

# Report on the implementation of 'A Strategy for Cancer Control in Ireland 2006'

National Cancer Control Programme

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'A Strategy for Cancer  
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## Technical Documentation

- TD1. NCRI Cancer Projections 2014
- TD2. Symptomatic Breast Disease KPI Report 2010-2012
- TD3. Quality Assurance for Symptomatic Breast Cancer 2013
- TD4. Breast Cancer Referral Guidelines for Primary Care
- TD5. Report on the 2012 Pilot of Reporting of Key Performance Indicators (KPIs) in Oesophago Gastric Cancers. March 2014
- TD6. Report of the Key Performance Indicators (KPIs) for the National Surgical Centre for Pancreatic Cancer (NSCPC). March 2014
- TD7. National Neuro-Oncology Annual Report 2012
- TD8. Rarecare Cancer Definitions
- TD9. Radiotherapy Clinical Trials 2013 & 2014
- TD10. List of National Clinical Leads and Guideline Development Group Participants
- TD11. Research on Breast Cancer Referrals in Ireland
- TD12. The Development of Radiation Oncology Services in Ireland (Hollywood Report) 2003
- TD13. National Cancer Registry of Ireland – Research Report 2013
- TD14. ICORG Annual Progress Report 2013
- TD15. CervicalCheck Programme Report 2011-2012
- TD16. BreastCheck Report 2012-2013
- TD17. Community Oncology Supplementary Information
- TD18. Primary Care GP Referral Guidelines, Breast, Prostate, Lung cancers and Melanomas
- TD19. NCCP Key Performance Indicator Suite – June 2013
- TD20. Completed National Breast, Prostate, Gestational Trophoblastic Disease (GTD) Guidelines

(The technical documents are available on the web)

## Abbreviations

CUH	Cork University Hospital
DOH	Department of Health
GDG	Guidelines Development Group
HIPE	Hospital In Patient Enquiry
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
HTA	Health Technology Assessment
ICGP	Irish College of General Practitioners
ICS	Irish Cancer Society
KPI	Key Performance Indicators
MDM	Multi Disciplinary Meeting
MOU	Memorandum of Understanding
NCCP	National Cancer Control Programme
NCEC	National Clinical Effectiveness Committee
NCMG	National Centre for Medical Genetics
NCRI	National Cancer Registry Ireland
NCSS	National Cancer Screening Service (now NSS)
NPRO	National Programme for Radiation Oncology
NSS	National Screening Service
QA	Quality Assurance
RAC	Rapid Access Clinic
RCPI	Royal College of Physicians in Ireland
RCSI	Royal College of Surgeons in Ireland
SLA	Service Level Agreement
SLRON	St Luke's Radiation Oncology Network
SVUH	St Vincent's University Hospital
TD	Technical Document
UCHG	University College Hospitals Galway

# Introduction from the Director of the National Cancer Control Programme

I am pleased to introduce the Seven-Year Report on the National Cancer Control Programme's (NCCP) implementation of 'A Strategy for Cancer Control in Ireland 2006' (hereafter referred to as the **2006 National Cancer Strategy**).

## Progress from 2007 to 2014

### Cancer Prevention

The NCCP's Community Oncology Programme has worked collaboratively with the HSE Population Health Division and now, the Health and Wellbeing Division, to provide a joint approach to the lifestyle risk factors common to many chronic diseases.

The focus on smoking cessation for the public and cancer patients has involved e-learning and training for GPs and Allied Health Professionals, development of advice and pharmacotherapy approaches for the public.

Alcohol, nutrition, physical activity and obesity have all required a shared approach to education and support.

Sun exposure is a specific risk factor for cancer. The NCCP's submission to the Department of Health contributed to the introduction in 2014 of legislation banning sunbed use for children younger than 19 years.

Information leaflets, including an ABCs for being cancer aware, are available on the NCCP website.

### Cancer Screening

The National Cancer Screening Service commenced in 2007 and built on earlier work in rolling out breast and cervical cancer screening.

BreastCheck completed its second round of national screening for women age 50-64 years in late 2013 and has consistently achieved a high uptake (>70%) of invited women. Screening is offered every two years in a quality assured environment. Patients diagnosed with cancer benefit from multidisciplinary assessment and integration of surgical services.

CervicalCheck also completed its second round of national screening in 2013. Eligible women are aged 25-60 years. Uptake has been excellent, approaching 83% for younger women less than 30 years and 74% overall. Smear taking is carried out by trained GPs and nurses, cytology is externally procured and colposcopy provided on a money-follows-the patient basis in general hospitals. Information technology and quality assurance are integrated across the programme.

BowelScreen commenced in the final quarter of 2012 for men and women aged 60-69 years. The programme offers home sampling and FIT testing for occult blood, linked to accredited colonoscopy centres and surgery for cancer patients, again on a multidisciplinary money-follows-the patient approach. The programme is on track to complete its first national round of screening by the end

of 2015 and will then continue to offer screening every two years. A programme for follow-up colonoscopies for patients with polyps is in place.

Further expansion of screening to ages 55-74 years is planned after the first national round for patients aged 60-69 years is completed, subject to resources.

## Implementation of Designated Cancer Centres

The 2006 National Cancer Strategy and the 2007 Health Service Executive framework 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres (Appendix 1)' led to the implementation of radical change in the delivery of hospital-based specialised cancer services.

Eight cancer centres were designated, to each serve approximately half a million population. Four cancer networks were established (two in the East, one in the West, and one in the South), each of which has two cancer centres. The networks are now evolving into the six new hospital groups.

The key characteristics of the designated cancer centres are sustainable high volume multidisciplinary cancer services spanning the range of diagnostics, surgery, radiation oncology and medical oncology. Those centres without on-site radiotherapy facilities have consultant radiation oncologists participating in treatment planning. All new patients and selected patients with recurrent cancer are reviewed at multidisciplinary team meetings comprising all diagnostic and therapeutic specialists.

Integrated care pathways from primary care into consultant oncology services have been developed in close collaboration with the Irish College of General Practitioners and with hospital consultants. Electronic GP referral has been developed and implemented for breast, lung and prostate cancer clinics and will soon include pigmented lesions.

The centralisation of breast cancer surgery from 32 hospitals to eight cancer centres (and a satellite centre at Letterkenny) was the first big step which began in 2008/09 and was finally implemented by December 2009. This service was delivered

in accordance with the Health Information and Quality Assurance (HIQA) Standards for Symptomatic Breast Disease (2007) and the NCCP Standard Operating Procedures (2009). Key Performance Indicators were developed and reported monthly. Timely access for urgent (two weeks) and non-urgent (12 weeks) referrals have been maintained, although, in 2014, some hospitals have struggled to meet targets, primarily due to staffing challenges and patient volumes. In 2013 the clinics, which offer service for both benign and potentially malignant breast diseases, saw 37,891 new referrals and a similar volume of return visits.

Centralisation of breast services has delivered timely access to excellent diagnosis and care and has replaced the fragmented services in 32 hospitals prior to 2008, a number of which had not consistently offered prompt referral and multidisciplinary diagnosis and care.

Building on the successes in centralising breast services, the NCCP has progressively moved to centralising prostate, lung, pancreas, rectal and oesophageal cancer services in specified cancer centres.

In 2014, the designated cancer centres offer rapid access clinics for GP referrals of suspected lung and prostate cancer in all eight centres. Prostate surgical services are available in six cancer centres. Two other non-cancer centres still provide some surgical services and work is ongoing to complete their transfer. Lung cancer and upper gastrointestinal surgical services are each in four cancer centres.

Rectal cancer centralisation is progressing, with 77% of surgeries taking place in cancer centres and the small number of additional services having access to MDTs (Appendix 2). This is a radical change from the 36 hospitals involved prior to 2009.

The national pancreatic cancer programme is based in one centre in Dublin with one satellite centre in Cork. The national neuro-oncology programme has a similar model. The majority of gynaecological cancers are referred to seven designated cancer centres.



Centralisation of uncommon cancers, such as head and neck and mouth cancers, neuroendocrine cancers, sarcomas and testicular cancers is a work in progress.

Work is ongoing with the HSE Divisions of Primary Care and Acute Hospitals to expedite GP referral for women suspected to have ovarian cancer.

### **The National Programme for Radiation Oncology (NPRO)**

Significant investment in staff and facilities for radiotherapy has positioned Ireland to address the need for radical/curative (60% of treatments) and palliative therapy. Two new facilities opened in 2011 on the sites of St James's and Beaumont Hospitals in Dublin, each offers Rapid Arc Technology and excellent intensity modulated therapy. Funding is in place and planning well advanced for replacement, expanded facilities in Cork and Galway to open in 2017/18 and the Republic of Ireland and Northern Ireland have collaborated in a cross-border initiative which will see patients from Donegal accessing treatment in Altnagelvin, Derry, when a new service starts in 2016.

Intracranial stereotactic and extracranial stereotactic services were launched in Dublin in 2013 and 2014 respectively. Further investment in expansion of facilities in Dublin will be required to address demographic growth.

Expertise in prostate brachytherapy has been leveraged to develop and roll out a national programme in 2013, with services now available in Galway, Cork and Dublin.

### **The National Programme for Medical Oncology & Haematology**

Following on the successful sequential change management of introducing designated cancer centres, centralising high volume surgical services and developing appropriate multidisciplinary teams, the attention of the NCCP turned to the development of a national approach to medical oncology and haematology. This area of oncology

expertise was not a feature of the 2006 National Cancer Strategy, but nevertheless, has now become an absolutely critical component of optimal management for cancer patients.

In 2011, the NCCP embarked on a National Oncology Drug Management Programme to replace the previous system of 26 hospitals each paying for new cancer drugs. The first step was the establishment of an NCCP Technology Review Committee for new drugs and related predictive laboratory tests. This well constituted committee provides recommendations to the HSE Drugs Committee regarding funding of new drugs which exceed the €45,000 per quality adjusted life year threshold. In parallel with approval for funding for new drugs, the NCCP Chief Pharmacist develops treatment protocols in collaboration with the Irish Society of Medical Oncology or the Irish Haematology Society to provide a national protocol and a national physician order set for each new product. Since 2012, patients are registered by diagnosis for access to each new drug and hospitals are reimbursed via the Primary Care Reimbursement Service (PCRS) technology process on a money-follows-the-patient basis. Prices are negotiated by the HSE Corporate Pharmaceutical Unit, in collaboration with the NCCP, and national discounts are available to PCRS. Hospitals are no longer at risk of increasing erosion of their revenue base to fund new drugs, and patients are better able to transfer from designated cancer centre hubs to a number of smaller ambulatory chemotherapy services throughout the country.

In addition to new drug funding, in 2013, the NCCP initiated a fund for growth in cancer drugs to reflect the significant growth in incidence and prevalence of cancer. This growth was having an impact on hospital base budgets for the top ten most expensive drugs which had been approved prior to the implementation of the oncology drug management system for new drugs. At present, hospitals report their utilisation of these ten drugs quarterly and are reimbursed proportional to growth. In the longer term, work is ongoing to develop automated data feeds from hospital pharmacy systems to PCRS in order to provide real time tracking of drug expenditure and

appropriate reimbursement. These significant changes in national oncology drug management have imbedded quality, safety, audits, consistency and access in a money-follows-the-patient model supported by national protocols and physician order sets.

In January 2014, the NCCP published its Oncology Medication Safety Review Report conducted across the 26 hospitals in Ireland involved in administering drug therapy in adults and children. The recommendations of this report were made available to all hospitals and a tracking system put in place to monitor compliance with these recommendations. A new national Policy Development Programme for Cancer Drugs is in evolution and will provide national policy direction by 2015.

### **Community Oncology**

The Community Oncology Programme expands the range of cancer prevention, primary care guidelines and educational support, patient discharge and survivorship. This Programme has been integral to the development of patient care pathways from primary care referral into the designated cancer centres and has led to the development of electronic referral from GP offices into the hospitals for breast, lung and prostate cancer. Electronic referral of suspected melanoma is being piloted.

The Programme has developed a number of nursing education programmes including the programme for registered nurses in primary care which has now been delivered to 700 nurses through specialist centres and the use of video links. An e-learning version is now under development. A continuing professional development programme for registered nurses working in an inpatient setting has focused on a three day programme commencing in 2014 which will lead to an accredited programme. The skills-based Community Oncology Nursing Programme equips public health nurses to undertake care for patients at home who are undergoing systemic therapy. This programme, which was initially implemented in the Northwest and the West, has

now been expanded to a university accredited programme to be delivered in multiple locations across the country.

Cancer Survivorship is now a high priority as 60% of diagnosed patients are likely to survive free of disease and may, over the course of their lives, develop a range of physical and psychological needs related to their prior diagnosis of cancer and its treatment that can best be addressed through an empowered primary care community, and through education and information of the patients in relation to consequences of cancer or its treatment. The initial focus is on development of treatment summaries and care plans.

### **Hereditary Cancer Programme**

The Hereditary Cancer Programme has been in place for a number of years under the leadership of the National Centre for Medical Genetics. This service provides excellent guidelines and algorithms to determine which patients diagnosed with cancer are at risk of having a hereditary mutation and which family members should be subsequently tested. The original programme was under considerable strain in terms of the volume of referrals and growth in demand for counselling and testing. The NCCP has developed a partnership with the National Centre for Medical Genetics and they have jointly moved to develop a more comprehensive programme for patients and public at risk for hereditary cancers. The NCCP has funded public services at St James's Hospital and the Mater Hospital, and has developed a reimbursement process to these hospitals for the costs of the genetic tests. Approval has been received in mid 2014 to appoint a national clinical lead for the NCCP in hereditary cancer to work on a further expansion of this programme.

