translational studies is an integral part of any cancer control programme. The Department of Health and NCCP should work with the Health Research Board and other stakeholders to:

- Develop a comprehensive infrastructure to facilitate research
- Establish a National Research Ethics Board for multi-institutional studies as has been done in other jurisdictions.
- Review the mandate and role of the Health Research Board in cancer research.

Introduction:

In 2006, the National Cancer Forum developed the Second National Cancer Plan for Ireland, *A Strategy for Cancer Control in Ireland* and over the past 7 years the recommendations of this strategy have guided the development of Cancer Services in Ireland. The vision of the strategy was that:

“Ireland will have a system of cancer control which will reduce our cancer incidence, morbidity and mortality rates relative to other EU-15 countries by 2015. Irish People will know and practice health-promoting and cancer-preventing behaviors and will have increased awareness of and access to early cancer detection and screening. Ireland will have a network of equitably accessible state-of-the-art cancer treatment facilities and will become an internationally recognized location for education and research into all aspects of cancer.” (1)

The Minister for Health, Leo Varadkar T.D., requested an external panel be drawn together (Professors Harry de Koning, Alison Richardson and Padraig Warde) to review and report on progress in cancer control since 2006. The review was carried out with the support and help of the Cancer, Blood and Organ Policy Unit (Department of Health), the Office of the Chief Medical Officer (Department of Health), and the Health Services Executive National Cancer Control Programme.

The terms of reference of the review panel are outlined in Appendix 1 and the areas they were asked to comment on included:

- i. evaluate the extent to which the recommendations of the strategy have been implemented;
- ii. identify deficits in the implementation of the strategy;
- iii. summarise success factors or barriers to success;

- iv. identify key learning points arising from the strategy;
- v. assess the overall impact of the 2006 Strategy in terms of the policy indicators outlined in that strategy (Appendix 2);
- vi. examine the projected need for cancer services over the next 10 years;
- vii. evaluate the level of patient input into the design of services, patient engagement in services and patient feedback on experiences and outcomes;
- viii. indicate areas for development in the next strategy;
- ix. comment on Ireland's evolution in cancer control in the light of international trends, to include areas such as prevention, screening, system performance, KPIs, medical/surgical/radiation oncology, medical oncology and drug management programme, data capture & information systems, health intelligence, physical infrastructure and equipment;
- x. outline the options for cancer service configuration and supporting governance arrangements;

The review was conducted between September 29th and October 3rd 2014 in both Dublin and Cork with multiple meetings with senior management in the Department of Health, Health Services Executive, and the National Cancer Control Programme. In addition, the panel met with various stakeholder groups from across the country (Appendix 3) and with patients in a number of the institutions visited. A list of the documents supplied to the review team is given in Appendix 4.

In this report, we have chosen not to include a detailed breakdown of the extent to which each recommendation of the National Cancer Strategy 2006 has been implemented, but instead we have taken a more holistic approach, combining review of data supplied to us and integrated this

with our own analysis of various issues, including comparisons with international norms as appropriate. We have however outlined, in a summary table, our assessment of the degree of success in implementing the 55 recommendations of the National Cancer Strategy 2006 (Appendix 5). Data on 17 of the 19 cancer policy indicators from the 2006 strategy are available and are summarized in Appendix 6.

We will initially comment on various issues that transcend the whole patient pathway e.g. IT infrastructure, research, multidisciplinary care delivery, workforce planning, and Quality Assurance etc. We will then address progress over the past 7 years in various components of the patient journey: Prevention, Screening, Diagnosis, Treatment, Recovery, and End-of-Life care. We will make recommendations for consideration in developing the next cancer strategy and, where appropriate, will indicate where specific changes should be considered for implementation as soon as possible.

Section A: Issues that transcend the whole patient pathway.

The evaluation panel was very impressed with the significant progress in the cancer control system in Ireland since the publication of “A Strategy for Cancer Control in Ireland” in 2006. Major improvements have been made across the whole spectrum of the patient journey from prevention to end-of-life care. A major achievement of the National Cancer Control Programme (NCCP) is that cancer services are now centralized in 8 designated Cancer Centers established in 4 networks. This has led to major (and positive) changes in how cancer treatment is delivered with high volume multidisciplinary cancer services in diagnostics, surgery, radiation oncology and medical oncology. The various policies and strategies around Cancer Prevention developed during the past 7 years are excellent and these should be incorporated into the next cancer strategy.

There has been significant progress in the area of early cancer diagnosis with the development of rapid access clinics, with electronic GP referral, in breast, lung and prostate and the implementation of three national screening programmes with excellent integration with diagnostic and surgical services. National referral guidelines and pathways have been developed in multiple cancers. Overall, in terms of achieving the vision of the *National Cancer Strategy 2006*, the evaluation panel felt the NCCP has made good progress. However, there is a long way to go before Ireland becomes an internationally recognized location for education and research into all aspects of cancer.

The major factor that contributed to success in driving change in the cancer control system was the leadership of the NCCP. As pointed out by the World Health Organization, proficient management is needed to integrate these activities into a coherent programme:

“Key to competent management is the leadership of the programme, who should be facilitative, participatory and empowering in how vision and goals are carried out.” (2)

Overall, the evaluation panel believes that the NCCP has done a magnificent job in driving positive change in the cancer system. Looking to the future, we would stress that we believe that the NCCP should continue in its current role overseeing the Irish cancer system.

This will be especially important as over the next decade there will be a major growth in incidence of cancer and demand for cancer services (27% projected increase in incidence from 2015 to 2025). Also, this is important in the context of acute hospital services being reorganized into hospital groups. With regionalization of acute care delivery, attention is needed to ensure the cancer control system evolves appropriately. We believe that the cancer system would continue to benefit from leadership at a national level.

A.1 Legislative/Structural issues:

The lack of a unique patient identifier is a major issue which significantly inhibits tracking of patients through the public and private systems and makes care co-ordination and workforce capacity planning difficult. The evaluation panel feels that this should be rectified as soon as possible (as planned in the Health Identification Act 2014). The *National Cancer Strategy 2006* recommended that HIQA should “Establish a National Framework for Quality in Cancer Control”. With the publication in 2012 of the National Standards for Safer Better Health Care this has largely been implemented. The NCCP has developed many strategies to assure access and quality of care in the public system including KPIs that are monitored on a monthly basis.

However, up to 30% of cancer care occurs in the private sector and at present there is no assessment of the quality of care these patients receive. Implementation of *National Cancer Strategy 2006* recommendation number 42:

“HIQA should develop a system of licensing and accreditation of Cancer Centres and services that should apply to the public and private sectors; the systems of licencing should be given statutory effect,”

- would largely deal with this issue provided appropriate accreditation standards are put into place (e.g. the need for all cancer patients to have their cases discussed at an MDT).

HIQA does not have as part of its current mandate the quality of care patients receive in the private health care system and the evaluation panel feels that this should be reviewed as part of the next cancer strategy. This framework needs to embrace all the dimensions of quality as

outlined by the Institute of Medicine in its landmark report on Quality (and contained in the National Standards for Safer Better Healthcare in Ireland 2012): Safety, Efficiency, Patient Centredness, Effectiveness, Equity and Timeliness (3,4). This licensing and accreditation framework should also be applied within the publicly funded cancer system.

The National Cancer Registry of Ireland (NCRI) collects data on cancer cases in Ireland and provides some analysis on treatment outcomes. The *National Cancer Strategy 2006* (**rec. 44**) recommended that “*Mandatory notification of cancer should be put in place through appropriate legislation*” This has not been done and the review panel feels that this should be implemented and that this change, along with the introduction of a unique patient identifier, would allow the Department of Health to work more closely with NCCP to monitor progress in improvements in delivery of care and patient outcomes (e.g. development of new Quality Indicators such as adherence to treatment guidelines).

Public reporting on quality of care and performance is an essential aspect of a high-performing cancer system and while the NCCP currently does an excellent job on reporting various key performance indices on a regular basis, the evaluation panel feels that continuous quality improvement is another hallmark of a high-functioning health care system. To promote the sharing of information and open discussions among health professionals, (which can lead to improved patient care and safety) consideration should be given to legislative protection from disclosure in legal proceedings for information provided to hospital quality of care committees (and other designated quality of care committees) that deal with quality improvement. This legislative protection should be designed to encourage health professionals to share information and hold open discussions to improve patient care, without fear that the information will be used against them. Under such legislation, information that deals with quality improvement would be shielded from disclosure in legal proceedings. However, the legal protections for quality of care information should be designed so that it cannot be used as a shield to prevent the disclosure to the patient of the facts of any adverse medical event. More openness about errors would help devise potential solutions to ensure they do not recur and is a key component of the patient safety agenda in other jurisdictions (5).

A.2 Information Technology Infra-structure issues:

The *National Cancer Strategy 2006* (rec. 48) recommended that:

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

Suboptimal IT infrastructure throughout the health care system, including multiple stand-alone Electronic Medical Records (EMRs) throughout the country was a recurrent theme in many of our meetings. This, along with lack of a unique patient identifier, results in poor communication between care providers, lack of appropriate data for planning and coordinating services, difficulties with monitoring performance using KPIs, and makes clinical and translational research difficult on a national level. There has been considerable progress in this area, especially with electronic referrals from GPs to designated cancer centres. However, data collection for many hospitals remains a challenge. The development of an EMR for cancer patients, underpinned by a unique patient identifier, which can be shared across all health care providers and “mined” for cancer data, should be actively considered. A key area currently under review is a national medical oncology IT system for the prescription and safe administration of chemotherapy. While this is very important, the evaluation group would suggest that the development of multiple “stand-alone” systems could lead to unnecessary fragmentation and that the purchase or development of one system that links all treatment disciplines be considered.