## National Guideline Development Groups (Tumour Groups)

Oncologists in Ireland have traditionally relied on a variety of local or international guidelines to aid treatment decisions. As cancer diagnosis, staging and treatment continues to grow in variety and complexity, the need to develop national evidence-based clinical practice guidelines was identified as a priority.

In 2011, the Royal Colleges of Physicians and Surgeons were invited by the NCCP to nominate specialists in pathology, radiology, surgical oncology, radiation oncology and medical oncology to form five National Guideline Development Groups for breast, prostate, lung, gastrointestinal and gynaecological cancers. Each group worked collaboratively with NCCP project managers, a methodologist, research support and HSE librarians to adopt, adapt or develop treatment guidelines which they had critically evaluated, based on best published evidence.

The Breast and Prostate National Guideline Development Groups completed their work in mid 2014. Their comprehensive and succinct guidelines have been through stakeholder review and are proceeding to external review. Publication and implementation will be in late 2014.

The Gynaecology Guideline Development Group has completed its first guideline and the lung and gastrointestinal guidelines have made good progress. Once all the Guideline Development Groups have completed their tranche of guidelines, the NCCP will develop five more national Guideline Development Groups to address haematology, skin cancers, sarcomas, brain cancers and head and neck cancers.

Guidelines have been developed according to the principles and processes of the Department of Health National Clinical Effectiveness Committee. They will be periodically reviewed and revised as necessary.

## Cancer Intelligence

The National Cancer Registry of Ireland (NCRI) provides comprehensive capture of cancer incidence, prevalence, mortality and site-specific trends.

This excellent registry is an independent entity with its own Board. Its Director works closely with hospitals, the NCCP and the National Cancer Screening Service to capture data on demographics, pathology, staging and the first year of treatment. Collaboration and comparison of international outcomes is a key element of their work. For patients diagnosed up to 2007, Ireland has similar outcomes to England, Wales and Scotland, but falls short of the better five year age-adjusted survivals reported by mature cancer control systems, such as some of the Scandinavian countries, Australia and Canada.

The reorganisation of cancer services in Ireland is expected to show significant improvement in survival over the next decade.

The Cancer Intelligence Unit of the NCCP relies on NCRI data and HSE hospital data from the Hospital Inpatient Enquiry (HIPE) system to evaluate workload and plan for revenue, staff and capital developments. In addition the NCCP develops and implements key performance indicators for cancer services, including access times and other quality clinical parameters. These are consistently monitored by hospitals, screening services, the NCCP and the wider HSE. Planning and guidance is conducted in partnership with hospitals and HSE divisions.

## National Programmes in Quality Assurance

### Histopathology

Accuracy and consistency in cancer diagnoses are the critical elements in determining best patient outcomes. The Faculty of Pathology of the Royal College of Physicians of Ireland leads in the development and implementation of clinical audit and quality assurance. The NCCP provided sponsorship and collaborative input into this programme (from 2009), which spans all tissue histopathology, not just cancer. The programme has been successfully implemented nationally in 2013 and published its first report on the initial 3 benchmarks in February 2014.

### Radiology

The National QA Programme in Radiology has been funded by the NCCP since 2010. It is managed by the Faculty of Radiology in the Royal College of Surgeons in Ireland and has just completed the roll out of the supporting ICT in its first site. National implementation is expected to be complete in 2016.

### Endoscopy

In 2011, the conjoint board of the Royal College of Physicians and Surgeons in Ireland, in association with the NCCP/HSE and its National Cancer Screening Service, launched the National Quality Assurance Programme in gastrointestinal endoscopy. QA Guidelines have been established and the programme is in its implementation phase. There are currently 18 sites live, with all sites expected to be live by 2015.

Overall, these National Quality Assurance Programmes, and their data capture and information technology infrastructure are available in public, private and voluntary hospitals in the country.

## Cancer Research

The National Cancer Control Programme does not have the mandate to develop strategy or fund research, however, it is committed to fostering clinical, epidemiology and related translational research as an essential element of national cancer services. Knowledge development, health services evaluation, clinical outcomes and quality of care all improve in an active research environment. Patients benefit from participation in clinical trials; oncologists and allied health staff benefit from fostering their intellectual curiosity, developing research experience, and engaging in innovative studies, all of which favour recruitment and retention of excellent staff. Cost savings in health services are also facilitated by access to new drugs and tests.

ICORG, the All Ireland Cooperative Oncology Research Group, conducts the majority of cancer clinical trials in Ireland. The cooperative research group has participation from most oncologists in Ireland. Its funding is principally derived from the Health Research Board, as well as the Irish Cancer Society and international cooperative groups or pharmaceutical sponsorship. ICORG has been very successful: in 2013, over 70 clinical trials were open to recruitment, 1600 patients were enrolled and active collaboration was ongoing with over 50 pharmaceutical companies and universities worldwide.

The National Cancer Registry of Ireland is actively involved in research. Its focus is on etiology and risk factors, impact of screening and treatment, outcomes of care including patient reported outcomes, quality of life and long-term sequelae of cancer and survival.

Scientists, allied health staff and physicians conduct a wide range of basic science, translational, epidemiology and clinical research in universities and hospitals, which are beyond the scope of this document.

## Challenges in 2014

The burgeoning incidence and prevalence of cancer, driven by both the demographics of an aging population and the success of long-term treatments in improving survival, will more than double demands on services in the next 25 years.

The exciting innovations in cancer diagnostics and therapeutics come with rapidly rising costs.

The current financial recession and its consequent recruitment moratorium impede the smooth planning for growth in highly specialised human resources or timely investment in capital equipment and new technologies. Investment in information technology to support clinical systems and performance management is a priority.

National health services reform and restructuring are well underway but the impact on the relatively “young” National Cancer Control Programme must be carefully managed to leverage ongoing commitment to the focus of cancer services in designated cancer centres.

## Opportunities

Research in molecular oncology has led to an explosion of knowledge of the genetic behaviour and chemical pathways of cancer cells. The consequent growth in sophisticated diagnostics and therapeutics has steadily improved both the curability of cancer and the ability to moderate the growth of advanced cancers. Now, more than 60% of cancers are cured. Advanced cancers are evolving into chronic diseases which require long term treatment, but some cancers remain refractory to current therapies.

The major focus of the next decade will be on personalised medicine where drugs target specific features of cancer cells.

Cancer prevention and screening will be a long-term priority and cancer survivorship will emerge as a dominant theme. The future of cancer control will reflect innovation and priority setting for cost effective interventions.

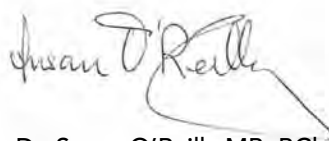
The progress the NCCP has achieved so far in implementing the National Strategy was contingent on the strong leadership and support of the following people and organisations:

- The Minister and the Department of Health
- The HSE
- The Royal Colleges of Medicine and Surgery in Ireland and the Irish College of General Practitioners
- The CEOs of hospitals and groups, especially those with designated cancer centres
- The oncology consultant community and their leaders in specific disciplines or cancer diagnoses
- The National Clinical Advisors to the NCCP, especially Professor Arnold Hill (Surgery), Dr Jerome Coffey (Radiation Oncology) and Dr Maccon Keane (Medical Oncology) and the Chairs and Clinical Leads of the National Guideline Development Groups and Clinical Services

Special thanks to:

- Professor Tom Keane, the first Director of the NCCP
- Mr Tony O’Brien, first CEO of the National Cancer Screening Service and former Deputy Director of the NCCP and now the Director General of the HSE
- Dr Harry Comber, recently retired Director of the National Cancer Registry of Ireland
- The excellent staff, both past and present, of the National Cancer Control Programme

Finally, it’s a privilege to work with the public, patients, their advocacy groups and charitable bodies such as the Irish Cancer Society, in the pursuit of improving the survival and quality of life for patients with cancer.



**Dr. Susan O’Reilly MB, BCh, BAO, FRCPC, FRCPI**  
National Director  
National Cancer Control Programme

# The Context

Ireland developed its first national Cancer Strategy in 1996. This strategy aimed to reduce the death rate from cancer in the under-65 age group by 15% in the ten-year period from 1994. Prior to the development of the first Cancer Strategy, there had been little dedicated investment in cancer services. This 1996 strategy resulted in a definite focus, prioritisation and investment (over €400m) in cancer services and gave rise to the appointment of 85 new cancer consultants (including 15 medical oncologists, 14 breast surgeons, 6 general surgeons, 19 histopathologists, 12 radiologists) and 245 clinical nurse specialists.

The first Cancer Strategy was evaluated by Deloitte in 2003. Their overall review was very positive noting that the 1996 National Cancer Strategy had raised the profile of cancer services across the health system and provided a clearer focus and direction in terms of planning processes. It concluded that the implementation of a new cancer strategy would ultimately be reliant on an ability to reconfigure existing structures, enhance system co-ordination and interaction and redefine accepted working practices and service management.

The review coincided with the publication of a National Cancer Registry of Ireland (NCRI) report in 2004, which found significant regional variations in treatment and, in the case of breast and colorectal cancer, significant differences in regional survival rates.

In 2006, the second national cancer strategy, 'A Strategy for Cancer Control in Ireland 2006', was developed by the second National Cancer Forum, an advisory body to the Minister for Health and Children. It aimed to address the rising burden of cancer in the Irish population at a time when Ireland compared poorly with other developed countries in terms of cancer risk, cancer incidence and deaths from cancer.

The 2006 National Cancer Strategy advocated a comprehensive cancer control approach i.e. a whole population, integrated and cohesive approach to cancer that involves prevention, screening, diagnosis, treatment, and supportive and palliative care. It also placed major emphasis on the measurement of need and on addressing inequalities as well as on reform and reorganisation of the delivery of cancer services. The aim of this new approach was to ensure that future services are consistent and are associated with a high-quality experience for patients and their families. The report highlighted concerns on the considerable variation in cancer survival between regions and the fragmentation of services for cancer patients.

The 2006 National Cancer Strategy's vision was that "Ireland will have a system of cancer control which will reduce our cancer incidence, morbidity and mortality rates relative to other EU15 countries by 2015. Irish people will know and practice health



promoting and cancer-preventing behaviours and will have increased awareness of and access to early cancer detection and screening. Ireland will have a network of equitably accessible state-of-the-art cancer treatment facilities and we will become an internationally recognised location for education and research into all aspects of cancer.”

The 2006 National Cancer Strategy envisaged the establishment of four geographic networks of cancer services, each covering a population of about one million people. Each network was to have a lead cancer institution /specialist cancer hospital with access to radiotherapy services. These centres were to deliver a full range of cancer care, and to oversee the delivery of cancer services at the other institutions in the network. Each cancer network was also to have regional centres dealing with cancers where a high degree of specialisation is not required.

‘A Strategy for Cancer Control in Ireland 2006’ identified a number of key shortcomings in the way cancer services were delivered in Ireland. The analysis in the report noted that while there had been a transformation in the range and capacity of cancer services as a result of the 1996 National Cancer Strategy, there continued to be a need for significant expansion in all aspects of cancer service capacity in order to meet the cancer needs of the population. With some exceptions, such as paediatric cancer, Ireland was performing poorly by international standards in relation to cancer risks, incidence and survival. The fragmented arrangements for the delivery of cancer services were not in accordance with best practice. Cancer services were spread across thirty six hospitals, many with small volumes and lacking full multidisciplinary teams. There was poor access as well as inequity in the provision, availability and performance of cancer services when examined by region, gender and by social class. The aim was to develop a cancer control system with the potential to achieve population and individual outcomes on a par with the highest international standards.

The 2006 National Cancer Strategy included 55 recommendations including the development of a cancer control framework.

In response to the publication of the 2006 National Cancer Strategy, the Health Service Executive (HSE) established the National Cancer Control Programme (NCCP) in 2007. The role of the NCCP was to provide a comprehensive programme of cancer control in Ireland, to transform how cancer care is delivered, and ensure that cancer services meet the highest standards. The programme was to provide the necessary governance, integration and leadership to create the essential framework for a successful transformation of cancer control activities in Ireland.

The establishment of the NCCP came at a time when the reputation of cancer services in Ireland had been undermined following a series of high profile breast cancer missed diagnoses, long waiting lists for colonoscopy, missed cancers as well as delayed diagnostics and treatment. Notwithstanding, the investment made since the publication of the 1996 Strategy, cancer services were still fragmented and disorganised with limited or no accountability. In 2007 breast cancer surgery was undertaken in 32 hospitals while rectal cancer surgery was undertaken in 36 hospitals.

The Deloitte report highlighted that while the concept of supra-regional centres had been accepted by policy-makers, limited progress has been made on their establishment on the ground. Clinical pathways from secondary services to tertiary services had not been clearly defined. Specifically the report noted that in some health boards, cancer services were spread across a number of hospital sites which was attributable to geographic and demographic considerations as well as a result of political influence and the desire to have “all services in all hospitals”.

There were many positive features of the cancer services including the development of regional and supra-regional cancer centres, approval for

expansion of Radiation Oncology facilities (outlined in the Hollywood Report<sup>1</sup>), additional funding for cancer services, high participation in clinical trials, a cadre of well-trained oncologists, clinicians, nurses, technicians and therapists skilled in oncology, early introduction of breast and cervical screening programmes (albeit not with national coverage) establishment of regional directors of cancer and approval for cancer liaison nurses.

However, at the time, there were few national standards, treatment guidelines, quality indicators, monitoring of targets or assurance processes in place for cancer services. Apart from the Hospital In-Patient Enquiry Scheme (HIPE), the only cancer data available related to incidence, treatment and survival rates from the National Cancer Registry of Ireland (NCRI).

Cancer was not managed as a function and there was no co-ordinated national plan for cancer prevention, early detection, diagnosis, treatment, survivorship and end-of life care.

Another key impetus for change was the publication of the EUROCARE results<sup>2</sup>, which showed cancer outcomes in Ireland were not as good as other European countries.

In September 2007, in response to the publication of the 2006 National Cancer Strategy, the HSE published a plan which provided an outline of the proposed configuration of cancer care services. This plan, 'Establishment of Managed Cancer Control Networks and for the Designation of Eight Cancer Centres' (Appendix 1) specified that eight hospitals were to be designated as cancer centres for the purpose of providing primary curative surgery in the context of full multidisciplinary care.

A cancer centre was to be characterised by the geographic concentration of all oncology disciplines with sub specialised expertise on a tumour specific/discipline basis to provide the critical mass and support to achieve best practice in cancer care. Designated cancer centres were anticipated to address the needs of a 500,000

population base. Four of the eight designated centres were in Dublin: The Mater Hospital, Beaumont Hospital, St. Vincent's University Hospital, St. James's Hospital; the other four centres were Waterford Regional Hospital, Cork University Hospital, Mid Western Regional Hospital Limerick and University College Hospital Galway. It was also agreed that Letterkenny, because of the unique geographical circumstances would become a satellite of University College Hospital Galway subject to certain conditions on patient volumes, governance and outcomes. Apart from designating the eight cancer centres, this document also recommended further centralisation of certain types of cancer surgery.

The NCCP was established with a remit to lead and implement the change management process required to reorganise cancer services and set up a system of quality assurance and oversight designed to improve the care and outcomes for cancer patients. It was to adopt a population based approach to planning and would integrate all aspects of cancer care and oversee all activities.

Prof. Tom Keane was seconded from his role as provincial radiation programme leader for the British Columbia Cancer Agency in Canada and appointed Interim Director of the NCCP in September 2007 for a two year period to oversee its implementation. He engaged widely with radiation, surgical and medical oncologists, GP and nursing representatives and voluntary agencies across the country. He appointed part-time advisers to the NCCP in surgical oncology, medical oncology and radiation oncology and established the community oncology team. Following the completion of Professor Keane's contract in February of 2010, Mr. Tony O'Brien (CEO of the National Cancer Screening Service (NCSS) and current Director General of the HSE) was appointed Interim Director until the commencement of Dr. Susan O'Reilly as Director of the National Cancer Control Programme in September 2010.

1 The Development of Radiation Oncology Services in Ireland, 2003, [http://www.dohc.ie/publications/expert\\_working\\_group\\_on\\_radiation\\_oncology\\_services.html](http://www.dohc.ie/publications/expert_working_group_on_radiation_oncology_services.html)

2 The Lancet Oncology, Volume 8, Issue 9, Pages 784 - 796, September 2007



Change management and leadership of this complex strategy initially focused on:

1. Delivering radical change in the centralisation of surgical services for selected common diagnostic categories (breast, prostate and lung cancers) and for selected clinical diagnoses requiring complex treatments (rectal, pancreatic and upper oesophageal cancers) in high volume, expert multidisciplinary centres.
2. Planning and building radiation oncology capacity.
3. Improving quality assurance in diagnostic specialities.
4. Developing evidence based referral pathways from primary care to specialist services.

Building on this logical sequence, national programmes in medical oncology and haematology, and their essential national drug management were next developed.

Simultaneously, the establishment of a quality assurance system which incorporated the development and monitoring of key performance indicators and the establishment of national tumour groups as well as guideline development and evaluation of patient safety were prioritised.

This report will assess the impact of the establishment of the National Cancer Control Programme in implementing the 2006 National Cancer Strategy. This is particularly important as Ireland looks to develop a new cancer strategy.

# Overview of Key Service Developments

In 2007, the HSE established a National Cancer Control Programme (NCCP) in response to the publication of the new 2006 National Cancer Strategy.

The Interim Director, Prof. Tom Keane, was seconded to oversee its implementation. The agreed approach taken for the implementation of the Strategy was one of a step-wise, sequential implementation with the identification of a number of key priority areas which could be significantly progressed. The immediate priority was the centralisation of symptomatic breast disease services along with the expansion of radiation oncology facilities, and improving access to diagnostic services for some common cancers. The development of evidence-based GP referral pathways was another early initiative. Centralisation of rectal cancer surgery was also a high priority as, similar to breast surgery, this service was widely dispersed. Other cancer priorities were to be addressed in sequence subsequently. The focus on medical oncology commenced in earnest in 2012 along with the establishment of the hereditary cancer programme.

In its plan 'Establishment of Managed Cancer Control Networks and the Designation of Eight Cancer Centres' published in September 2007, the HSE had provided the blueprint for the configuration of cancer services. It had already identified the eight designated cancer centres which were to be characterised by the geographic

concentration of all oncology disciplines, with sub specialised expertise on a tumour specific/ discipline basis, to provide the critical mass and support to achieve best practice in cancer care (Appendix 1).

Priority was initially given to centralising the surgery for high volume cancer cases with the transfer of breast surgery as the main priority in the first two years. Commencing with the lowest volume hospitals, services were to be moved in sequence from hospitals which did not meet the defined criteria for delivery of surgical care into the eight designated cancer centres. In parallel to the centralisation of hospital services, work was undertaken with the Irish College of General Practitioners to ensure prompt and appropriate referrals.

## **Symptomatic Breast Disease**

In 2007, the Health Information and Quality Authority (HIQA) approved the National Quality Assurance Standards for Symptomatic Breast Disease which were subsequently mandated by the Minister for Health and Children. Around this time a series of investigations were undertaken into serious incidents of delayed or missed breast cancer diagnosis which raised concerns about the quality and safety of breast cancer services. These events gave urgency and momentum to efforts to improve the quality and safety of symptomatic

breast disease services. The then Minister for Health and Children convened a special meeting of experts in breast cancer care in November 2007, an indication of the widespread level of concern about the services at that time.

In 2007, there were 32 hospitals providing some level of symptomatic breast disease surgery. Between September and November of that year, breast cancer surgical services were discontinued in hospitals which were carrying out fewer than 20 breast cancer surgeries per annum. There remained 22 hospitals providing a service. It was agreed that by the end of 2009, 90% of all breast cancer surgeries would be concentrated in the eight designated centres (and a satellite centre at Letterkenny General Hospital).

Over 2008-2009, transition plans were developed for consolidating the remaining symptomatic breast disease services into the eight designated centres. Most transitions involved a combination of transfer of resource and some additional funding to the designated cancer centre. Arrangements were put in place for patient follow up and details of the new arrangements were communicated to GPs and the public. By December 2009, all symptomatic breast disease surgery was provided only in the eight designated centres and the satellite unit at Letterkenny General Hospital. The centralisation of breast cancer surgery was controversial particularly in parts of the West of Ireland. Strong leadership from key clinicians and managers, the backing of patient groups and unwavering political support were key factors in implementing this change within the target time-frame.

In 2010, the Health Information and Quality Authority published the Quality Review of Symptomatic Breast Disease Services, the culmination of two and a half years of interaction with the services since the launch of the National Quality Assurance Standards in 2007. This involved self-assessment, validation of the self-assessment process, feedback to designated centres and a quality review visit with in-depth review of performance prior to publication of the

findings. While identifying many areas for further improvement, the Review acknowledged the progress that had been made "From a position in 2007 when symptomatic breast disease services in Ireland were dispersed, unspecified and unmonitored, there are now eight designated centres established, albeit the last of these became operational in December 2009".

A review of the National Quality Assurance Standards for Symptomatic Breast Disease Services was carried out in 2013. This review took into account the substantial reform programme for cancer services over recent years, the HIQA national quality review of symptomatic breast disease services, published in 2010<sup>3</sup>, and the subsequent development of key performance indicators (KPIs) and clinical guidelines by the National Cancer Control Programme. The review also took into account the National Standards for Safer Better Healthcare<sup>4</sup>, published in 2012.

Since February 2014, symptomatic breast disease services are monitored by HIQA under the National Standards for Safer Better Healthcare as the National Quality Assurance Standards for Symptomatic Breast Disease Services have been stood down.

There have been significant improvements in the care of patients with breast cancer since the establishment of the NCCP. A national clinical governance system is in place with designated lead clinicians from the eight cancer centres meeting on a regular basis to improve the implementation and standardisation of evidence based practice across the centres. Key performance indicators have been developed to monitor access, processes and outcomes for those referred to symptomatic breast disease clinics. As a result of the establishment of these clinics, over 95% of all women with an urgent referral are seen promptly within two weeks of referral, treatment is consultant-delivered, with a multidisciplinary team in place and outcomes monitored and KPIs measured. Partnership with general practitioners and the ICGP has been key in improving the referral pathway.

3 [http://www.hiqa.ie/system/files/Symptomatic\\_Breast\\_Disease\\_Services\\_National\\_report\\_2010%20.pdf](http://www.hiqa.ie/system/files/Symptomatic_Breast_Disease_Services_National_report_2010%20.pdf)

4 <http://www.hiqa.ie/standards/health/safer-better-healthcare>

Since all breast disease may be referred (not just suspected cancers) these clinics also see a high volume of non urgent benign cases within a target time of 12 weeks.

Additional information on breast cancer is available in Section 6.1

## Colorectal Surgery

Following the successful transfer of breast cancer surgery to the eight designated cancer centres in 2008-2009, the attention of the NCCP turned to colorectal cancer surgery. In 2008, colon cancer surgery was performed in 32 hospitals and rectal cancer surgery in 29 hospitals. The 2006 National Cancer Strategy envisaged that primary surgery for colorectal cancer would take place in the designated cancer centres. The 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' recommended that rectal cancer surgery would be confined to four designated centres.

These proposals were discussed at a large meeting of the colorectal surgical community at the Royal College of Surgeons in Ireland's (RCSI) annual Charter Day in 2008. The importance of maintaining competent surgeons in acute hospitals to deal with acute surgical cases was stressed. Concern was expressed that centralising experienced colonic surgeons into eight centres would result in a deficit in provision of emergency care in the non-designated general hospitals. In addition the relative frequency of presentation of colon cancer gave rise to concerns that cancer centres would struggle to deal with the needs of such a large group of patients. It was also recognised that there was not a strong evidence base indicating that outcomes were likely to be improved substantially by centralisation of colon cancer surgery. In view of these factors, it was agreed that colon cancer surgery would remain in all acute hospitals with Emergency Departments. However, the international literature was very clear that rectal cancer surgery should be carried out in high volume centres.

The Irish Association of Coloproctology (IACP) met with Prof. Tom Keane in 2008, indicating their support for improving standards of care in colorectal cancer surgery and confirming willingness to participate in an audit of rectal cancer surgery. Following this the RCSI began an audit of all rectal cancer surgery performed in public hospitals Ireland in 2007. While retrospective in nature, the audit provided independent verification of the number of rectal cancer operations performed in the audited hospitals as well as some data relating to quality of surgery and pathology. Following the audit, the IACP made a number of detailed recommendations:

- Rectal cancer surgery should not be performed in hospitals where fewer than 20 rectal cancer surgeries are carried out annually
- Rectal cancer surgery should be performed in all eight designated cancer centres with provisos in relation to number of operations, adherence to guidelines, surgeon training, nomination of a lead surgeon, discussion of patients at multidisciplinary team meetings and participation in audit
- Rectal cancer surgery could be performed in a small number of high volume non-designated centres, with similar provisos as the cancer centres, on an interim basis.

The IACP considered that implementation of these recommendations would immediately reduce the number of hospitals providing rectal cancer surgery to 14.

Prof. Keane met with the four HSE Regional Director of Operations, early in 2010, outlining the findings of the audit, the rationale for the proposed changes and recommending that they be implemented in the acute hospital system. The transfer to the designated cancer centres was to be resourced through inter-hospital transfer of resources within the HSE Regions, proportionate to the volume of surgery being transferred. The Interim Director held separate discussions in Letterkenny General Hospital and agreed that subject to certain conditions including linkage with

the multidisciplinary team in Galway and routine monitoring, rectal cancer surgery could continue to be performed at the hospital. Some patients with particularly complex surgery would be transferred to Galway for surgery.

Subsequent to the audit, many low volume surgeons ceased their rectal cancer surgery. Some surgeons with moderate volume elected to transfer that part of their practice to a designated cancer centre. At the end of 2009, 51% of rectal cancer surgery took place in the eight designated cancer centres and Letterkenny; by the end of 2012 (last complete year of data), this had risen to 72%. However, rectal cancer surgery continued to be performed in six other hospitals. Preliminary information in relation to 2013 indicates that there has been continued transfer of rectal cancer surgery to the designated centres from a number of smaller hospitals. However, there is a substantial rectal cancer surgery practice remaining in two non-designated hospitals.

The national colorectal screening programme BowelScreen began at the end of 2012 and is currently being rolled out nationally. Under the programme all surgery for screen detected cancers must be carried out in the eight designated cancer centres.

The slow progress and lack of completion of transfer of rectal cancer surgery to the designated centres over a four year period 2010-2014 is in sharp contrast to the rapid, complete transfer of breast cancer services in a two year period 2008-2009. There are a number of contributing factors in addition to the resistance to change which is also present. This transfer coincided with a period of financial retrenchment in Ireland, when the HSE experienced budget reductions and a recruitment moratorium was in place with resulting reductions in staffing levels. The anticipated transfer of resources into the designated centres, and the export of intermediate level benign surgery to the non-designated centres could not be effected. The designated centres therefore were trying to absorb an increased workload at a time when not only did they not receive additional resources but

their own budget and workforce were reduced. A number of cancer centres were also impacted by acute hospital reconfiguration, where the role of other hospitals in their region changed, and more complex non-cancer work was also being diverted to the cancer centre. At the end of 2013, rectal cancer surgery was undertaken in 19 hospitals. The NCCP has identified the continuation of the process of rectal cancer centralisation in its service plan priorities for 2014.