The “minimum dataset” for collection on each cancer patient should be reviewed to ensure that all factors relevant to Quality of Care and Cancer System Performance are collected (to ensure Safe, Effective, Accessible, Responsive, Equitable, Integrated, Efficient care as per Institute of Medicine).

A.3 Models of Care/Workforce planning

We believe there are considerable opportunities for deployment of new models of care. In particular, the establishment of “Comprehensive Multidisciplinary Oncology Teams”

underpinned by service specifications that embrace a major and increased role for clinical nurse specialists, Advanced Nurse Practitioners and allied health professionals in patient assessment, delivery of treatment, survivorship and end-of-life care should be pursued. Similarly, there are opportunities for moving to different delivery models (which can often result in a higher quality of care) along the whole continuum of the patient journey. This will become increasingly important in the future as the population ages and there is increasing need to contain health care costs. Along with this, manpower needs for the future should be examined for all medical, nursing and allied health specialties as suggested by the *National Cancer Strategy 2006* (rec. 48): “The HSE should develop a national cancer workforce plan to fully implement national cancer policy”.

A.4 Oncology Nursing

Nurses play a key role in all aspects of patient care along the cancer journey. The review panel was very impressed with the *Strategy and Educational Framework for Nurses Caring for Patients in Ireland* document and progress with implementation to date. This has been achieved in large part by a small group of committed individuals, and despite the absence of investment in specialist cancer nursing leadership at a local and national level. The panel believes that action should be taken to strengthen the leadership of specialist cancer nursing within the context of the NCCP through the nomination of named individuals to all relevant workgroups. Moving forward consideration needs to be given to more fully utilising the scope of practice of oncology nurses in the delivery of services.

A.5 Quality Assurance

Quality assurance programmes are a key cornerstone of all Cancer Control programmes. The evaluation panel was very impressed by the progress to date of the National Quality Assurance Programmes (developed by the Royal College of Physicians of Ireland and the Royal College of Surgeons in Ireland with the support of the NCCP) in Histopathology, Endoscopy and Radiology. These programmes are focused on the work of clinicians and are building a culture of quality in these fields, and are crucial for evaluation of screening programmes.

A.6 Research

The promotion of research is an important part of any Cancer Control programme. ICORG, the Ireland Clinical Oncology Group has been successful in making oncology clinical trials available to Irish patients. ICORG is funded by grants primarily from the Health Research Board, with some support from the Irish Cancer Society, and accrues patients to studies in the Republic of Ireland, whilst also being open to patients in Northern Ireland. The panel was impressed with the breadth of studies available to patients and with accrual to trials. (6) However, the lack of a comprehensive infrastructure to facilitate research was commented on by many groups and what is there, appears not to be co-ordinated to best effect. Establishment of a national Research Ethics Board for multi-institutional studies, as has been done in other jurisdictions, would be very helpful. (7) The Health Research Board is an autonomous statutory agency whose mandate is to promote health care research in Ireland. It is funded by a grant from the Department of Health (around €30m per annum) and approximately 25% of their grants go to promote cancer research. The review panel examined the grants approved by the HRB and in our discussion with staff we were unable to discern a clear strategic vision as to what the HRB wished to achieve in the cancer domain. We would suggest a multidisciplinary research agenda that spans the spectrum of basic laboratory to clinically relevant research to population level research (bench to bedside) should be promoted by the HRB.

A.7 The Patient Voice

We believe that patient input, engagement, and feedback has not received the attention it deserves from all parties involved in national cancer strategy implementation and that there is a lack of a strategic approach to engaging patients and families at the national and local level. Activities, where they occurred, have been largely consultative or focussed on review of patient information materials and ad-hoc patient satisfaction surveys, rather than involving them in co-producing patient centred services. We believe that this is a serious gap and must be addressed if the NCCP is to be assured that the cancer programme is responsive to the needs of patients and families. There is extensive experience in other jurisdictions as to appropriate ways to engage families and patients in all aspects of the cancer systems. (8)

A.8 Public reporting

Public reporting on quality of care and performance is an essential aspect of a high-performing cancer system. Whilst the NCCP currently does an excellent job on reporting various key performance indices on a regular basis, the evaluation panel feels that a cancer system quality reporting system based on the various components of Quality of Care as described by the U.S. Institute of Medicine and the National Standards for Safer Better Healthcare, should be developed by the NCCP. This is similar to what is done in other jurisdictions and provides a regular public assessment of the quality of care and performance in the cancer system. (9)

Recommendations:

For Implementation as soon as possible:

1. Implementation of a national unique patient identifier as planned in the Health Identification Act 2014.
2. Mandatory notification of cancer diagnosis should be put in place through appropriate legislation as recommended in the National Cancer Strategy 2006.
3. Extension of the mandate of HIQA to monitor the quality of care patients receive in the private health care system.

For Consideration going forward:

1. The current model of delivery of services should be re-examined, with particular attention given to the development of “Comprehensive multi-disciplinary oncology teams” with clear delineation of responsibility and authority for individuals in these teams. This should be underpinned by an integrated workforce strategy. We strongly recommend that the NCCP and HSEvappoint senior cancer nurses to all workstreams supported by a leadership development programme.
2. The IT infrastructure issue needs to be addressed in a comprehensive fashion. In particular, the evaluation panel would suggest that the development of an Electronic Patient Record be considered as a matter of some urgency.
3. Clinical and translational research support should be considered a core function in the next National Cancer Strategy
4. The mandate and role of the Health Research Board in cancer research funding should be reviewed
5. Establishment of a national research ethics board for multi-institutional studies.
6. Expansion of the role of the NCRI to report on (with HIQA and the NCCP) progress in improving cancer control.
7. Patient and public involvement in strategy formulation, service development and evaluation should be integral to the next national cancer strategy. All providers of cancer services should develop and implement a strategy to ensure patients and families are involved in the development and evaluation of services with a focus improving outcomes and experiences of most importance to them. An overarching framework is needed to underpin evaluation of patient outcomes and experience in a comprehensive manner.
8. Legislative protection from disclosure in legal proceedings for information provided to hospital quality of care committees (and other designated quality of care committees) that deal with quality improvement should be considered. This legislative protection should be designed to encourage health professionals to share information and hold open discussions to improve patient care, without fear that the information will be used against them.

9. Development by the NCCP of a publicly reported cancer system quality reporting system based on the various components of Quality of Care as described by the U.S. Institute of Medicine.

Section B: Issues along the patient pathway

B.1 Cancer Prevention

The *National Cancer Strategy 2006* made 12 recommendations for Health Promotion and there has been excellent progress in this area by the Department of Health in conjunction with the HSE, including the development of national disease specific policies and strategies as outlined in Appendix 3 of the *Report on the Implementation of A Strategy for Cancer Control in Ireland 2006* (September 2014) produced by the NCCP (10). These include an increased focus on obesity prevention, stopping smoking, decrease in alcohol ingestion, and the need to promote physical activity as outlined in Healthy Ireland. (11) In particular the *National Cancer Strategy 2006 (rec. 3-5)* made 3 specific recommendations aimed at reducing smoking prevalence in Ireland including

- *Compliance with all provisions of the Public Health (Tobacco) acts, 2002 and 2004 should be monitored.*
- *Excise Duty on cigarettes should be substantially increased each year above the rate of inflation.*
- *Nicotine replacement therapy should be made available free of charge to all medical card holders.*

These recommendations have largely been implemented and have been remarkably successful in reducing smoking prevalence. In 2007 approximately 29% of the population smoked and this has dropped to 24% in 2010 and 22% in 2012, which is in accordance with international standards.

As regards alcohol misuse the National Substance Misuse Strategy of 2012 identified a number of concrete measures that have been incorporated into the proposed Public Health (Alcohol) Bill. These include:

- Minimum unit pricing for alcohol products
- The regulation of advertising and marketing of alcohol
- Structural separation of alcohol from other products in mixed trading outlets
- Health labelling of alcohol products
- Regulation of sports sponsorship.

If these alcohol misuse measures are introduced in Ireland, it will become an international leader in the field.

There has been substantial progress in all the other health promotion recommendations of the *National Cancer Strategy 2006* including implementation of the National Task Force on Obesity recommendations, promotion of safe sun practices, radon measurements, and in particular monitoring of the inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes by the National Cancer Registry of Ireland.

The Evaluation Panel feels overall there has been excellent progress in the area of Prevention over the past 7 years and that the recommendations of the *National Cancer Strategy 2006* have largely been implemented.

Recommendations:

1. The various policies and strategies developed in the past 7 years are excellent and should be incorporated into the next cancer strategy.
2. The fact that cancer prevention is everyone's business should be emphasised in the next strategy – in particular we would recommend that a strategy be developed to incorporate education on prevention into all aspects of the Cancer Control Programme e.g. use Screening Programmes, Treatment Programmes, venues and staff to promote healthy lifestyle behaviour. Smoking cessation programmes should be promoted and readily available within all health care facilities and especially within Cancer Centres. The promotion of healthy life style behaviours should be a central component of the cancer survivorship strategy moving forward. As the cancer workforce are a key enabler in that

they support and influence patients, a framework to support practice change in health professionals should be developed.

B.2 Screening

The *National Cancer Strategy 2006* made 8 recommendations for screening/early detection and there has been very good progress in this area including the development of the National Screening Service which currently delivers 4 national programmes, BreastCheck, CervicalCheck, BowelScreen, and the Diabetic RetinaScreen.