Additional information on rectal cancer is available in Section 6.4.

## Prostate Cancer

The 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' concluded that there is a need for four centres nationally, one within each Network, for the curative surgical treatment of primary urological cancer.

The original intention has been reconsidered and the NCCP now intends to centralise all prostate cancer surgery into six centres (University College Hospital Galway, Cork University Hospital, the Mater, Beaumont, St. James's and St. Vincent's University Hospitals). Two non designated hospitals are also undertaking significant volumes of prostate cancer surgery (Appendix 2). Efforts to centralise prostate cancer surgery remain a work in progress with the transfer of existing surgery from two large non cancer centres identified as a priority of the NCCP in 2014.

Joint working with the ICGP takes place to ensure best practice in relation to prostate assessment in primary care and appropriate referrals. E-learning in prostate disease has been developed by the ICGP, in collaboration with the NCCP.

Additional information on prostate cancer services is available in Section 6.2

## Lung Cancer

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that four centres nationally were required, for the curative surgical treatment of primary thoracic cancers.

In recent years, significant advances have been made towards the integrated delivery of lung cancer services with the introduction of rapid access lung clinics in each of the designated cancer centres and the establishment of four designated surgical lung cancer centres (Mater Hospital and St. James' Hospital Dublin, University College Hospital Galway, and Cork University Hospital,) staffed with multidisciplinary teams.

Smoking prevalence in Ireland is now 22%. Partnership with GPs and HSE prevention services is critical in relation to lung cancer prevention and early detection. E-learning in smoking cessation has been developed for GPs, in collaboration with the ICGP, and for allied health professionals.

Additional information on lung cancer services is available in Section 6.3.

## Centralising Other Cancers

As outlined above, the priority for the NCCP was to centralise the high volume cancer surgeries into the designated centres. With all breast cancer surgery undertaken in a designated centre by December 2009, the focus turned to less common cancers and the expansion of radiotherapy facilities.

## Upper Gastrointestinal Cancers

The 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' recommended that "there is a need for two centres nationally for the curative surgical treatment of primary upper gastrointestinal cancers". In 2007, there were nine hospitals (four of them designated cancer centres) undertaking oesophagectomies for upper gastrointestinal cancer and 28 hospitals (including all of the designated cancer centres) undertaking gastrectomies for gastric cancer.

The NCCP undertook an examination of the activity in these hospitals, looking at volumes, bed utilisation, intensive care usage and the geographical patterns of patient referral for both oesophageal and gastric resections. Cognisant of the strong association between volume and outcomes for oesophageal resections and in consultation with clinical advisors, it was agreed to designate four hospital units to undertake the primary surgical management of oesophageal cancer. A more in-depth audit of these hospitals would be undertaken prior to final determination of surgical centres.

In 2010, Beaumont Hospital, St James's Hospital, University College Hospital Galway and Cork University Hospital were designated as the four candidate units and a national lead was appointed for Upper Gastrointestinal Cancer. At that time, surgical activity in Cork was undertaken in the Mercy University Hospital; it is however planned to transfer this activity to Cork University Hospital. This remains a priority in the NCCP's operational plan for 2014.

Additional information on upper gastrointestinal cancer is available in Section 6.5.

## Pancreatic Cancer

In 2008, there were nine hospitals (six of them designated cancer centres) undertaking excision of pancreatic tumours. A process was undertaken in 2009 to identify the optimal location for a national centre – this resulted in St. Vincent's University Hospital (SVUH), Dublin being designated the national centre in late 2009.

During 2010, the NCCP reviewed the data in relation to the units that provided pancreatic cancer surgery at that time. Based on this review it was then proposed that a satellite unit be established in the Mercy University Hospital pending transfer of the service to the designated cancer centre in Cork University Hospital.

All cancer surgeries were to be concentrated in the new national centre (incorporating the Cork satellite service), with patients continuing to undergo diagnostic and staging investigation and non-surgical management in other hospitals and



designated cancer centres. Significant additional funding was transferred to St. Vincent's University Hospital in 2010 to support the centralisation of pancreatic cancer surgery. Casemix costings for the surgical episode of care was transferred from those hospitals that had previously carried out resections, with funding for work up, diagnostics and non-surgical treatments remaining in the referring hospitals. Some surgeons who previously undertook pancreatic surgery in other Dublin hospitals had their contracts adjusted to enable them to operate in St. Vincent's University Hospital.

Members of the national surgical team for pancreatic cancer met with their colleagues around the country to discuss and agree patient pathways, referral criteria and patient information for pancreatic cancer surgery. A national lead surgeon was appointed for pancreatic cancers and a National Pancreatic Imaging Network was also established to agree standards for diagnostic imaging prior to referral to the national pancreatic centre.

The transfer of pancreatic surgery from the Mercy Hospital to the designated cancer centre in Cork took place in June 2012.

Additional information on pancreatic cancer services is available in Section 6.6.

## **Gynaecological Cancers**

In 2007, there were 27 hospitals undertaking surgery for cervical, ovarian or uterine cancer. The NCCP undertook an examination of the activity in these hospitals, looking at volumes, bed utilisation, intensive care usage and the geographical patterns of patient referral for gynaecological resections. In consultation with clinical advisors, a decision was taken early in 2012 to centralise surgical gynaecology oncology services into seven designated cancer centres (the existing cancer centres apart from Beaumont Hospital). Improving quality of Surgical Gynaecology Oncology Services in Ireland is a key priority for the National Cancer Control Programme (NCCP), in conjunction with the appointed lead consultant for gynae oncology. The more complex gynae cancer surgery and

surgery for rarer tumours is carried out in St James's Hospital and the Mater Hospital. The development of a GP referral guideline for ovarian cancer is at an advanced stage.

Additional information on gynaecological cancers services is available in Section 6.8.

## **Pigmented Lesions and Melanoma**

The NCCP developed a national melanoma GP referral guideline to assist GPs in the early recognition of suspicious pigmented lesions and to provide advice on evidence-based referral. Following a pilot study in Cork, a pigmented lesion referral form was circulated to GPs nationally in 2013 and in 2014 electronic referral commenced on a phased basis.

In 2014 a review of pigmented lesion referrals was undertaken. This recommended the introduction of a national standardised approach to managing urgent pigmented lesions together with standard operating procedures (SOPs) for multidisciplinary team meetings, including the diagnoses to be discussed, procedures for listing cases and attendance requirements. In addition, measurable key performance indicators are being developed.

There are currently 15 hospitals with specialist services (including dermatology, oncology and plastic surgery) providing services for melanoma. It is envisaged that this arrangement will continue, but all non-cancer centres will have formal arrangements with a designated cancer centre with respect to the MDM process.

## **Rarer Cancers**

While there is already a considerable degree of centralisation of the diagnosis and management of cancers to the cancer centres, work to complete the centralisation of cancer is still underway particularly for rarer cancers. Work has commenced to develop a plan for the management of head and neck cancers and discussions have commenced with lead clinicians in the areas of sarcomas, neuro-endocrine tumours and early upper GI mucosal programmes.

Progress by the NCCP in relation to centralising these services has to date been modest. The available resources reside within the acute hospitals which provide these services and in the current economic circumstances, additional new resources are unlikely become available in the foreseeable future. The NCCP has reviewed available data on incidence and distribution of services and engaged with clinicians involved. The process of identifying lead clinicians, establishing national networks and planning future configuration of services is in train. Any further consolidation can be achieved only by collaboration and through transfer of existing resources. A plan to complete the centralisation is being finalised and will be implemented in conjunction with the HSE Acute Hospitals Directorate.

A recent analysis of data from the Hospital In-Patient Enquiry System (HIPE) has demonstrated the impact of the NCCP cancer surgery centralisation policy - 'Cancer surgery activity, within and without cancer centres 2007-2013' (Appendix 2). This reflects the successes achieved in the centralisation of many cancer surgeries; 55% of breast cancer surgery was undertaken in a cancer centre in 2007 – in 2013 this had increased to 99.8%; 43% of all rectal cancer surgeries had been undertaken in a cancer centre in 2007, by 2013 this has increased to 77%.

### **Rapid Access Clinics**

Part of the explanation for poor cancer survival in Ireland related to late diagnosis. Comparison with other jurisdictions showed that advanced state of disease at presentation was more common in Ireland. Early diagnosis is an issue that is wider than the hospital setting as it necessitates primary care involvement and education of both the public and family doctors to enable them to recognise symptoms and signs of cancer. The NCCP prioritised the establishment of Rapid Access Clinics in 2009 focusing on lung and prostate cancers.

### **Prostate Rapid Access Clinics**

In 2007/8, access to diagnosis for prostate cancer was considered particularly problematic. The pathway for the diagnosis of prostate cancer was through referral of patients suspected of having prostate cancer to general urology clinics in over 20 hospitals with variation in wait times around the country. In many cases, there was no formal triage in clinics and this produced unacceptable delays in diagnosis. The first two Rapid Access Diagnostic Clinics for Prostate Cancer opened in St James's and Galway University Hospitals in June 2009. They were developed by the two hospitals with the National Cancer Control Programme and the All Ireland Cancer Foundation Ltd. The Foundation specifically targeted prostate cancer and provided the initial two clinics with capital funding which started the implementation of this national initiative. The aim was to provide rapid access to a consultant opinion, and prostate biopsy if appropriate, to patients likely to have prostate cancer, with discussion at a multidisciplinary specialist cancer meeting following definitive diagnosis to establish appropriate management of care. Given the large number of suspect cases, it was agreed that patients at higher risk based on agreed high risk criteria should be fast tracked directly into Rapid Access Diagnostic Clinics in the designated cancer centres. Targets were set whereby patients were to have access to a specialist opinion within four weeks of initial appointment; those confirmed as having cancer have immediate access to a multidisciplinary cancer care team to arrange appropriate treatment. In 2012, a system was established by the NCCP's Cancer Intelligence Unit to monitor patient access to these clinics and the clinics' cancer detection rate.

The NCCP supported the other designated centres in developing and opening clinics. Funding was provided for the recruitment of consultant urologists, radiologists, pathologists, radiographers and medical laboratory scientists as well as some administrative funding. By the end of 2010, there were six rapid access prostate clinics operating in designated cancer centres. All eight clinics were operational by April 2012.



In parallel to the establishment of the clinics, the Community Oncology division of the NCCP developed National Prostate Cancer GP Referral Guidelines and a National Rapid Access Prostate Clinic Referral Form. Educational meetings were also held across the country providing GPs with the opportunity to hear at first hand how the clinics operated.

Additional information on prostate cancer services is contained in Section 6.2.

### Lung Rapid Access Clinics

Lung cancer is the leading cause of cancer deaths in Ireland and survival compares poorly with best international outcomes. Historically patients with respiratory problems suspicious of cancer were referred to respiratory clinics and had a series of investigations following the first consultation, often with delays at each step along the way. These clinics were present in some 20 hospitals and only a small number were specifically organised to address the diagnostic challenge of lung cancer. The majority of referrals related to general respiratory ailments and only a small minority of referrals had an eventual diagnosis of lung cancer. As a consequence, it was possible for a lung cancer patient to wait months to be seen unless such patients were triaged on the basis of symptoms or radiological findings.

The Irish Thoracic Society (ITS) developed guidelines with a view to improving outcomes for lung cancer patients in Ireland. The Society pointed out that earlier diagnosis, efficient and correct diagnosis and staging, and modern multidisciplinary management lead to improved short and long term survival with good quality of life. Improvements in the delivery of care were necessary through earlier diagnosis, rapid access to diagnostic and staging procedures, and provision of co-ordinated multidisciplinary treatment.

In consultation with the ITS, it was agreed that patients with sentinel symptoms or radiological findings with a high index of suspicion of lung cancer should be fast tracked to lung cancer diagnostic clinics in one of the eight designated cancer centres. These clinics would provide

comprehensive clinical assessment and enhanced access to diagnostic investigations such as imaging and bronchoscopy to reduce multiple hospital visits, reduce patient anxiety and shorten the time period to diagnosis. The NCCP provided funding for the recruitment of consultant respiratory physicians, radiologists, pathologists, radiographers and medical laboratory scientists as well as some administrative funding. By the end of 2010 there were functioning rapid access lung clinics in six of the designated cancer centres with all eight in place by March 2011. Targets were set whereby patients were to have access to a specialist opinion within two weeks of initial appointment; those confirmed as having cancer have immediate access to a multidisciplinary cancer care team to arrange appropriate treatment. In 2012, a system was established by the NCCP's Cancer Intelligence Unit to monitor patient access to these clinics and the clinics' cancer detection rate.

Endobronchial ultrasound (EBUS) is a diagnostic technique which improves localisation and diagnostic yield when sampling mediastinal or hilar lymph nodes and paratracheal masses. This may provide essential staging information and may provide a tissue diagnosis where the primary lesion is not visible within the airway. This technique was not available in the majority of designated cancer centres in 2009. Over €1.3m was made available nationally to fund EBUS ultrasound bronchoscopes and ancillary equipment for those centres which did not already have this service in place.

In parallel with the development of the clinics, the Community Oncology division of the NCCP developed National Lung Cancer GP Referral Guidelines and a National Lung Cancer Rapid Access Service Referral Form. As the Rapid Access Clinics became operational, these documents were circulated to GPs. Educational meetings were also held where GPs had an opportunity to hear at first hand how the clinics operated and to have their questions answered directly by personnel running the clinics.

Additional information on lung cancers services is available in Section 6.3.

## Radiation Oncology

The publication in 2003 of the report 'The Development of Radiation Oncology Services in Ireland', known as the Hollywood Report, provided a blueprint for the future provision of radiation oncology services nationally (TD 12). The report outlined the significant deficit that existed at that time in relation to meeting the radiation oncology needs of cancer patients.

The implementation of this national radiation oncology plan became a major focus for the NCCP in 2007 following its establishment. It was agreed that the first phase, the commissioning of four Linear Accelerators each in St James' and Beaumont Hospitals would be procured and funded by the HSE, with the tender process beginning in 2008. At that time, it was still planned that Phase 2 encompassing developments in Cork and Galway and their integrated satellite units at Waterford and Limerick, would be developed under a Public Private Partnership (PPP).

The two new radiotherapy centres in St James' and Beaumont Hospitals were completed and became operational in 2011. From 2008 onwards, the economic outlook in Ireland changed significantly. Following a detailed internal review, the Department of Health decided to meet further patient needs in radiotherapy by traditional means from within existing capital resources. Funding has been made available from the existing HSE Capital Plan to replace and expand the current facilities at Cork University and Galway University Hospitals and enabling works have already commenced on both sites. Both units will be relocated and expanded and the new facilities are due to open in 2017/2018.

In the meantime, radiation oncology services have been contracted from two private providers in Waterford and Limerick, thus improving access for patients in those areas.

It had been intended to deliver additional radiotherapy capacity in Dublin through a Public Private Partnership (PPP) to design, build, finance, maintain and partially operate the facility. However the changed economic environment resulted in a decision to progress expansion by traditional means. In recent weeks (June 2014) approval has

been given by the Minister for Health to expand the radiotherapy facilities in St. Lukes' hospital which will provide capacity until 2018 based on NCRI patient projections and private radiotherapy continuing at the current level. Funding approval for long term expansion in Dublin has yet to be agreed.

Planning is underway for the development of a radiation therapy facility at Altnagelvin Hospital, Derry, with capacity to treat the majority of patients residing in Donegal. It is anticipated that this facility will come on stream in 2016. The HSE is to provide both a capital contribution and ongoing revenue funding.

A full review of expansion plans and development of radiation oncology services from 2006-2013 is addressed in Section 7 of this report.

## Community Oncology

In parallel to the centralisation of cancer surgery and the establishment of rapid access clinics, significant engagement was undertaken to support GPs and primary care providers in ensuring that patients were referred in a timely manner to the designated cancer centres.

A GP was employed to liaise with the Irish College of General Practitioners. General practice referral guidelines and standardised referral forms to the designated cancer centres have been developed for suspected lung, prostate, breast cancers and melanoma. Considerable work has been done on the development of an ovarian cancer referral guideline.

National electronic referrals were introduced to facilitate referrals with suspected lung, prostate, or breast cancer to designated centres. Electronic referral of pigmented lesions is currently being introduced on a phased basis. These electronic referrals have now been embedded in all ICGP accredited software systems (see community oncology Section 9) and standards are in place and monitored to ensure that referrals are addressed in a timely manner.

A full review of the work undertaken by the Community oncology division of the NCCP is covered in Section 9 of this report.

## Medical Oncology

The NCCP established a National Medical Oncology and Haemato-oncology Programme in 2012 to ensure that the needs of the anticipated increased incidence in cancer diagnosis and requirements for treatment continue to be met. The national Medical Oncology and Haemato-oncology Programmes incorporate a number of initiatives aimed at coordinating and managing cancer drug services, ensuring appropriate access to and monitoring of cancer drug use and ensuring that appropriate forward-planning is undertaken. This included the establishment of a Technology Review Committee in early 2011 which is responsible for reviewing proposals received from industry or expert groups in Ireland for funding of new cancer drugs, expanded indications for existing cancer drugs or related predictive laboratory tests. The recommendations of the Technology Review Committee are based on the degree of clinical effectiveness, the acute and chronic toxicity and the cost effectiveness of the proposed technology.

A comprehensive Cancer Drug Management Programme was established in 2012 to develop and improve the care provided to patients receiving treatment with cancer drugs. This national medications management system for cancer drugs was set up so that the health service can continue to provide quality cancer treatment to patients within difficult budgetary conditions. The national management system facilitates:

- National oversight of the spend on high-cost cancer drugs, allowing for coordinated planning and, potentially, national approaches to provision of cancer drugs.
- Detailed information about drug utilisation as well as cancer incidence and prevalence.
- A mechanism for assuring adherence to national drug protocols, which is a key quality and patient safety objective for the NCCP.
- A coordinated system for HSE and NCCP, hospitals and the Primary Care Reimbursement Service (PCRS) in relation to high-cost cancer drugs.

A national Oncology Medication Safety Review Report was undertaken in 2012 which assessed the oncology medication policies and practices in day units nationally, from a patient safety and quality perspective. The report, which was conducted across the 26 hospitals in Ireland involved in the administration of systemic cancer therapy in adults and children, was published in January 2014. The report made a total of 93 recommendations, the implementation of which is currently being monitored. National safety policies are currently in development.

Detailed information on the National Medical Oncology and Haemato-oncology Programme is available in Section 8 of this report.

## Hereditary Cancer

Building on the work in cancer genetics carried out by the National Centre for Medical Genetics (NCMG), the NCCP established a national hereditary cancer programme in 2011 in collaboration with NCMG. The aim of the programme is to improve access to assessment and genetic testing for those patients and their families whose cancer may have a hereditary component. Dedicated out-patient clinics have been established and funded by the NCCP in St James's and the Mater Hospitals. Demand for the programme, which is primarily focused on hereditary breast, ovarian and bowel cancer has been increasing significantly since its establishment.

The NCCP has also identified the need to expand this diagnostic programme and embed standardised surveillance for the high risk population.

Additional information on the hereditary cancer programme is contained in Section 10 of this report.

## Cancer Screening

The National Cancer Screening Service Board was originally set up under statute in 2006. Under the leadership of Tony O'Brien (current Director General of the HSE) it transferred into the Health Service Executive under the National Cancer Control Programme (NCCP) in 2010.

There are three national cancer screening programmes in operation: BreastCheck - The National Breast Screening Programme for women aged 50-64 was implemented on phased basis commencing in 2000. It completed its first round of national screening in late 2011 and its second round in 2013. CervicalCheck - the National Cervical Screening Programme for women aged 25 to 60 became available to all eligible women in September 2008. It completed its first three-year round of screening in August 2011 and a second round in 2013. A national bowel screening programme (BowelScreen) was introduced in the final quarter of 2012. The programme offers home faecal immunochemical testing (FIT) to men and women aged from 60 to 69 every two years.

The National Cancer Screening Service (NCSS) transferred to the Health and Wellbeing Directorate of the Health Service Executive in January 2014. There is joint governance between the NCCP and the Health & Well Being Directorate in relation to the strategic direction of cancer screening and the development and monitoring of cancer screening key performance indicators.

Detailed information on the national cancer screening programme is available in Section 11 of this report.

## Criteria for Success

The 2006 National Cancer Strategy for cancer control provided a clear vision and focus for change. Strong political, policy and HSE support, combined with effective clinical leadership across disciplines and tumour site specific diseases, were, and remain essential.

Broad based communication strategies including briefings, interviews and the development of literature and a dedicated website were crucial in establishing links with all stakeholders, including

the public, cancer patients, politicians, the media, professional bodies (Royal Colleges of Medicine and Surgery), the Irish College of General Practitioners, other divisions within the HSE, hospital leaders and cancer charities such as the Irish Cancer Society.

Financial investment in staffing, technology and equipment are essential to ensure state of the art diagnostics and therapeutics appropriate to the anticipated patient volumes. Modest new investment was required to scale up screening programmes for the population and diagnostic therapy for patients. The ability to transfer hospital resources and staff to designated cancer centres was essential to mitigate costs.

Persistence in working across stakeholder groups and local interest groups (whether public, political or professional) remains a key focus. Ensuring that each patient's cancer is optimally managed by a multidisciplinary team in an expert cancer centres is central to the aim of improving cancer outcomes.

## The Challenges

While considerable progress has been made in the implementation of many of the recommendations of the 2006 National Cancer Strategy (Appendix 3) there are a number of priorities which remain work-in-progress.

Key challenges include:

- Increasing incidence: Ireland because of its relatively young population and inevitable "boom" in the number of ageing people will have the highest growth of cancer incidence in Europe. The National Cancer Registry of Ireland predicts there will be a **doubling** in the incidence of cancer by 2040.
- The Current financial climate leading to capacity constraints in beds, theatre and ICU and uncertainty re availability of development funding at a time of rising incidence and prevalence of cancer.
- Drug costs and related laboratory testing which are predicted to rise sharply in the coming years.

- Challenges for hospitals and their cancer centres in managing competing priorities, including access for cancer patients, improving A&E waiting times and reducing surgical waiting lists.
- Current HR environment – retirements and voluntary redundancy, recruitment moratorium, lack of clerical support, cumbersome recruitment processes, lack of key grades e.g. physicists, radiation therapists, theatre nurses, mammographers, sub specialist pathologists and medical oncologists.
- Rapid growth and service pressures in cancer centres without transfer out of many benign disease services.
- Need for a policy decision regarding Phase 2 of the National Plan for Radiation Oncology in Dublin so that there is adequate capacity to meet growing demands beyond 2019.
- Delays in finalising centralisation of rectal, prostate and upper GI services.
- Diagnostic services in general hospitals need to continue in accordance with current clinical pathways in order to ensure patient centred care and the retention of clinical skills outside of the cancer centres.
- Achievement of targets stipulated by the Key Performance Indicators in a challenging financial and human resources environment.

## Risks

- The reorganisation of hospitals into Groups may undermine the existing national policy in relation to centralisation of cancer surgeries into the eight designated centres; there is a need to develop a national framework within which Groups are aligned to develop and deliver services such as cancer services in accordance with national policy.
- Serious risk re future funding of necessary radiation oncology development inclusive of capital plan for extending facilities and equipment replacement and related staffing revenue resources.
- Constraint on growth of oncology drugs budget may impact patient access to new evidence based, clinically beneficial and appropriately cost effective drugs.
- May not recruit specialist staff in sufficient numbers (e.g. mammographers, physicists, theatre and critical care nurses, histopathologists, breast radiologists), with consequences for patient care and reputational damage to NCCP and the cancer centre.
- May not attract or retain consultants, with consequences for patient care and reputational damage to NCCP and host hospitals.
- Competing demands for hospital beds may impact timely access for cancer patients.
- May not be able to fulfil data requirements due to loss of clerical administrative support and poorly developed ICT infrastructure.

Good strategy implementation requires constant reiteration of taking action followed by thoughtful analysis which subsequently modifies further actions. It is timely to review the implementation undertaken to date by the NCCP, celebrate the successes and identify the gaps that remain NCCP challenges.



# How the NCCP Works

The National Cancer Control Programme was set up to implement the National Cancer Strategy 2006 with three goals:

- To reduce cancer incidence,
- To reduce cancer mortality and morbidity, and
- To improve the quality of life of people living with cancer.

The Programme was given the terms of reference to manage, organise and deliver cancer control on a **whole population basis**. Its remit was:

- To **control** all cancer activities
- To **integrate** all elements of cancer control through a variety of settings, and ensure a programmatic approach to cancer control through the application of evidence-based policy to clinical practice and all other components of cancer control.
- To **implement** regional cancer centres and their networks

Since its establishment, the NCCP has been afforded a unique identity and role within the health services to enable it to achieve its aims. With the agreement of Government and the Health Service Executive (HSE) the NCCP was formed as a separate directorate within the HSE to implement the National Cancer Strategy. It was provided with

its own corporate identity, office, branding and key functions including HR, communications and finance as well as dedicated clinical and support staffing. The Director was appointed to the HSE senior management team reporting to the CEO and was supported with part time clinical advisors for surgery oncology, medical oncology and radiation oncology. These advisors were appointed members of the NCCP Executive.

In the period from 2007 to 2014, the NCCP was allocated considerable financial investment (€56.8m revenue) to support the establishment and resourcing of the eight designated cancer centres and the new oncology drug management system (Appendix 4). This funding supplemented that which was already within the base funding of the acute hospitals and was allocated towards agreed service priorities.

Significant funding was also provided to support the expansion of radiotherapy capacity: in addition to €25.9m in revenue, €65m was invested in the development of two new units in Dublin and an additional €100m has been approved under the HSE capital plan for expansion in Cork and Galway. Recently, funding of approximately €6m has been approved to support the refurbishment of bunkers and purchase of additional linear accelerators in St. Luke's hospital.

Both the BreastCheck and CervicalCheck programmes were fully funded when they transferred to the HSE. Between 2012 and 2014, the National Cancer Screening Service (NCSS) was provided with an additional €19m to support the implementation of the new bowel cancer (and diabetic retinopathy) screening programmes.

The role and structure of the NCCP has evolved over time to reflect the changes related to the ongoing restructuring of the health services. The current governance structure of the HSE is outlined below.

When the NCCP was first established it had both a strategic/planning and an operational remit. The St. Luke's Radiation Oncology Network

(SLRON) and the National Cancer Screening Service (NCSS) were both directly managed by the NCCP. However, arising from changes within the HSE structures in January 2014, operational and financial responsibility for the NCSS transferred under the governance of the Health & Wellbeing Directorate of the HSE while the St. Luke's Radiation Oncology Network (SLRON) transferred to the Dublin Midlands Hospital Group.

The NCCP's role is now predominantly focused on planning, quality assurance and performance management of publicly delivered cancer services nationally.

The current organisational structure of the NCCP and the roles are outline in Figure 4.2.