Breast cancer screening is currently offered to women aged 50-64 and since 2007 two rounds of national screening have been completed. In total, nearly 450,000 women have been screened and there has been a consistently high rate of uptake of invited women (71%). The BreastCheck location toured by the group (Eccles Street) was very well designed and the evaluation panel noted with approval that digital mammography is exclusively used. The evaluation panel also noted that if cancer is diagnosed, that there appears to be excellent integration with surgical services.

Extension of the upper screening age to 69 was announced by the Irish Government in October 2014. This age extension fulfils one of the key screening recommendations of the *National Cancer Strategy 2006* and brings Ireland in line with both EU and international guidelines in breast cancer screening. The evaluation panel was impressed with the quality assurance and audit programme of BreastCheck and in particular the voluntary accreditation with the European Reference Organisation for Quality Assured in Breast Screening and Diagnostic Services (EUREF).

Cervical cancer screening is currently offered to women aged 25-60 and since 2007 two rounds of national screening have been completed with excellent uptake, 83% for women aged < 30 and 74% overall. Access to Colposcopy services is monitored and has improved significantly. The national roll-out of this programme fulfils another key screening recommendation of the *National Cancer Strategy 2006*. The evaluation panel was impressed with the plans of CervicalCheck to perform a formal Health Technology Assessment on possible changes required to the screening strategy going forward with the change in population being screened (after incorporation of HPV vaccination), and the evolving role of primary HPV testing for cervical cancer. The panel also noted the high level of satisfaction by the women screened and that > 99% would recommend using the service to a family member or friend. (12)

Bowel Cancer screening is being introduced in a phased way between 2013 and 2015 starting with men and women aged 60-69. There is a plan to extend the age to between 55-74 in the future, in line with international recommendations. The evaluation panel noted that it is the first national screening programme to use the fecal immunochemical test (FIT) test. The programme appears to be well integrated with accredited colonoscopy services and surgery for cancer patients. Going forward it will be essential to ensure that there are sufficient endoscopists, which can be either nurses or doctors, to deal with the demand as the screening age is extended. The national roll-out of this programme fulfils another key screening recommendation of the *National Cancer Strategy 2006*.

Independent evaluation of the impact of screening programmes at a national level to assess possible harms and benefits should be performed on a regular basis. This would be facilitated by a regulatory/legislative change to allow for data collection from those who decline participation in screening programmes.

The Evaluation panel feels overall there has been excellent progress in the area of Screening over the past 7 years and that the recommendations of the *National Cancer Strategy 2006* have largely been implemented.

Recommendations:

1. The approved age extension for those aged 65 – 69 inclusive, to be rolled out in the BreastCheck programme, should be completed and appropriately resourced as soon as possible.
2. Likewise, rapid extension in the BowelScreen Programme is essential.
3. Extension of screening programmes to high-risk populations should be considered. This is particularly relevant in breast cancer screening and should be linked to the hereditary cancer programme.
4. The opportunity for the National Screening Service to be involved in promoting cancer prevention strategies should be explored.
5. Independent evaluation of the impact of screening programmes at a national level to assess possible harms and benefits should be performed on a regular basis and there

should be a regulatory/legislative change to allow for data collection from those who decline participation in screening programmes

B.4 Diagnosis

An important recommendation of the *National Cancer Strategy 2006 (rec. 20)* was that “The HSE should develop specific programmes that promote early detection of cancer.” There has been definite progress in this area with the development of rapid access clinics in breast, lung and prostate. Electronic patient referral to these clinics appears to be working well. National referral guidelines for GPs have been developed in Breast Cancer, Lung Cancer, Prostate Cancer and Melanoma and are being finalised in Ovarian Cancer and Head & Neck Cancer. Referral pathway documents for GPs have also been developed in Breast Cancer, Lung Cancer and Prostate Cancer, and a pathway for Ovarian Cancer is in development. However, while these pathway and guideline documents appear to be excellent and appropriate the evaluation panel found significant problems with the implementation of these services:

- Access to diagnostic services appears to be a major problem for some General Practitioners. It was pointed out to the panel there are often considerable delays in obtaining appropriate diagnostic tests and outpatient appointments for symptomatic patients. In addition, there appears to be considerable regional variation in access to laboratory and imaging services. In discussions with representatives of the Irish College of General Practitioners we were informed that 20% of GPs have no access to diagnostic ultrasound. This is concerning given the fact that the “Ovarian Cancer GP Referral Pathway” document produced by the NCCP Community Oncology Programme specifically recommends “urgent ultrasound of the Abdomen and Pelvis” in certain cases.
- Communication with GPs from the rapid access clinics and hospital services in general needs to be improved.
- In discussion with patients the lack of “Equity” in this area was mentioned. Some patients we talked to had quite different experiences with diagnosis – those who could afford to access the Private System for imaging tests and biopsy were apparently

diagnosed in a more timely fashion than those who had to rely on services in the Public System .

- GPs and patients made the point on a number of occasions that while they were in general satisfied with the “Cancer Programme” when they “managed” to access the “Cancer System”, that securing a diagnosis in a timely manner was often very frustrating and associated with considerable delays and anxiety.
- There appears to be considerable regional variation in timely access for prostate cancer diagnosis with the South-East of the country having especially poor service.
- The fact that the Breast rapid access clinics are being stretched by non-urgent patients who likely do not need specialised evaluation was pointed out to the panel on a number of occasions (the term “overwhelmed” was used by a number of physicians).

Another important recommendation of the *National Cancer Strategy 2006* (**rec. 34**) was that “*A National Cancer Genetics Policy should be developed*”. While the National Center for Medical Genetics in Crumlin does some work in this area the panel heard from many sources that the nascent National Hereditary Cancer Programme is poorly resourced and developed, and requires considerable expansion to meet the needs of patients and their families.

The Evaluation Panel feels overall there has been definite progress in the area of Diagnosis over the past 7 years, and that the recommendations of the *National Cancer Strategy 2006* have largely been implemented, with the exception of the recommendation on the development of a National Cancer Genetics Policy.

Recommendations:

For Implementation as soon as possible:

1. The issue of consistent timely access to appropriate diagnostic tests for GPs and hospital appointments for symptomatic patient’s needs to be addressed as a matter of urgency.
2. Refine referral pathways and service models to ensure specialist oncology referral is reserved for those who need it and to avoid the worried well overloading specialist cancer clinics. This should be accompanied by public education programmes.

3. Disparities in access to diagnostic ultrasound and other tests should be addressed.
4. Variation in access to rapid diagnosis clinics should not be allowed to continue – the panel believes that this likely will involve recruitment of additional specialists in some communities.
5. A National Lead for the Hereditary Cancer Programme should be appointed by the NCCP and tasked with development of a National Cancer Genetics Policy as a matter of urgency.

For Consideration going forward:

1. Extension of the rapid access clinic model to other cancers.
2. Development of further National Referral Guidelines and Pathways for GPs
3. Investment in educational strategies for GPs in these Guidelines and Pathways

B.5 Treatment

The *National Cancer Strategy 2006* made numerous recommendations on how cancer care should be delivered. Specifically it recommended that “All Cancer Care should be delivered through a national system of four managed Cancer Control Networks, each serving a population of approximately one million people”. A major achievement of the NCCP is that cancer services are now centralised in 8 designated Cancer Centres established in 4 networks (with Letterkenny Hospital acting as a satellite of University College Galway for Breast Cancer surgery). This has led to major (and positive) changes in how cancer services are delivered in Ireland. Prior to the development of the *National Cancer Strategy 2006* cancer treatment was fragmented with many patients treated in small centres with low volumes and little access to multidisciplinary consultation.

The key aspects of the designated cancer centres are sustainable high volume multidisciplinary cancer services spanning the range of diagnostics, surgery, medical oncology and access to radiation oncology. All new patients and selected patients with complex recurrent disease are

reviewed in multidisciplinary team meetings comprising all diagnostic and therapeutic specialists.

It was recommended in the *National Cancer Strategy 2006 (rec 32)* that:

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

Breast cancer surgery has now been centralised from 32 hospitals to 8 cancer centres. The NCCP has moved to centralise services into designated cancer centres in prostate, lung, pancreas, rectal and oesophageal cancers. This is work in progress with for example 77% of rectal cancer surgeries currently being performed in cancer centres. While improvements in 5-year survival are expected these will not be evident until there is 5-year follow-up after implementation of these changes.

National Tumour Groups have been developed by the NCCP, in collaboration with the Royal College of Physicians of Ireland and the Royal College of Surgeons in Ireland. These have produced comprehensive, succinct and evidence based guidelines for the management of many clinical conditions and these are now being introduced into practice. In the future, these will facilitate the introduction of an important quality metric – adherence to guidelines in the treatment of patients.

Overall, the evaluation panel was very impressed with the excellent progress in the treatment of cancer patients by the NCCP over the past 7 years. However, we heard from stakeholder groups (and especially from patients) regarding many problematic areas in the treatment domain. We recognise that many of these problems arose because of the fiscal crisis in the country but feel that they need to be highlighted so that they can be addressed. The specific problems included:

- ***HR issues:***

Inadequate staffing was a major theme throughout virtually all meetings with staff and patients throughout the country. We heard descriptions of a fragmented cancer delivery system, a system in crisis, held together by goodwill. Morale appears to be very poor in certain professional groups. It would appear that insufficient attention is being paid to developing alternative models of care such as moving care delivery to

less expensive models e.g. integration of advance practice nurses in Oncology Teams, thereby reducing the need for additional Consultant Physicians. It was pointed out to the evaluation panel that it is difficult to plan for the future when the prevailing feeling among many health care workers is that the system is in crisis. We highlight here some of the major issues but staff shortages leading to gaps in care delivery are evident throughout the Cancer Programme.

- **Nursing:** The Employment Control Framework has had a major detrimental effect in the cancer programme. We heard repeatedly, including on a number of occasions from patients, that staff are overworked, demoralised and cannot deliver appropriate care. Patients told us that that they do not feel safe at night in hospital, largely because of the widespread use of agency nurses who are often unfamiliar with patient issues and with hospital processes. Nursing shortages in chemotherapy delivery units is another major concern as regards safe delivery of treatment. The lack of Advanced Nurse Practitioners throughout the programme was startling compared to other jurisdictions.
- **Allied Health:** There is a severe shortage of allied health professionals in the Cancer Programme and there would appear to be no comprehensive strategy to ensure patients have access to appropriate rehabilitation facilities to better enable them to recover after treatment and in some cases actually continue with treatment (e.g. Social Worker support, Speech Therapist for swallowing difficulties). The shortage of pharmacists is another concern and while excellent work has been done by the NCCP in developing an Oncology Medication Safety Review Report, the shortage of pharmacists gives rise to patient safety concerns.
- **Administrative staff:** Again here, the Employment Control Framework has had a major detrimental effect in the cancer programme. One specific example the evaluation group found hard to believe was that apparently a National Neuro-Oncology Lead was recruited without appropriate administrative support.
- **Neuro-Oncology;** The National Neuro-Oncology Programme is based in one centre in Dublin with a satellite unit in Cork. This would appear to be.

an appropriate organisational model. However, the committee was concerned to hear that, while local and regional referral pathways have evolved for treatment of patients with spinal metastases, that a national or programmatic approach does not exist at this time— this would appear to be a potential major gap in patient care and should be addressed as soon as possible.

- **Medical Oncology:** There are currently 34 Medical Oncology posts in Ireland of which 31 are filled by permanent staff. International standards would suggest that the appropriate number of staff should be approximately 60 at a minimum (4). The situation is especially acute in the Cork and Kerry area, where for a catchment area of nearly 800,000 people there are only 2 fulltime Medical oncologists in practice, helped by 1 locum physician. In addition, there would appear to be no Advanced Nurse Practitioners who can make a significant contribution to the management of chemotherapy patients. An additional problem appears to be that Non-Consultant Hospital Doctor support in Medical Oncology is poor, likely due to difficulty filling training posts as these are not seen to be attractive due to excessive workload.

- ***Palliative Care:***

The *National Cancer Strategy 2006 (rec. 35)* recommended that:

“The HSE should ensure that each Managed Cancer Centre Control Network has a comprehensive specialist palliative care service.”

In contrast to the well-designed Palliative Care Centre we visited, we heard repeatedly that the palliative care services available to patients are not integrated with mainstream cancer care for a whole variety of reasons including lack of specialist palliative medical and nursing teams. In addition, we heard that there is some resistance from cancer specialists to the contribution palliative care can make to patient management.

Palliative Care often appeared only to be introduced to patients in the last few weeks of life and this is contrary to international best practice. There is a need to transform

the model of care and ensure actions are taken to achieve an effective interface between palliative care and cancer care, especially in acute hospitals (perhaps by involving palliative care teams in MDTs and establishing joint clinics) and to link services to primary care. This will require attention to organisational and structural aspects of care delivery, such as the integration of specialists in palliative medicine within the comprehensive multidisciplinary oncology teams (and other work to ensure the standardisation of and access to palliative care for all cancer patients). In addition, attention should be paid to fostering a culture which values the role of palliative care alongside the delivery of cancer treatment.

We would however point out that there are some areas in which there is excellent Palliative Care Delivery, but this tends to be confined to the hospice context as opposed to enabling patients and their families to access specialist palliative care early in their disease trajectory. Education of non-specialist palliative care providers in the skills, knowledge and attitudes necessary to provide good palliative is important. This can be achieved in a number of ways including ensuring palliative care training is incorporated into the curriculum for trainees in all disciplines.

- ***Psychosocial Care:***

The National Cancer Strategy 2006 (rec. 37) recommended that:

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

This recommendation has not been implemented in any meaningful way and we heard repeatedly that this aspect of cancer care is poorly organised and delivered in the Cancer Programme. The various cancer charities appear to provide excellent support in this area, where they can, but there would appear to be no service delivery plan for psycho-oncology and psychosocial support for cancer patients in the country. There was a perception amongst patients and families of inadequate support being available in the voluntary sector. In addition, there would appear to be a need to train cancer health care professionals in the psycho-social issues that cancer patients face and how

to manage communication about diagnosis and prognosis sensitively – we heard on a number of occasions from patients that, while most staff were caring and professional, that some were dismissive and added to patients difficulties in coming to terms with their illness.

- *Surgical Services:* While there has been great success in centralising surgical services in the past 7 years the evaluation panel heard that there are some opportunities to continue this process. Specifically, in Gynae Oncology it would seem that having 7 centres in a country of 4.5m people would seem excessive. In addition, approximately 50% of lung cancer surgery is performed in one large centre and there may well be an opportunity for consolidation of services in this area as well, perhaps by considering the concept of Level I and Level II centres as has been done in other jurisdictions. Level I centres would be tertiary care facilities equipped to manage the full range of thoracic surgical care and Level II or secondary care units would provide basic thoracic surgical needs. (13)

While both medical and radiation oncology services are delivered in an ambulatory care setting surgical care is mainly delivered on an in-patient basis. Patients frequently have their surgery delayed because of lack of beds – due to admissions from the Emergency Department. This often leads to considerable delays in diagnosis and treatment and is a major source of frustration for both patients and medical staff. Surgery is by far the most important curative treatment strategy for cancer and some method of ensuring that beds for cancer patients requiring surgery are available when required. Frequent cancellation of planned cancer surgery should not occur.

- ***Lack of facilities to assess cancer patients requiring urgent care while on active treatment.***

The lack of access to cancer care “after hours” was a major theme in our discussion with patients. Many of them told us that they would “in no circumstances” go to the Emergency Department for care unless they absolutely had to because of long waits to be seen, lack of access of medical staff to their records and lack of understanding of the care they required. Even when they were admitted to hospital via Emergency Departments there appeared to be a lack of continuity of care in certain circumstances from the Oncology Team. One patient recounted that during one admission for a chest infection while on chemotherapy he was moved on 16 different occasions around the hospital and had limited contact with his oncology team. This problem is not confined to chemotherapy patients as patients with complications after surgery also appear to suffer from a similar lack of continuity of care.

Chemotherapy day-care facilities: Most chemotherapy day-care centres were not designed for this purpose and demand for chemotherapy is outstripping capacity. This has led to significant difficulties in the delivery of modern state-of-the-art care including integration of pharmacists into the delivery team, patient privacy and comfort, and inability to segregate immune-compromised patients. The lack of facilities to assess patients with urgent care needs when they arrive for their chemotherapy appointment (as noted above) was a recurring theme.

Radiation Facilities: The National Cancer Strategy 2006 (rec. 40) recommended that “The National Network for Radiation Oncology Services should be established by the HSE in accordance with the timelines set by Government. Since 2007 there has been great progress in this area and two new facilities have opened in Dublin and expanded facilities are being built in Cork and Galway. The evaluation panel heard on a number of occasions that additional capacity, if needed, could possibly be purchased from the private sector. The committee does not recommend this approach as the provision of Radiation Medicine services is not simply reliant on procuring fractions of radiotherapy but rather relies on a complex multidisciplinary team approach to patient care. The average life span of linear accelerators is approximately 10-12 years and while many of

the treatment units currently in use are quite new, a machine replacement plan should be developed as part of the next cancer strategy.

Recommendations:

For Implementation as soon as possible:

1. Appointment of permanent staff rather than reliance on agency nursing staff, and locums. This is especially important in in-patient and chemotherapy day care units.
2. Review of the National Neuro-Oncology services, with a special emphasis on the role of neurosurgery in the management of spinal metastases.
3. Review of Medical Oncology staffing needs with a particular emphasis on staffing in areas outside Dublin.
4. Review of how to ensure that treatment delays are minimised for patients who require surgery for cancer control.

For Consideration going forward:

1. The National Palliative Care Strategy should be re-examined with particular attention as to how to integrate palliative care across the whole patient journey.
2. A comprehensive psycho-oncology and psychosocial support service plan should be developed in conjunction with the voluntary sector. This should include:
 - a. A strategy to improve education of all health care workers in the psychosocial support needs of patients.
 - b. The introduction of a standardised approach to assessment of psychosocial distress.
3. Consideration should be given to increased consolidation of surgical services.

4. Models of providing 24/7 care to cancer patients should be explored – outside of the default position of sending them to Emergency Departments.
5. Chemotherapy day-care facilities should be re-evaluated with possible design changes considered to improve patient capacity and flow among other issues.
6. A replacement plan for radiation therapy equipment should be implemented in line with target dates.

B.6 Recovery

Planning for cancer survivorship appears to have received little attention over the past 7 years and was not specifically addressed in *National Cancer Strategy 2006*. The Community Oncology division of the NCCP presented an outline of a three year plan with an emphasis on the development of a treatment summary and care plan for patients as they transition out of acute cancer care. This plan includes promotion of self-management by patients, training and education and research. Until recently there has only been a modest amount of effort applied to thinking about how service delivery models might need to evolve (including the contribution of GPs and primary care) to meet the needs of the growing population of patients requiring follow up of their cancer and support for recovery. The impact of cancer and cancer treatment on the health and quality of life of cancer survivors is substantial and advances in early detection, effective therapies and supportive care has led to burgeoning numbers of cancer survivors in many developed countries.