**Figure 4.1 HSE Directorate and Leadership Team**

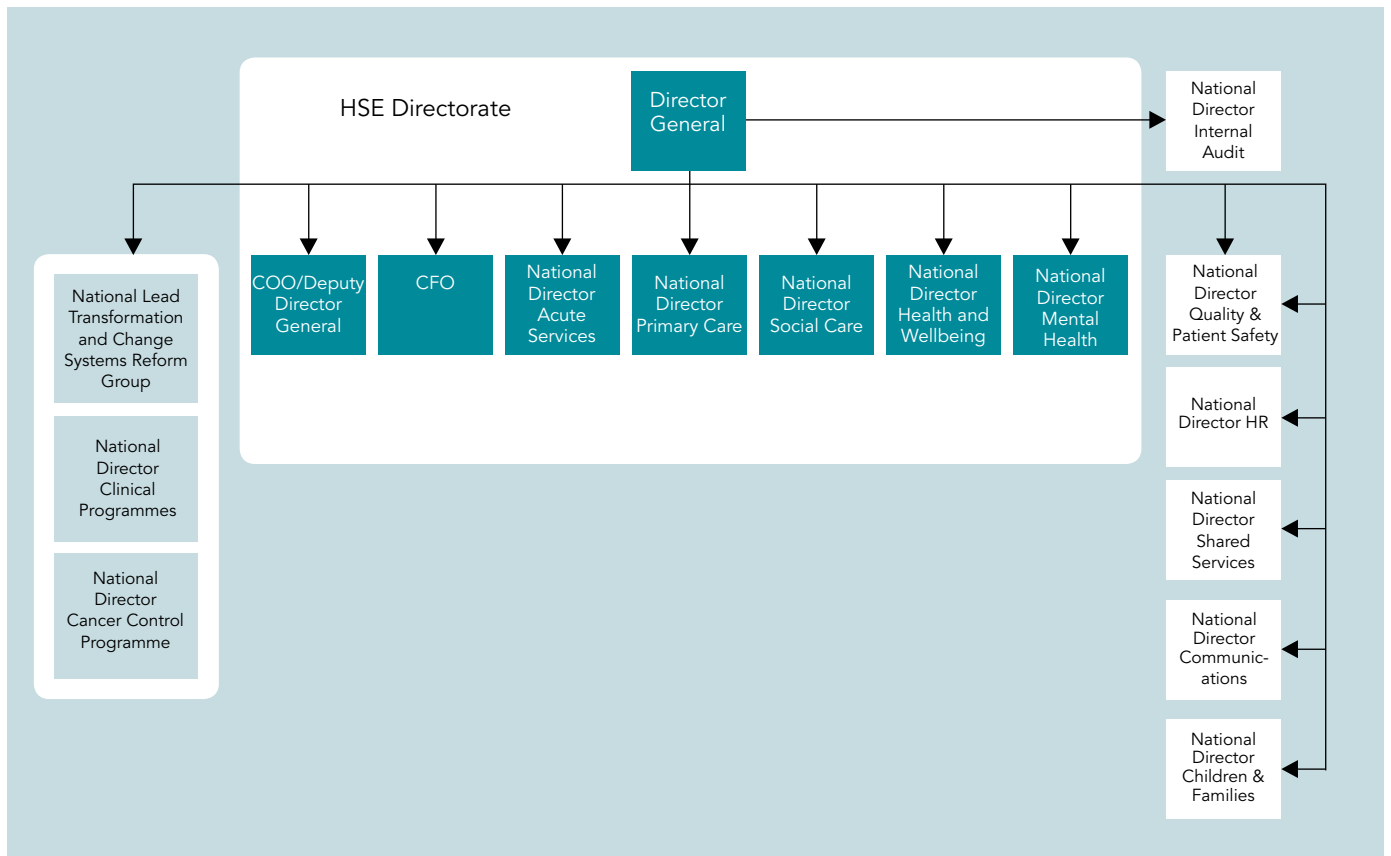
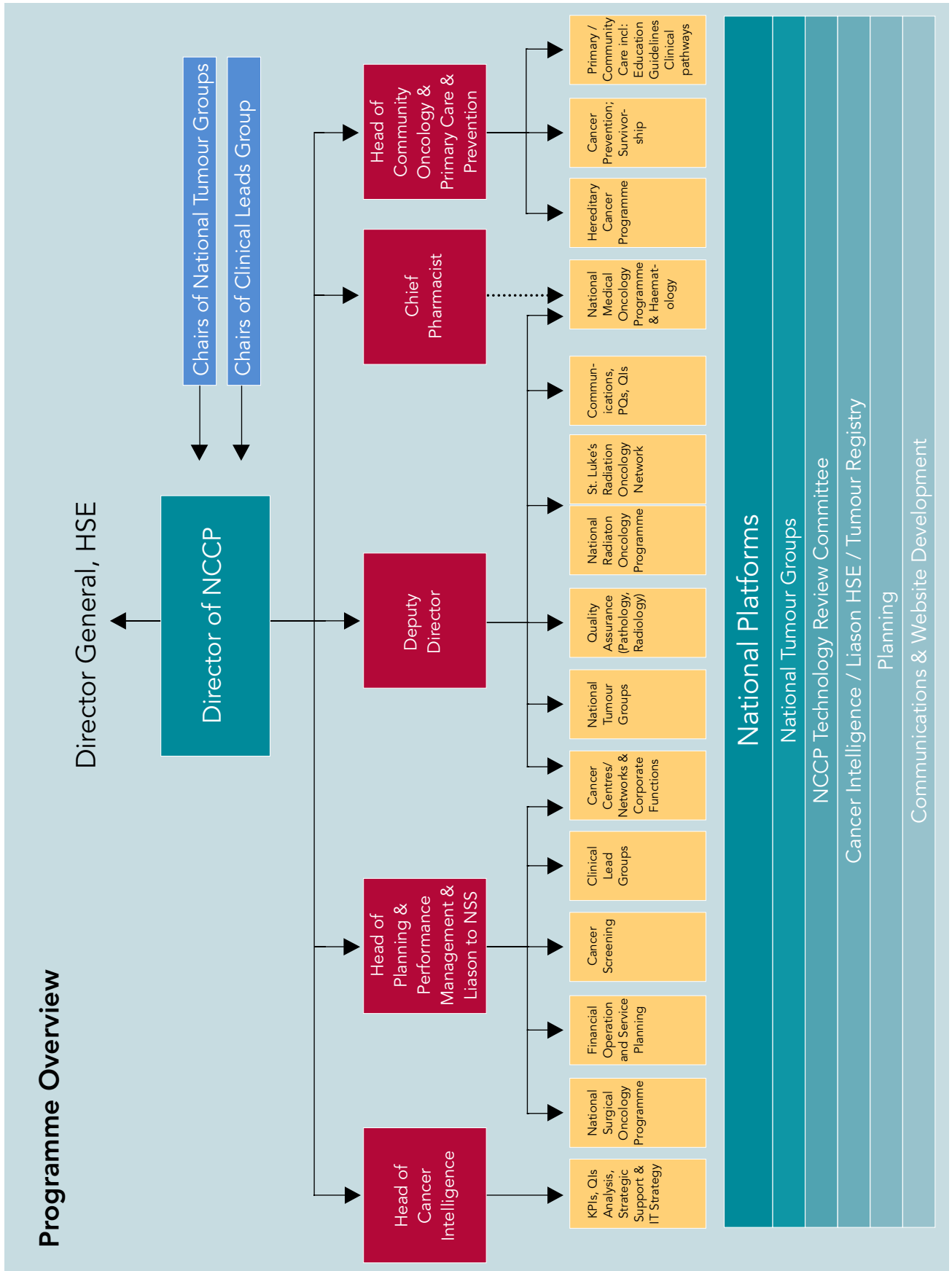


Figure 4.2 Overview of the NCCP Structure and reporting relationship





## **Programme Overview**

### **Director**

The Director of the NCCP is responsible for the planning and implementation of the National Strategy for Cancer Control in Ireland, across the spectrum of prevention, screening programmes, surgical oncology, radiation oncology and medical oncology as well as the development of national treatment guidelines and performance management.

The Director is a member of the HSE leadership team reporting to the Director General. The Director and relevant NCCP staff meet regularly with key cancer service providers and leaders including clinicians, professional bodies, the CEOs/ General Managers of the designated cancer centres as well as industry, research and academic stakeholders. Monthly meetings are also held with the Department of Health.

### **Deputy Director**

The Deputy Director is responsible for overseeing the development of national tumour guidelines groups, diagnostic quality assurance, communications, radiation oncology and supporting the development, delivery, monitoring, quality assurance and performance management of the NCCP for assigned Hospital Groups. The Deputy Director also has oversight, and provides support, of the development, delivery, monitoring, quality assurance and performance management of the St. Luke's Radiation Oncology Network (SLRON).

### **Head of Cancer Intelligence**

The main responsibilities of the Cancer Intelligence function are to source and analyse data required by the NCCP to perform its functions. Such data comes from a variety of data resources including HSE data, other sources such as the Cancer Registry (NCRI) and the Central Statistics Office (CSO). Development of Key Performance Indicators is also a key role. In addition, the Cancer Intelligence function supports the NCCP in setting up new databases and overseeing clinical audits.

### **Head of Planning, Performance, & Programme Management**

The Head of Planning, Performance and Programme Management liaises with HSE's Chief Operating Officer (COO) Planning, Performance, and Business Functions. They Lead the NCCP's Commissioning and Money Follows the Patient activities, liaising with Chief Financial Officer's Business Functions. They have oversight of the National Clinical Leads Group and support the development, delivery, monitoring, quality assurance and performance management of the NCCP for assigned Hospital Groups. They also act as liaison to the National Screening Service (NSS) of the HSE Health & Wellbeing Directorate.

### **Head of Community Oncology, Primary Care, and Prevention**

The Assistant National Director for Community Oncology is responsible for leading the community oncology team. This includes cancer prevention, integration of care between primary and specialist services and survivorship.

### **Chief Pharmacist**

The Chief Pharmacist is responsible for the development of the Medical Oncology and Haemato-Oncology Programme focusing on Quality & Safety, Drug Approval & Funding, Medical Oncology Clinical Information System, NCCP Cancer Data Repository and Clinical Audit. They Interact with Acute Care, including direct clinician interaction, Primary Care Reimbursement Services, Transformation and change, Systems Reform Unit and ICT Shared Services.

The Director and NCCP executives are supported by the following:

### **National Surgical Oncology Programme**

The clinical advisor and programme manager lead on strategic development and implementation of surgical oncology services nationally (See Section 6).

### **National Radiation Oncology Programme**

The clinical advisor and programme manager lead on strategic development and implementation of radiation oncology services nationally (See Section 7).

### **National Medical Oncology and Haemato-Oncology Programme**

The clinical advisor and programme manager lead on strategic development and implementation of medical oncology and haemato- oncology services nationally (See Section 8).

### **Community Oncology Team**

The work of the community oncology team includes cancer prevention, integration of care between primary and specialist services, and survivorship. An integral component of this work is to build Primary Care capacity to care for patients with cancer in the community setting. The team works within the NCCP, with the wider HSE, general practitioners and voluntary agencies to undertake research, and to plan, implement and evaluate services. Evidence based referral, integration of care and appropriate follow up are central to this work. The development and implementation of a cancer survivorship programme is now a key priority (see Section 9).

### **Communications**

Responsible for the development and management of NCCP internal and external communications.

## **Clinical Governance for Cancer Care**

In order to ensure that cancer services are operated within the agreed standards, there was a requirement to put in place robust governance arrangements across each of the eight cancer centres.

NCCP receives monthly performance and activity reports from each of the eight cancer centres. Key Performance Indicators (KPIs) are reviewed and discussed at monthly NCCP Executive team meetings. Any performance issues which are outside of target are subsequently followed up with clinicians and management at the relevant cancer centres which are responsible for putting in place measures to address any non performance. In addition KPI data on systemic therapy is received from the 26 chemotherapy hospitals nationally

Nationally cancer KPIs are reported by the HSE on a quarterly basis as part of the HSE Performance Reporting Mechanism (<http://www.hse.ie/performanceassurancereports/>).

### **Clinical Leads Group**

In line with the recommendations of the 2006 National Cancer Strategy (Recommendation No. 23), lead clinicians have been nominated to lead the development of cancer care pathways for each major site-specific cancer.

The NCCP developed the role of 'Lead Clinician' initially in the Symptomatic Breast Service in 2010, whereby a clinician in each of the cancer centres is nominated by the hospital CEO as the lead Clinician for Symptomatic Breast Services. A National Lead Clinicians Network was established for this group of lead Clinicians to meet regularly as a group. This network of Lead Clinicians has since been extended to a number of tumour sites including thoracic (lung), urology (prostate) and gastrointestinal (rectal) cancer services in the eight designated cancer centres (see TD 10 for members).

The Lead Clinicians within the designated cancer centres are appointed by the hospital managers and Clinical Directors in consultation with the NCCP for a two year period. The Lead Clinician reports directly to the CEO /General Manager/ Clinical Director in their hospital through the governance arrangements of the hospital. They also have a collegiate relationship with a nominated clinical advisor in the NCCP for the quality of the services provided. Their role is to act as the clinical liaison between the National Cancer Control Programme and the relevant cancer service.

The purpose of the national Clinical Lead Network is to ensure that the eight centres build on robust local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving. Terms of reference also include development of key performance indicators and informing decision making and leading on national multidisciplinary audit, quality and risk. Each Network of Lead Clinicians has a chairperson who reports to the Director of the NCCP (see Figure 4.2). Key projects relating to audit and standardisation of services form the basis of feedback from the group to the NCCP Director and Executive. The Leads groups are supported by a project manager from within the NCCP to coordinate their work and meetings.

There are also lead clinicians for upper gastrointestinal cancers in the four national centres and national leads have been appointed for pancreatic cancer, neuro oncology, gynaecological and neuro endocrine cancers. These nominated clinicians are responsible for facilitating adherence to national standards and key performance indicators for the specific service. They play an important role in contributing to the continuous development and improvement of the service in their own cancer centre and nationally, through participation in NCCP processes, including annual national Audit, Quality and Risk (AQR) meetings.

## **National Clinical Guidelines Groups (Tumour Groups)**

In 2011, the NCCP commenced the development of national evidence-based clinical guidelines for the diagnosis, staging and treatment of selected cancers. These guidelines are being developed by a range of consultant specialists (including surgery, medical oncology, radiation oncology, radiology, pathology) and focus on a particular type of cancer with the support of NCCP methodology specialist, project managers, researchers and librarians. There are currently Guideline Development Groups in place for breast, prostate, lung, gynaecological, upper gastrointestinal, hepatobiliary and lower gastrointestinal cancers. The chairs of each individual Guideline Development Group report directly to the Director of the NCCP in relation to this role.

For further information see Section 12 of this report.

# Cancer Epidemiology in Ireland

## Introduction

The document 'A Strategy for Cancer Control in Ireland 2006' reviewed cancer epidemiology in Ireland from 1994-2001. On reviewing the cancer incidence in the intervening years, an average of 28,668 new cases of cancer were registered every year in Ireland between 2002 and 2011, an increase of over 40% since the period 1994-2001 (Table 5.1). Over 17,000 of those cases were invasive cancers, an increase of one third since 1994-2001.

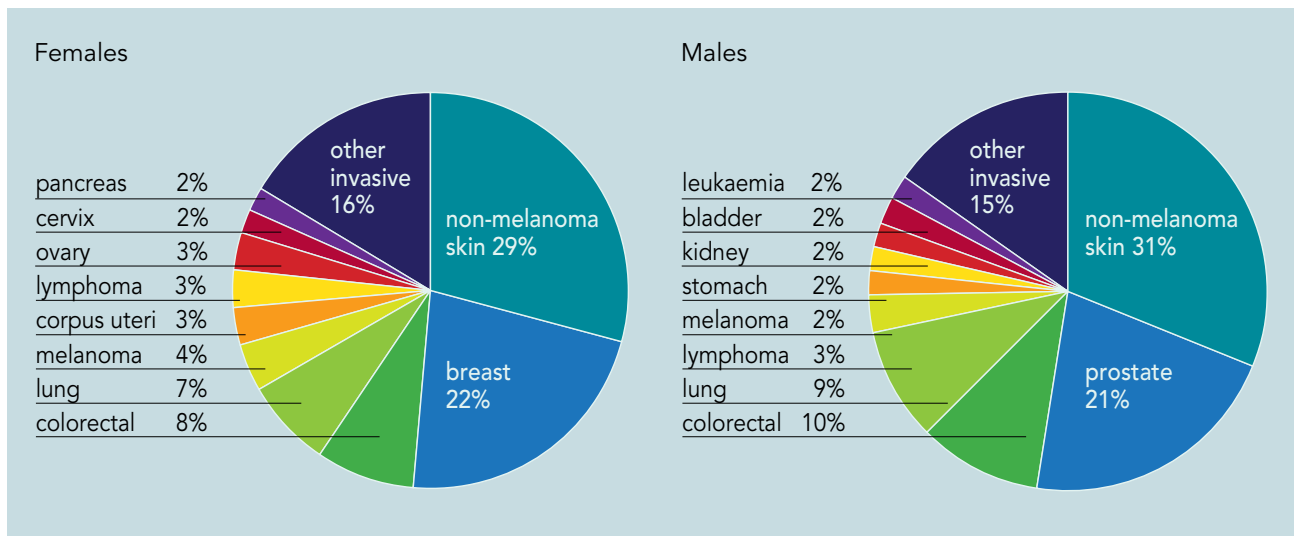
Reviewing the annual figures, there were over 34,700 new cases of cancer registered in Ireland in 2011 an increase of 57% since 2001, when 22,175 cases were documented. Over 28,700 of these were invasive cancers in 2011, compared to almost 19,500 in 2001, a 48% increase. Excluding the commonest invasive cancer, non melanoma skin cancer, all other invasive cancers are now close to the 20,000 mark with over 19,500 cases of invasive cancer registered in 2011, a 39% increase from 2001.

**Table 5.1: Annual Average Numbers of Cases**

	Both sexes		Females		Males	
	1994-2001	2002-2011	1994-2001	1994-2001	1994-2001	1994-2001
All cancers	20,211	28,668	10,323	14,849	9,887	13,819
All invasive cancers (excluding non melanoma skin cancer)	12,838	17,165	6,178	8,068	6,660	9,096

Source: NCRI, 2013

**Figure 5.1 Relative frequency of the main invasive cancers diagnosed, 2008 - 2010**



Source: NCRI, 2013

Looking at the period 2008-2010, non melanoma skin cancer (NMSC) is still the commonest invasive cancer representing 29% of cancers in women and 31% of cancers in men, a higher proportion than in the period 1994-2001 when the percentages were 23% for women and 28% for men respectively (Figure 5.1). Between 1994 and 2001, the next commonest cancers in women were breast (16%), colorectal (8%) and lung (5%). The order has not changed in 2008-2010, but breast cancer is now 22% of all cancers in women and lung cancer has risen to 7%.

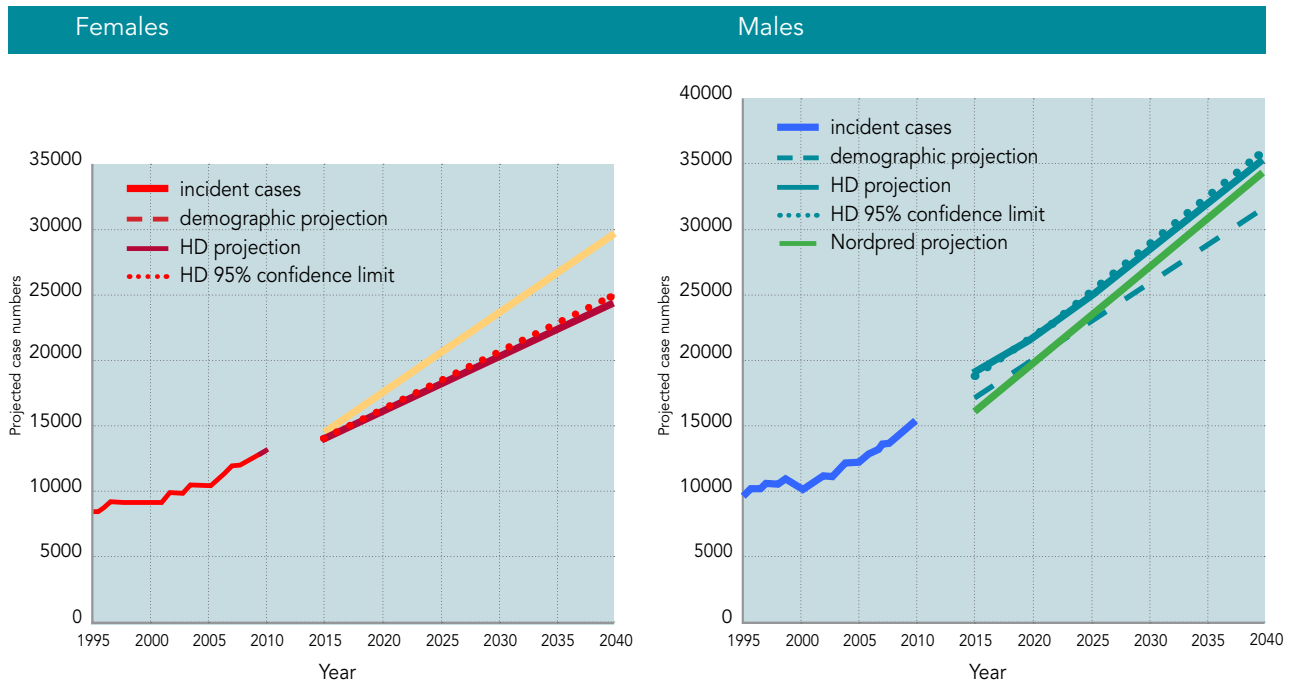
For men, the commonest cancers apart from NMSC were prostate (14%), colorectal (10%) and lung (10%) between 1994 and 2001. More recent data (Figure 5.1) show that the order remains the same but prostate cancer now accounts for 21% of all cancers in men.

### Cancer Projections

Ireland has an unusual demographic profile compared to many of its European neighbours. A high birth rate and the deep and lasting period of emigration in the 1950s along with further egress of the population in the 1980s had resulted in a population with a very young profile up to recent decades. Immigration in recent years as well as the return of emigrants who left in the 1980s has meant that the population is only now experiencing the rapid aging seen in our neighbouring countries in earlier decades. As cancer is predominantly a disease of older people, the NCRI projections for cancer based on the population projections from the Central Statistics Office make sober reading (Figure 5.2).

**Figure 5.2: Projected Numbers of Invasive Cancers**

Projected numbers of all invasive cancers, based on M1F0 population projections 2015-2040, with actual numbers



Source: NCRI, 2013

Models predict that the number of cases of invasive cancers in women will increase by 86%-125% between 2010 and 2040. Cases are thus predicted to rise from 13,185 in 2010 to between 24,548 and 29,715 in 2040. For men, invasive cancers are predicted to increase by 126%-133% in the same period so cases are predicted to rise from 15,295 in 2010 to between 34,511 and 35,561. Thus, the total annual number of new cases of cancer is predicted to increase from 28,480 in 2010 to between 59,059 and 65,256 in 2040.

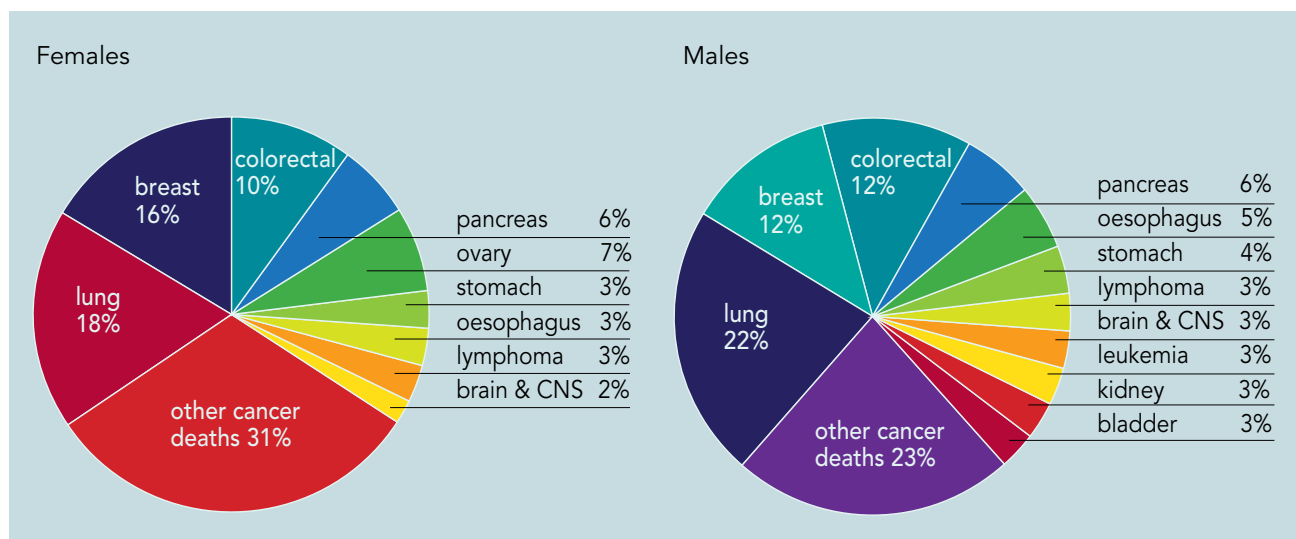
### Cancer Mortality

In 2010, there were 8,316 deaths from cancer reported, which was about 30% of all deaths in Ireland that year. Cancer was the second commonest cause of death after cardiovascular disease. This compares to 7,500 cancers deaths each year in the period 1994-2001, which was about 25% of all deaths during that period.

Lung cancer was the commonest cause of cancer death in both women and men in 2010 (Figure 5.3) representing 18% of cancer deaths in women and 22% of cancer deaths in men.

For women, lung cancer was followed by breast (16%) and colorectal cancer (10%). This represents a significant change from the 1994-2001 period, when breast cancer was the commonest cause of cancer deaths in women (18%) followed by lung (15%) and colorectal (11%) cancers. The order of cancer deaths remains the same in men with lung cancer remaining the commonest cause of cancer deaths at 22%, though the proportion has fallen from 24% in the 1994-2001 period. Prostate and colorectal cancer were the next commonest cause of cancer deaths in both the 1994-2001 period where each was 13% compared to 12% to 2010.

**Figure 5.3: Relative Frequency of the Main Cancer Deaths 2010**



Source: NCRI, 2013

### Cancer Hospital Activity

The initial phase of cancer diagnosis and treatment takes place in the hospital setting. Further admissions to hospital can be generated by treating morbidity brought on by the disease itself or by earlier treatments and for end of life care. The increasing number of cases is thus reflected in increasing utilisation of hospital facilities. The Hospital Inpatient Enquiry System (HIPE) is the only national hospital information source that can give a breakdown of hospital activity by diagnosis, but

this system covers inpatient and day case activity only. There is no national source of data on outpatient or emergency department activity that can break down activity by diagnosis. Between 2005 and 2012, there was a 53% increase in the number of inpatient and day case discharges from the public hospital sector for cancer. Much of this increase occurred in the day case setting which increased by 67% over the time period (Table 5.2).