The last decade has ushered in a new era in the United States, Canada, Australia and Europe, heralded by an interest in health, functioning and psychosocial well-being of those living with and beyond a cancer diagnosis. This has naturally led to questions about the most appropriate configuration of services and models of care for follow up care. It is recognised that many survivors have ongoing needs and they may encounter fragmented, poorly co-ordinated follow up care. It is now widely accepted that this demands comprehensive management namely: prevention and surveillance for recurrent and new cancers as well as psychosocial late effects; intervention for the physical and psychosocial consequences of cancer and its treatment; and coordination between specialists and primary care providers (14,15). Many jurisdictions are

developing evidence-based models to address the needs of cancer survivors that are underpinned by a philosophy centred on recovery, health and well-being and include programmes designed to better enable people to manage self-care requirements in the period of cancer survivorship following treatment completion. This will be an important area going forward, currently Ireland has > 100,000 long term survivors from cancer and this will grow considerably over the next decade. Attention also needs to be given to those living with advanced cancer, alongside those who have received curative treatment.

Recommendation:

1. A National Plan for cancer survivorship should be an integral component of the next cancer strategy.

B.7 End-of-Life Care

This has already been discussed in the treatment section above. However, it should be emphasised again that Palliative Care and Symptom Management services should be integrated across the whole continuum of cancer care. The strategy going forward should address by consensus service models to underpin the delivery of exemplary end of life care and consideration given to the development of service specifications for specialist palliative care.

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Glossary

NCCP – National Cancer Control Programme

ICORG All Ireland Cooperative Oncology Clinical Research Group

HIQA - Health Information and Quality Authority

ED – Emergency Department

HRB Health Research Board

HSE Health Services Executive

MDT Multidisciplinary Tumour Board

NCRI National Cancer Registry Ireland

EMR Electronic Medical Record

EUREF European Reference Organisation for Quality Assured Breast Screening and Diagnostic Services

FIT Fecal Immunochemical Test

HPV Human Papillomavirus

Appendix 1

Evaluation of the National Cancer Strategy 2006 (*A Strategy for Cancer Control in Ireland*)

1. Scope of Evaluation

The evaluation of the 2006 strategy will include consideration of the outcomes of the recommendations therein and indicate the overall impact of the strategy on cancer control. The evaluation will also review where Ireland is located in terms of developments internationally and will make recommendations for the future. The evaluation will also assess current practice in cancer control against the policy indicators outlined in *A Strategy for Cancer Control in Ireland*.

2. Monitoring Structures

An Advisory Group comprising representatives of the Cancer, Blood & Organs Policy Unit, the Office of the Chief Medical Officer (Department of Health) and the HSE National Cancer Control Programme (Appendix I) has been established and it will support and facilitate the work of the Evaluation Group.

An Oversight Group (Appendix II) has been put in place to oversee the work of the Evaluation Group.

3. Terms of Reference of Evaluation Group

The terms of reference of the Evaluation Group will be as follows:

- x. evaluate the extent to which the recommendations of the strategy have been implemented;
- xi. identify deficits in the implementation of the strategy;
- xii. summarise success factors or barriers to success;
- xiii. identify key learning points arising from the strategy;
- xiv. assess the overall impact of the 2006 Strategy in terms of the policy indicators outlined in that strategy (Appendix III);
- xv. examine the projected need for cancer services over the next 10 years;
- xvi. engage in appropriate consultation with stakeholders;
- xvii.

- xviii. evaluate the level of patient input into the design of services, patient engagement in services and patient feedback on experiences and outcomes;
- xix. indicate areas for development in the next strategy;
- xx. comment on Ireland’s evolution in cancer control in the light of international trends, to include areas such as prevention, screening, system performance, KPIs, medical/surgical/radiation oncology, medical oncology and drug management programme, data capture & information systems, health intelligence, physical infrastructure and equipment;
- xxi. outline the options for cancer service configuration and supporting governance arrangements;
- xxii. provide a report in draft form to the Oversight Group; and
- xxiii. submit a final report in writing to the Department.

4. Work Plan

A recommended work plan for the Evaluation Group is set out below. This will be discussed in greater detail with the Evaluation Group.

Task	Timeframe for delivery	Lead responsibility for delivery
<p>Teleconference Meeting to be held involving the Evaluation Group and the Oversight Group</p> <p>Such meetings to be hold as required during the evaluation process.</p>	Early September	Evaluation Group and Oversight Group
Review of relevant quantitative and qualitative information by the Evaluation Group	September	Evaluation Group
Stakeholder consultation, including on-site meetings in Ireland	29 September – 3 October	Evaluation Group
Provide Draft Report for consideration	End October	Evaluation Group

and feedback from the Oversight Group		
Feedback from Oversight Group	Mid November	Oversight Group
Provide Final Report	Early December	Evaluation Group

The Evaluation Group will hold meetings with stakeholders and visit a number of sites in Ireland.

Cancer, Blood & Organs Policy Unit will support the work of the Evaluation Group and will arrange site visits and consultation with stakeholders. The Department's Office of the CMO and the National Cancer Control Programme will also be available to support the work of the Evaluation Group.

The Chair of the Evaluation Group will coordinate the activities of the Group and be responsible for the production of the evaluation report. He will decide on the work plan for the individual members of the group, including attendance at site visits and meetings with stakeholders.

5. Composition of Evaluation Group

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6. Expenses of Evaluation Group

Travel, accommodation and meal expenses incurred in carrying out the evaluation will be reimbursed by the Department of Health.

OVERSIGHT GROUP MEMBERSHIP

- Tracey Conroy (Chair). Assistant Secretary, Acute Hospitals Policy Division, Department of Health
- Dr Tony Holohan, Chief Medical Officer, Department of Health
- Dr Siobhán O'Halloran, Chief Nursing Officer, Department of Health
- Dr Susan O'Reilly, National Cancer Control Programme, HSE
- Dr Deirdre Mulholland, Office of the CMO, Department of Health
- Michael Conroy, Cancer, Blood & Organs Policy Unit, Department of Health

ADVISORY GROUP MEMBERSHIP

- Michael Conroy (Chair), Cancer, Blood & Organs Policy Unit, Department of Health
- Keith Comiskey, Cancer, Blood & Organs Policy Unit, Department of Health
- Dr Deirdre Mulholland, Office of the CMO, Department of Health
- Dr Susan O'Reilly, National Cancer Control Programme, HSE
- Dr Mary Hynes, National Cancer Control Programme, HSE
- Fidelma MacHale, National Cancer Control Programme, HSE

Appendix 2

A Strategy for Cancer Control in Ireland 2006

Cancer Policy Indicators

1. Percentage of the population who are smokers by age, sex and social class.

Data on smoking prevalence is available from a HSE telephone survey since 2003. Overall smoking prevalence declined from 28% in 2003 to 21.5% at end 2013.

Smoking rates have decreased for both genders and across all age groups since 2003. The rate of smoking has decreased among most socioeconomic groups since 2003, with the highest smoking rates being in the lower socio economic groups (DE¹ and C2²), 25.9% and 24.6% respectively in 2013. The higher economic group (AB³) had the lowest rate at 13.0% at December 2013.

2. Percentage of the adult and childhood populations who are overweight or obese by age, sex and social class.

The SLÁN survey (2007) found that 36% of respondent reported being overweight with 14% being obese. Men were more likely to report being overweight or obese.

Consistent with international research, Body Mass Index (BMI) based on self-reported height and weight measurements provided an underestimation of the true prevalence of overweight and obesity. Based on measured data, higher percentages were overweight and obese. Approximately 2 out of 3 adults were at an unhealthy (either overweight or obese) weight and almost one out of 4 adults was obese in 2007.

The Irish Longitudinal Study on Ageing (TILDA) 2009-2011 found that 36% of Irish over 50s are obese and a further 43% are overweight.

The Growing up in Ireland survey found that in 2007/2008 (based on physical measurement) 75% of nine-year-olds were defined as being of healthy BMI, 19% were overweight and 7% were obese. Girls are more likely to be defined as being overweight or obese. Also, there are pronounced social-class inequalities, with 19% of boys and 18% of girls from professional households being overweight/ obese, compared to 29% of boys and 38% of girls from semi- and unskilled social-class households.

¹ D: All semi skilled and unskilled manual workers; E: All those entirely dependent on the state long-term; those unemployed for period exceeding 6 months

² C2: All skilled manual workers and those manual workers with responsibility for other people

³ A: Professional people, very senior managers in business and commerce, or top-level civil servants;

B: Middle management executives in large organizations; Principal Officers in local government and civil service; top management or owners of small business concerns, education and service establishments

3. Percentage of the population who consume more than the recommended alcohol weekly limits by age, sex and social class.

“Alcohol consumption in Ireland 2013” published by the Health Research Board indicates from survey results that more than 150,000 people are dependent drinkers, more than a 1.35 million are harmful drinkers according to WHO standards. Thirty per cent of people interviewed say that they experienced some form of harm as a result of their own drinking. The report also reveals that the respondents underestimate what they drink by about 60%.

Furthermore, the rate of abstinence, defined as consuming no alcohol in the previous 12 months, was 20.6%. Almost two-thirds (63.9%) of males and half (51.4%) of females started drinking alcohol before the age of 18 years. 67 % of drinkers and 80% of male drinkers consumed six or more standard drinks on the occasion that they consumed the highest number of standard drinks in the last year.

4. Incidence of major site-specific cancers, to include at a minimum lung, breast, prostate and colorectal cancer

National Cancer Registry data on Cancer Incidence shows that incidence has been steadily increasing for total cancers from approx 15,000 in 2002 to 20,000 in 2012 (24,800 in 2002 to 36,000⁴ in 2012 including non-melanoma skin cancers). Over half of this number is accounted for the four most common malignancies – prostate (3,400 cases in 2012), breast (2,800) colorectal (2,500) and lung (2,300). Time trends vary by cancer type; many increased during the period 2002 to 2012, but some have seen decreases, notably stomach cancer and male lung cancer.

5. Incidence of invasive and in-situ melanoma

National Cancer Registry data on Incidence of Invasive and in-situ melanoma shows that incidence is rising for both genders in the period from 2002 to 2012. Melanoma skin cancer has risen from 550 cases in 2002 to approx. 900 in 2012, while in-situ melanoma has risen from 220 cases in 2002 to 500 in 2012 – incidence has increased in both genders, with the greatest increase in males.

6. Uptake of screening and incidence of interval breast cancers in populations covered by BreastCheck.

BreastCheck, the National Breast Screening Programme, is a population-based call re-call programme that offers women aged 50 to 64 a free mammogram every two years. Provisional uptake for 2013 is 70.9%.

⁴ Data for 2012 was preliminary and incomplete at the time of the Cancer Strategy Evaluation

The BreastCheck interval cancer rate (based on National Cancer Registry data for interval cancers for women screened 2000-2007) is:

	First Round	Subsequent Round – Initial Screening	Subsequent Round – Subsequent Screening	Total
Total Interval Cancers Rate per 10,000 negatively screened	21.85	16.65	19.13	19.24

7. Percentage of women in the target age-groups for whom population based cervical cancer screening is available.

CervicalCheck, the National Cervical Screening Programme provides free smear tests through primary care settings to all of the approximately 1.2 million women aged 25-60 years that are eligible for screening.

7a: Percentage of men and women in the target age-groups for whom population based colorectal cancer screening is available.

BowelScreen, the National Bowel Screening Programme commenced in October 2012 with the ultimate aim of reducing mortality from colorectal cancer in men and women aged 55-74 in Ireland. The programme is being implemented on a phased basis commencing with men and women aged 60-69 years. The programme aims to complete the first round of screening to all 60-69 year olds by end 2015.

8. Percentage uptake of screening in areas covered by the Irish Cervical Screening Programme

Coverage of women by age group in first 5 years of CervicalCheck.

Age group	Number screened	Eligible women	% coverage
25-29	148,136	187,408	79.0
30-34	156,948	199,171	78.8
35-39	142,933	182,024	78.5
40-44	128,239	164,482	78.0
45-49	114,211	153,669	74.3
50-54	94,418	137,649	68.6
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60	13,121	22,459	58.4

Total	876,634	1,169,263	75.0
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8a. Percentage uptake of screening for BowelScreen, the National Bowel Screening Programme.

In 2013 there were 60,000 invitations issued. To end June 2014, 100,000 invitations have been issued and the Programme is on target to invite a total of 200,000 in the calendar year 2014. The first round of screening is on track for completion at the end of 2015, at which time all identified men and women aged 60-69 will have been invited to participate. Participation in the BowelScreen programme was in the region of 42% in 2013, and this will increase over time. It is anticipated that participation will be around 50% by the end of the first screening round at the end of 2015.

9. Stage of presentation of common cancers: appropriate stage indicators should be defined for lung, breast, colorectal and cervical cancers

Data on stage of presentation for cancers is collected by the National Cancer Registry. Stage of presentation varied widely according to the cancer type, depending on a range of factors, e.g. diagnostic methods available. No discernable change in overall stage of presentation is visible over the period 2002 to 2012. However, the trend is towards earlier stage diagnosis for prostate, lung and non-melanoma skin cancer.

10. Percentage of patients with cancer whose care is consistent with national, multidisciplinary guidelines, as developed by HIQA

The HSE compiles data showing compliance with a range of indicators based on the HIQA Quality Assurance Standards for Symptomatic Breast Disease Services. The HSE report measures a range of performance standards such as (i) access to diagnostic clinics and diagnostic procedures; (ii) the level of involvements of multidisciplinary meetings, (iii) time to treatment for surgery, radiation oncology and chemotherapy, etc.

11. Trends in quality of life for cancer patients, determined by ongoing quality of life measurement, at different stages in the care pathway for major cancers.

No "time trend" data is available. Some study has been carried out by the National Cancer Registry.

12. Waiting times from diagnosis to definitive treatment for major cancer and 13. Percentage of patients waiting for longer than one month from the time of diagnosis to the start of treatment

Approximately 35% of all cancers (excluding non-melanoma skin cancer) had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 65%, at three months to 88% and at six months to just under 95%.

Approximately 43% of all Colorectal cases had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 74%, at three months to just under 97% and at six months to 99%.

Approximately 17% of all Lung cases had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 54%, at three months to 89% and at six months to 97%.

Approximately 14% of all Breast cases had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 77%, at three months to 98% and six months to 99%.

The National Cancer Control Programme Symptomatic Breast Disease 3 year report 2010-2012 shows that in that period, over 88% of patients had their surgery carried out within 4 weeks of the discussion of the management of their disease at a multidisciplinary meeting.

14. Percentage of breast cancer patients undergoing therapeutic surgical procedures who do so in a designated breast cancer treatment centre

Data from the National Cancer Registry shows the number of cases in each hospital of a tumour directed surgery or site specific principal surgical procedure. Data for Breast Cancer shows that following the reorganistaton of cancer surgery into the designated cancer centres, 100% of breast cancer surgery in the public sector was undertaken in the designated centres in 2010 and 2011. However, some 25% of total breast cancer surgery is carried out in the private sector.

15. Survival rates:

- a. 5-year Relative Survival Rate for Breast Cancer**
- b. 1-year Relative Survival Rate for Lung Cancer**
- c. 5-year Relative Survival Rate for Prostate Cancer**
- d. 5-year Relative Survival Rate for Colorectal Cancer**

Survival estimates for most cancers have improved over time, although the trend is clearer for some cancers than for others. Net survival to five years for all cancers (excl. non-melanoma skin cancer) increased from 45% for patients diagnosed during 1994-1999 to 59% for patients daignosed during 2008-2012. The greatest improvements have been seen for colorectal, breast, kidney, testicular and prostate cancers. Net survival over 70% to five years is recorded for melanoma skin (86%), hodgkin lymphoma (83%), thyroid (83%), bladder (73%), prostate (91%), testicular (96%), breast (81%). However, five year survial was very low (under 30%) for cancers of the lung, pancreas, liver, stomach, oesophagus and malignant brain.

16. Mortality rates:

a. Direct Age Standardised Mortality rate (5-year, all ages) for all causes of cancer

b. Direct Age Standardised Mortality rates (5-year, all ages) for the top six causes of cancer mortality

Cancer is the second most common cause of death in Ireland with 7,900 to 8,800 deaths per annum in the period from 2007 to 2012. However, the annual rate of cancer mortality decreased significantly for both males and females in the period 1994-2012 largely due to improved treatments and earlier diagnosis.

Lung cancer remains the highest cause of death from cancer for both men and women with approximately 1,700 to 1,900 cases in total from 1994 to 2012. Age standardised mortality rates for men have decreased; however, female lung cancer death rates are continuing to rise. Mortality from colorectal cancer is decreasing for both men and women due in part to advances in treatment surgery over the last two decades. The prognosis for breast cancer has improved since the 1990s due to earlier diagnosis and treatment advances and mortality rates have decreased by almost 2% annually from 1994-2012. While prostate cancer incidence rates have increased dramatically, mortality rates have decreased.

17. Percentage of cancer patients seen by a member of a Specialist Palliative Care Team

Data not available

18. Percentage of cancer patients dying by place of death (home, hospice, hospital)

In the period from 2002 to 2012, about 40% of cancer deaths took place in acute hospitals, with about 10% of these being in private hospitals. The percentage of deaths in hospices has increased from 14% to 18% in the period. The proportion of patients dying at home has remained relatively stable at around 26% in the period. The number of patients dying in community and district homes has reduced from around 9% to 6% in 2012.

19. Percentage of cancer patients participating in clinical trials

Data on the total number of patients participating in clinical trials is not available. However, the Irish Cooperative Oncology Research Group (ICORG) provides information on the number of patients participating in its clinical trials. ICORG is majority funded by the Health Research Board with a grant from the Irish Cancer Society.

More than 1,600 new patients enrolled with ICORG in 2013 and there are more than 4,000 patients under active surveillance on treatment or in follow-up. ICORG had more than 70 open trials in 2013. ICORG's membership of international collaborative groups continues to grow.

Appendix 3

List of Groups/People met by Evaluation Team

Department of Health

Minister for Health
Office of the Chief Medical Officer
Office of the Chief Nursing Officer
Acute Hospitals Division
Tobacco & Alcohol Unit
Health Promotion Unit
Health & Wellbeing Programme
Palliative Care Unit

HSE National Cancer Control Programme

Director
National Surgical Oncology Programme
National Medical Oncology & Haematology Programme
National Radiation Oncology Programme
Community Oncology & Primary Care & Prevention

Other HSE Officials

Director General
National Screening Service
Acute Services Division
Clinical Strategy & Programmes
Palliative Care Programme
Quality and Patient Safety Division
Transformation Programme
Nursing & Midwifery Planning & Development Unit
Public Health Nursing and Community Oncology

St James's Hospital

Senior clinicians and senior management

Cork University Hospital

Senior clinicians and senior management

National Cancer Registry

Interim Director

Medical Colleges

Royal College of Surgeons in Ireland
Royal College of Physicians of Ireland
Irish College of General Practitioners

Irish Association for Nurses in Oncology

President

Health Research Board

Director of Funding Programme

Head of Clinical and Applied Biomedical Research

Hereditary Cancer

Director, National Centre for Medical Genetics, Crumlin

Medical Oncologist and Medical Geneticist, Mater Private Hospital

Irish Clinical Oncology Research Group

Clinical Leader

Marymount Hospice

Senior clinicians and senior management

All Ireland Institute for Hospice and Palliative Care

Director

Hospice Foundation

Director

Voluntary Hospice Group

Chair of the Voluntary Hospice Group

Principal Cancer Charities

Irish Cancer Society

Marie Keating Foundation

Europa Donna

Cancer Care West

ARC Cancer Support Centre

Appendix 4

List of Documents reviewed by Evaluation Team

Documents

A Strategy for Cancer Control in Ireland 2006
Policy Indicators for 2006 Strategy for Cancer Control
Data for Policy Indicators from 2006 Strategy
Healthy Ireland
The Establishment of Hospital Groups as a transition to Independent Hospital Trusts
Briefing on Health Identifiers Act
7-Year National Cancer Control Programme Report
Patient Engagement Activities NCCP October 2014
Final Full Suite of NCCP KPIs - Sept 2014
ICORG Activity Report Jan-Dec 2013
ICORG Activity Report Jan-Jun 2014
Health Research Board Annual Report 2012
Final National Histopathology QA Programme Implementation Report 2014
HIQA National Standards for Safer Better Healthcare
Irish Cancer Society Strategy Statement 2013-2017
Childhood Cancer Trends Report July 2014
Medical Oncology Strategy review Oct 2014
National Cancer Registry Prostate Cancer Report
Notes on QA programme Meeting with Evaluation Team
QA Programmes Summary Oct 2014

Dept. of Health Presentations

Cancer Policy in Ireland
Diet and Cancer
Healthy Ireland - Health & Wellbeing Programme
Palliative Care Policy
Tobacco & Alcohol Control

Other Presentations

Summary of NCCP progress to date
Medical Oncology Strategy review
NCCP Patient Engagement activities
NCCP Community oncology update
Cancer Screening
A Strategy and Education Framework for nurses caring for people with cancer in Ireland
Nursing Strategy Update
Marymount Hospice

Appendix 5

Evaluation Panel report on the implementation of the 55 Recommendations of the 2006 Cancer Control Programme. November 2014

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
1	A third National Cancer Forum should be appointed by the Minister with terms of reference and composition reflecting the changed health system.			X	
2	The recommendations of the Review of the National Health Promotion Strategy, 2004 should be implemented across all sectors.	X			
3	Compliance with all provisions of the Public Health (Tobacco) Acts, 2002 and 2004 should be monitored.	X			
4	Excise duty on cigarettes should be substantially increased each year above the rate of inflation. To this end the National Cancer Forum should produce a pre – Budget submission to the Minister for Finance each year in order to continue advocating for price increases on tobacco.	X			
5	Nicotine replacement therapy should be made available free of charge to all medical card holders.	X			

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
6	The Report of the Strategic Task Force on Alcohol, 2002 should be implemented in full.			X	
7	The recommendations of the Report of the National Task Force on Obesity, 2005 should be implemented in full. In particular, there is a need for measures that raise the awareness of the links between diet and cancer.		X		
8	The health services should work with the food industry in order to encourage it to produce, market and improve access to attractive and healthy options.		X		
9	The recommendations of the Report of the National Task Force on Obesity, 2005 in relation to physical activity should be implemented in full.		X		
10	In conjunction with campaigners to promote safe sun practices and to reduce exposure to ultraviolet radiation, regulation of sunbed use, including restriction to use by adults only, should be put in place.	X			
11	The public should be made aware that radon measurements can be undertaken by the Radiological Protection Institute of Ireland. Consideration should be given to providing financial support for testing in high-radon	X			

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
	areas and for any necessary remedial work, on a means-tested basis.				
12	The HSE should put in place arrangements to monitor inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes.		X		
13	Population-based screening programmes should only be introduced where their population health benefit can be demonstrated using the National Cancer Forum criteria.	X			
14	Breast screening should be extended to include all women aged between 50 and 69.	X			
15	The national roll-out of the Irish Cervical Screening Programme should be completed as a matter of priority.	X			
16	A colorectal cancer programme should be established to encompass population screening, high risk screening and necessary developments in symptomatic colorectal cancer services. In preparation for this programme, the Department of Health and Children should establish a working group under aegis of the National Cancer Forum to address a range of implementation issues.		X		

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
17	The Department of Health and Children in conjunction with the HSE and BreastCheck should plan the alignment of population-based screening programmes.	X			
18	Population-based prostate screening should NOT be introduced in Ireland at present. The National Cancer Forum should keep emerging international evidence on population screening for prostate cancer under review.	X			
19	Opportunistic testing of asymptomatic individuals for cancer is not recommended.		X		
20	The HSE should develop specific programmes that promote early detection of cancer.		X		
21	All cancer care should be delivered through a national system of four Managed Cancer Control Networks, each serving a population of approximately one million people.	X			
22	A Network Director should be appointed by the HSE as soon as possible to each Managed Cancer Control Network to support and direct implementation of cancer policy.	X			
23	A lead clinician for each Cancer Centre should be appointed. In addition, a clinician should be		X		

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
	appointed to lead the development of cancer care pathways for each major site specific cancer in partnership with all stakeholders within the network. The Cancer Control Network Director should head this team of lead clinicians.				
24	The HSE should develop care pathways for cancer care to link primary care services, hospital services and other relevant services.		X		
25	Improved cancer information services should be available to primary care.		X		
26	The HSE should develop programmes that support primary care professionals in the provision of cancer services.		X		
27	The HSE should ensure that systems are in place to identify and support a 'designated health professional' as a contact person for each individual cancer patient who may require it.			X	
28	Cancer Centres that each serve a minimum population of 500,000 should be designated by the HSE as soon as possible. Ireland will require about eight such centres.	X			
29	The HSE should conduct a needs assessment for cancer services		X		

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
	with a particular emphasis on hospital-based cancer treatment that addresses the need for continued expansion in capacity and maximises the use of ambulatory care.				
30	The National Network for Radiation Oncology Services should be established by the HSE in accordance with the timelines set by Government.	X			
31	Patients should have their diagnosis established and their treatment planned by site-specific multidisciplinary teams.	X			
32	The HSE should conduct a review of the number of centres required for the management of symptomatic breast disease to bring them into line with designated Cancer Centres.	X			
33	The HSE should conduct a national needs assessment for rare cancers.	X			
34	A National Cancer Genetics Policy should be developed by the National Cancer Forum.			X	
35	The HSE should ensure that each Managed Cancer Centre Control Network has a comprehensive specialist palliative care service.			X	
36	A formal linkage should be established between the National Cancer Forum and the National				X

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
	Council for Specialist Palliative Care.				
37	The HSE should ensure that access to comprehensive psycho-oncology and psychosocial support is provided for cancer patients and their families in each Managed Cancer Control Network.			X	
38	A partnership framework should be developed between the HSE and the voluntary sector.			X	
39	A code of practice should be developed for self-help groups, support groups and support centres.	X			
40	HIQA should establish a National Framework for Quality in Cancer Control.		X		
41	HIQA should establish site-specific multidisciplinary groups at a national level to develop guidelines for quality in major cancers.	X			
42	HIQA should develop a system of licensing and accreditation of Cancer Centres and services that should apply to both the public and private sectors. The systems of licensing and accreditation should be given statutory effect.			X	
43	HIQA should develop a cancer surveillance system that will build on the existing system of cancer		X		

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
	registration.				
44	Mandatory notification of cancer should be put in place through appropriate legislation.			X	
45	HIQA should ensure that a minimum national dataset should be collected for all cases of cancer.			X	
46	HIQA should ensure that the public has access to high-quality up to date information about all aspects of cancer.		X		
47	General practitioners should have comprehensive information that enables informed referral and other management decisions.		X		
48	Information systems and information technology should be developed by the HSE to support the management and delivery of cancer services.		X		
49	HIQA should establish a Cancer Health Technology Assessment Panel.		X		
50	The HSE should develop a National Cancer Workforce Plan designed to fully implement national cancer policy.			X	
51	The third National Cancer Forum, in partnership with the HRB, should advise on the development of a specific plan for cancer research.			X	
52	There should be improved clinical		X		

	RECOMMENDATION	FULLY/LARGELY IMPLEMENTED	PARTIALLY IMPLEMENTED	NOT IMPLEMENTED	NO INFORMATION/NOT REVIEWED
	trial entry for patients, both in terms of the number of trials conducted and the enrolment to them.				
53	Ireland should establish a national tissue bio bank to support research and service delivery.			X	
54	The HRB should establish a national cancer research database.			X	
55	The HSE should present a report on policy indicators each year to the National Cancer Forum.		X		

A Strategy for Cancer Control in Ireland 2006

Cancer Policy Indicators

1. Percentage of the population who are smokers by age, sex and social class.

Data on smoking prevalence is available from a HSE telephone survey since 2003. Overall smoking prevalence declined from 28% in 2003 to 21.5% at end 2013.

Smoking rates have declined across the majority of age groups since 2003, with the largest reductions seen in the 18-24 and 25-34 age groups. However, these two age groups still have the highest rates of smoking prevalence at 30.7% and 28.1% respectively at December 2013.

Smoking rates have decreased for both genders since 2003. Rates for men have declined to 22.85% at end 2013, with 20.2% of women reporting being smokers.

The rate of smoking has decreased among most socioeconomic groups since 2003, with the highest smoking rates being in DE and C2, 25.9% and 24.6% respectively. The AB group had the lowest rate at 13.0% at December 2013.

2. Percentage of the adult and childhood populations who are overweight or obese by age, sex and social class.

The SLÁN survey (2007) found that 36% of respondent reported being overweight with 14% being obese. Men were more likely to report being overweight or obese.

Consistent with international research, Body Mass Index (BMI) based on self-reported height and weight measurements provided an underestimation of the true prevalence of overweight and obesity. Based on measured data, higher percentages were overweight and obese. Approximately 2 out of 3 adults were at an unhealthy (either overweight or obese) weight. Almost one out of 4 adults was obese in 2007.

The Irish Longitudinal Study on Ageing (TILDA) found that 36% of Irish over 50s are obese and a further 43% are overweight.

The Growing up in Ireland survey found that 75% of nine-year-olds were defined as being of healthy BMI, 19% were overweight and 7% were obese. Girls are more likely to be defined as being overweight or obese. Also, there are pronounced social-class inequalities, with 19% of boys and 18% of girls from professional households being overweight/ obese, compared to 29% of boys and 38% of girls from semi- and unskilled social-class households.

3. Percentage of the population who consume more than the recommended alcohol weekly limits by age, sex and social class.

“Alcohol consumption in Ireland 2013” published by the Health Research Board indicates that more than 150,000 people are dependent drinkers, more than a 1.35 million are harmful drinkers according to WHO standards. Thirty per cent of people interviewed say that they experienced some form of harm as a result of their own drinking. The report also reveals that the respondents underestimate what they drink by about 60%.

Furthermore, the rate of abstinence, defined as consuming no alcohol in the previous 12 months, was 20.6%. Almost two-thirds (63.9%) of males and half (51.4%) of females started drinking alcohol before the age of 18 years. 67 % of drinkers and 80% of male drinkers consumed six or more standard drinks on the occasion that they consumed the highest number of standard drinks in the last year.

4. Incidence of major site-specific cancers, to include at a minimum lung, breast, prostate and colorectal cancer

National Cancer Registry data on Cancer Incidence shows that incidence has been steadily increasing for total cancers from approx 15,000 in 2002 to 20,000 in 2012 (24,800 in 2002 to 36,000⁵ in 2012 including non-melanoma skin cancers). Over half of this number is accounted for the four most common malignancies – prostate (3,400 cases in 2012), breast (2,800) colorectal (2,500) and lung (2,300). Time trends vary by cancer type; many increased during the period 2002 to 2012, but some have seen decreases, notably stomach cancer and male lung cancer.

5. Incidence of invasive and in-situ melanoma

National Cancer Registry data on Incidence of Invasive and in-situ melanoma shows that incidence is rising for both genders in the period from 2002 to 2012. Melanoma skin cancer has risen from 550 cases in 2002 to approx. 900 in 2012, while in-situ melanoma has risen from 220 cases in 2002 to 500 in 2012 – incidence has increased in both genders, with the greatest increase in males.

6. Uptake of screening and incidence of interval breast cancers in populations covered by BreastCheck.

BreastCheck, the National Breast Screening Programme, is a population-based call re-call programme that offers women aged 50 to 64 a free mammogram every two years. Provisional uptake for 2013 is 70.9%.

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	First Round	Subsequent Round – Initial Screening	Subsequent Round – Subsequent Screening	Total
Total Interval Cancers Rate per 10,000 negatively screened	21.85	16.65	19.13	19.24

7. Percentage of women in the target age-groups for whom population based cervical cancer screening is available.

CervicalCheck, the National Cervical Screening Programme provides free smear tests through primary care settings to all of the approximately 1.2 million women aged 25-60 years that are eligible for screening.

7a: Percentage of men and women in the target age-groups for whom population based colorectal cancer screening is available

BowelScreen, the National Bowel Screening Programme commenced in October 2012 with the ultimate aim of reducing mortality from colorectal cancer in men and women aged 55-74 in Ireland. The programme is being implemented on a phased basis commencing with men and women aged 60-69 years. The programme aims to complete the first round of screening to all 60-69 year olds by end 2015.

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Coverage of women by age group in first 5 years of CervicalCheck.

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In 2013 there were 60,000 invitations issued. To end June 2014, 100,000 invitations have been issued and the Programme is on target to invite a total of 200,000 in the calendar year 2014. The first round of screening is on track for completion at the end of 2015, at which time all identified men and women aged 60-69 will have been invited to participate. Participation in the BowelScreen programme was in the region of 42% in 2013, and this will increase over time. It is anticipated that participation will be around 50% by the end of the first screening round at the end of 2015.

9. Stage of presentation of common cancers: appropriate stage indicators should be defined for lung, breast, colorectal and cervical cancers

Data on stage of presentation for cancers is collected by the National Cancer Registry. Stage of presentation varied widely according to the cancer type, depending on a range of factors, e.g. diagnostic methods available. No discernable change in overall stage of presentation is visible over the period 2002 to 2012. However, the trend is towards earlier stage diagnosis for prostate, lung and non-melanoma skin cancer.

10. Percentage of patients with cancer whose care is consistent with national, multidisciplinary guidelines, as developed by HIQA

The HSE compiles data showing compliance with a range of indicators based on the HIQA Quality Assurance Standards for Symptomatic Breast Disease Services. The HSE report measures a range of performance standards such as (i) access to diagnostic clinics and diagnostic procedures; (ii) the level of involvements of multidisciplinary meetings, (iii) time to treatment for surgery, radiation oncology and chemotherapy, etc.

11. Trends in quality of life for cancer patients, determined by ongoing quality of life measurement, at different stages in the care pathway for major cancers.

No “time trend” data is available. Some study has been carried out by the National Cancer Registry.

12. Waiting times from diagnosis to definitive treatment for major cancer and

13. Percentage of patients waiting for longer than one month from the time of diagnosis to the start of treatment

Approximately 35% of all cancers (excluding non-melanoma skin cancer) had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 65%, at three months to 88% and at six months to just under 95%.

Approximately 43% of all Colorectal cases had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 74%, at three months to just under 97% and at six months to 99%.

Approximately 17% of all Lungcases had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 54%, at three months to 89% and at six months to 97%.

Approximately 14% of all Breast cases had tumour-directed treatment within 1 week from date of diagnosis between 2002 and 2011. At one month this increased to approximately 77%, at three months to 98% and six months to 99%.

14. Percentage of breast cancer patients undergoing therapeutic surgical procedures who do so in a designated breast cancer treatment centre

Data from the National Cancer Registry shows the number of cases in each hospital of a tumour directed surgery or site specific principal surgical procedure. Data for Breast Cancer shows that following the reorganistaton of cancer surgery into the designated cancer centres, 100% of

breast cancer surgery in the public sector was undertaken in the designated centres in 2010 and 2011. However, some 25% of total breast cancer surgery is carried out in the private sector.

15. Survival rates:

a. 5-year Relative Survival Rate for Breast Cancer

b. 1-year Relative Survival Rate for Lung Cancer

c. 5-year Relative Survival Rate for Prostate Cancer

d. 5-year Relative Survival Rate for Colorectal Cancer

Survival estimates for most cancers have improved over time, although the trend is clearer for some cancers than for others. Net survival to five years for all cancers (excl. non-melanoma skin cancer) increased from 45% for patients diagnosed during 1994-1999 to 59% for patients diagnosed during 2008-2012. The greatest improvements have been seen for colorectal, breast, kidney, testicular and prostate cancers. Net survival over 70% to five years is recorded for melanoma skin (86%), hodgkin lymphoma (83%), thyroid (83%), bladder (73%), prostate (91%), testicular (96%), breast (81%). However, five year survival was very low (under 30%) for cancers of the lung, pancreas, liver, stomach, oesophagus and malignant brain.

16. Mortality rates:

a. Direct Age Standardised Mortality rate (5-year, all ages) for all causes of cancer

b. Direct Age Standardised Mortality rates (5-year, all ages) for the top six causes of cancer mortality

Cancer is the second most common cause of death in Ireland with 7,900 to 8,800 deaths per annum in the period from 2007 to 2012. However, the annual rate of cancer mortality decreased significantly for both males and females in the period 1994-2012 largely due to improved treatments and earlier diagnosis.

Lung cancer remains the highest cause of death from cancer for both men and women with approximately 1,700 to 1,900 cases in total from 1994 to 2012. Age standardised mortality rates for men have decreased; however, female lung cancer death rates are continuing to rise. Mortality from colorectal cancer is decreasing for both men and women due in part to advances in treatment surgery over the last two decades. The prognosis for breast cancer has improved since the 1990s due to earlier diagnosis and treatment advances and mortality rates have decreased by almost 2% annually from 1994-2012. While prostate cancer incidence rates have increased dramatically, mortality rates have decreased.

17. Percentage of cancer patients seen by a member of a Specialist Palliative Care Team

Data not available

18. Percentage of cancer patients dying by place of death (home, hospice, hospital)

In the period from 2002 to 2012, about 40% of cancer deaths took place in acute hospitals, with about 10% of these being in private hospitals. The percentage of deaths in hospices has increased from 14% to 18% in the period. The proportion of patients dying at home has remained relatively stable at around 26% in the period. The number of patients dying in community and district homes has reduced from around 9% to 6% in 2012.

19. Percentage of cancer patients participating in clinical trials

Data on the total number of patients participating in clinical trials is not available. However, the Irish Cooperative Oncology Research Group (ICORG) provides information on the number of patients participating in its clinical trials. ICORG is majority funded by the Health Research Board with a grant from the Irish Cancer Society.

More than 1,600 new patients enrolled with ICORG in 2013 and there are more than 4,000 patients under active surveillance on treatment or in follow-up. ICORG had more than 70 open trials in 2013. ICORG's membership of international collaborative groups continues to grow.