**Table 5.2: All Cancer Activity in Acute Public HIPE-Reporting Hospitals in Ireland, 2005-2012**

Year	2005	2006	2007	2008	2009	2010	2011	2012
Inpatient	41,270	42,483	44,346	45,880	45,451	44,944	44,273	45,020
Day cases	135,867	187,974	200,987	220,008	222,327	228,727	223,874	226,369
Total discharges	177,137	230,457	245,333	265,888	267,778	273,671	268,147	271,389

Source: HIPE, 2014



## Cancer Prevalence

The NCRI have matched all cancers registrations from 1994-2010 to a respective death certificate, where available. This enables an estimate to be made of the prevalence of patients who have survived cancer in Ireland. Between 1994 and 2010, there were 242,058 patients diagnosed with cancer. At the end of 2010, over 104,300 of these patients were still alive. The largest group of cancer survivors are patients who have been treated for breast cancer (24,383) followed by patients who have been treated for prostate cancer (21,551). This population can be very disparate. Many are well and do not require any further interventions. Some have sequelae from their cancer diagnosis and treatment which require further care and yet others will develop recurrent disease. Because the NCRI can only follow patients for the first year after their cancer diagnosis, it is not possible to enumerate how many patients are on active cancer treatment at any one time.

## Cancer Survival

Improvements in cancer detection and treatments have resulted in substantially better relative survival in the Irish population. For all cancers excluding non melanoma skin cancer, the five year relative survival in men has increased from 52.7% for those diagnosed in the period 2000-2004 to 60.3% for those diagnosed in 2008-2010. Equally for women, the five year relative survival has increased from 57.3% in 2000-2004 to 62.5% in 2008-2010. This global figure for all cancers masks some considerable differences between the tumour types (Table 5.3).

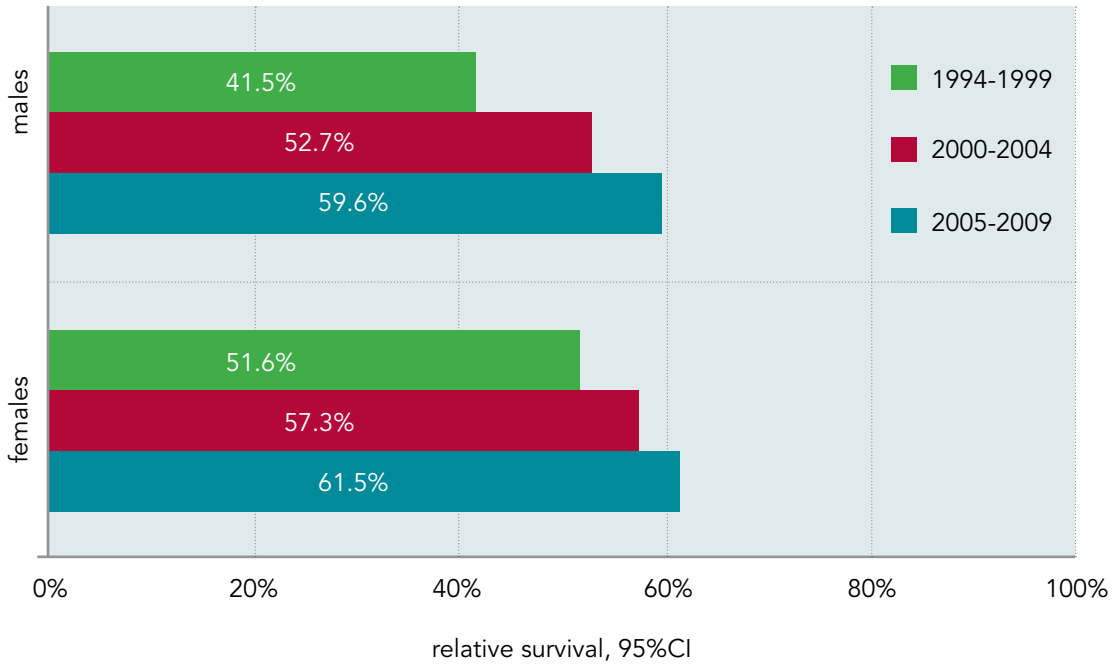
**Table 5.3: Five Year Relative Survival by Cohort and by Tumour Type**

	1994-1999	2000-2004	2005-2009	2008-2010
	Cohort	Cohort	Cohort	Hybrid
Female breast	72.6%	78.1%	82%	81.7%
Lung	9.3%	10.2%	13.7%	14.2%
Colorectal	49.9%	53.8%	59%	60.2%
Prostate	69.4%	85.2%	90.1%	90.7%
Melanoma	83.3%	85.7%	86.1%	84.7%

Source: NCRI, 2013



Figure 5.4: Five Year Relative Survival 1994-1999, 2000-2004 and 2005-2009



Source: NCRI, 2013

# Centralisation & Progress on Individual Cancer Sites

## 6.1 Breast cancer

The 2006 National Cancer Strategy recommended that “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”.

### Breast Cancer in Ireland

Between 2009 and 2011, there were 2,805 cases of invasive breast cancer registered in Ireland every year. This represents a rate of 124/100,000 for females and 1.1/100,000 for males (NCRI 2014). Most cases of breast cancer occur in women aged over 50 years. In addition to invasive cancer, there are approximately 340 in situ cancers registered annually (Table 6.1.1)

Excluding non-melanoma skin cancer, breast cancer is the most commonly diagnosed cancer in women in Ireland, comprising 31% of female invasive cancers (NCRI 2013). There was a significant upward trend in breast cancer incidence rates for females between 1994 and 2011 of 1.8% per year for invasive cancers and 9.4% for in situ cancers (Cancer Factsheet: Female Breast NCRI 2013). Much of this increase can be attributed to the roll out of a national screening programme during this time period.

The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of cancers and five-year relative survival for this cohort is 85% with a 95% confidence interval of between 83.9%-86% (Cancer Factsheet: Female Breast NCRI 2013).

Recent cancer projections from the NCRI predict the number of female breast cancers to increase by 55- 152% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

**Table 6.1.1: Annual Average Incidence for Breast Cancer in Ireland, 2009-2011**

Types of Breast Cancer	Females	Males	Total
Breast (C50) invasive	2,781	23	2,805
Breast (D05) in situ	340	1	341

Source: NCRI 2013

## Cancer Strategy Implementation – Surgical Centralisation

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that "treatment of symptomatic breast disease will take place in all eight cancer centres with a satellite unit in Letterkenny".

In 2007, breast cancer surgery was undertaken in 32 public hospitals. Based on the recommendations of the National Cancer Strategy (2006) and its implementation document, the NCCP completed the centralisation of breast cancer surgery to eight designated Symptomatic Breast Disease (SBD) Units and one satellite unit, by December 2009.

## Summary of achievements of the National Cancer Control Programme in relation to Symptomatic Breast Disease

### 1. Establishment of the National Cancer Control Programme Symptomatic Breast Service

In 2000, the Department of Health (DOH) published the report of the subgroup to the National Cancer Forum 'Development of Services for Symptomatic Breast Disease'. This report outlined the recommended structure for specialist breast units, diagnostic principles, treatment principles and quality assurance standards.

The National Cancer Strategy (2006) built on these principles and recommended that the HSE should conduct a review of the number of centres required for the management of symptomatic breast disease.

The 2006 National Cancer Strategy recommended (no. 24) that "The HSE should develop care pathways for cancer care to link primary care services, hospital services and other relevant services"

The National Cancer Control Programme (NCCP) was established in 2007 to manage, organise and deliver cancer services on a whole population basis. Breast Cancer was a key area of focus of the NCCP since its inception. Rapid Access Clinics with triple assessment were established in each of the eight designated cancer centres, with GP referral guidelines and standardised referral forms.

The 2006 National Cancer Strategy recommended (no. 47) that "general practitioners should have comprehensive information that enables informed referral and other management decisions".

The 2006 National Cancer Strategy recommended (no. 25) that "Improved cancer information services should be available to primary care".

The scope of the clinics is symptomatic breast disease. For any patient with breast disease, there is one overall service, whereas for other cancers there are rapid access clinics for suspected cancers and parallel general clinics for other benign conditions e.g. general urology clinics for benign prostatic hypertrophy (BPH). This significantly increases the cohort of patients using the breast service. In view of the increasing volumes attending these clinics it is vital that access is prioritised for those with suspected cancers. This is achieved by triaging patients on receipt of referral into urgent and routine appointments.

## 2. National Quality Assurance Standards for Symptomatic Breast Disease (SBD) Services

In May 2007, the Health Information and Quality Authority (HIQA) adopted the National Quality Assurance Standards for Symptomatic Breast Disease Services, developed by an expert group in 2006, chaired by Professor Niall O'Higgins. The standards define what is expected of the providers of symptomatic breast disease services and provide the basis for service planning, development and continuous improvement. Since the publication of these standards, Symptomatic Breast Disease (SBD) services have evolved and developed. Multidisciplinary team working, triple assessment, image-guided biopsy, assessment of the axilla, collecting and using data to monitor performance and ensuring that sufficient numbers of patients are treated by clinicians in order that they maintain their expertise are now inbuilt into all SBD services nationally.

## 3. NCCP framework to implement the National Cancer Strategy

- The 2006 National Cancer Strategy recommended (no. 21) 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".
- The 2006 National Cancer Strategy recommended (no. 32) that "The HSE should conduct a review of the number of centres required for the management of symptomatic breast disease to bring them into line with designated cancer centres".
- The 2006 National Cancer Strategy recommended (no. 31) that "Patients should have their diagnosis established and their treatment planned by site specific multidisciplinary teams".

In line with the recommendations of the National Cancer Strategy, the HSE developed a framework for the 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' in September of 2007' (Appendix 1). This framework defined the criteria for the delivery of cancer services, and specifically recommended that the treatment of symptomatic breast disease should be delivered at eight Cancer Centres, with Letterkenny General Hospital providing a satellite service for Galway (Appendix 5).

The report mandated that Breast Services be sequentially withdrawn from hospitals which did not meet the defined criteria for delivery of symptomatic breast care, commencing with the lowest volume hospitals and ultimately including all hospitals which did not meet the guideline standards. Hospitals with low case volumes were directed to no longer provide symptomatic breast services and surgical treatment with immediate effect.

Under the NCCP the centralisation of Symptomatic Breast Disease services from 32 acute hospitals into 8 designated cancer centres (and a satellite unit at Letterkenny General Hospital) was completed in December 2009 (table 6.1.2). These designated centres, with multidisciplinary teams, have provided a significant advancement towards the integrated delivery of cancer services.

**Table 6.1.2: Resection of Breast Cancers by Designation of Hospital and by Year 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	2263	2550	2456	2480	2431	2446	2213
Number of procedures undertaken in a cancer centre	1237	1490	1917	2465	2421	2423	2209
% of procedures undertaken in a designated cancer centre.	54.7%	58.4%	78.1%	99.4%	99.6%	99.1%	99.8%

Source: NCCP. \*2013 is provisional data only. Includes screen detected cancers.

#### 4. Development of patient information

With the designation of cancer centres, patient information booklets were developed for each of the Symptomatic Breast Units in 2009. These booklets contained standard, important information for patients on what to expect at their appointment in the Symptomatic Breast Clinic, including information on triple assessment, mammography and biopsy. These booklets also included details on who to contact in the breast clinic with any queries or concerns.

Additional information has been developed for patients on breast examination, breast pain and general health promotion messages for cancer prevention and early detection.

- Triage and Referral
- Multidisciplinary teams
- Patient pathway of care including the designation of the Most Responsible Physician
- Communication and confidentiality
- Patient experience
- Facilities
- Data collection and information governance
- Adverse events reporting and management with particular reference to delayed diagnosis of cancer

#### 5. Development of Standard Operating Procedures (SOPs) for Breast Disease

The 2006 National Cancer Strategy recommended that “the HSE 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”.

The NCCP established Standard Operating Procedures for Symptomatic Breast Disease in 2009 for the following areas:

- Overview of Symptomatic Breast Disease Service
- Monitoring and updating of key performance indicators

The report from the HIQA quality review (2010) recommended that “the HSE together with the designated centres should formally evaluate the implementation of Standard Operating Procedures on a phased and prioritised basis, to ensure that they are fully embedded and being applied consistently within and between designated centres”.

Four SOPs were prioritised for evaluation: triage and referral, multidisciplinary teams, patient pathway through the pathway of care and adverse events reporting. All units scored highly, with little variability found between hospitals. Areas noted for improvement included GP access for annual follow-up mammogram, promotion of increased use of standardised GP referral form and audit of patients who did not attend appointments. A number of quality improvement plans are in development in the hospitals, linked to these areas of improvement.

Individual hospitals have undertaken initiatives to assess compliance in their breast units with the remaining SOPs (e.g. communication and confidentiality, patient experience).

## 6. Development of Key Performance Indicators (KPIs)

The 2006 National Cancer Strategy recommended that “the HSE should put in place arrangements to monitor inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes”.

A suite of Key Performance Indicators (KPIs) for breast disease were developed by the NCCP in 2009, along with data definitions, based on the national standards for Symptomatic Breast Disease (HIQA 2007).

Data collection of KPIs commenced in 2010, with a total of 28 KPIs for breast across the following areas:

- Access, Imaging, Diagnosis, Multidisciplinary working, Time to treatment (surgery, chemotherapy, radiation therapy) Surgery and Pathology

### Some Key Performance Indicators for Breast Disease include:

- Number of urgent attendances to the Breast Clinic and the percentage of those offered an appointment within two weeks
- Number of non urgent attendances to the Breast Clinic and the percentage offered an appointment within 12 weeks
- Number of patients newly diagnosed with breast cancer in the cancer centre and the percentage discussed at multidisciplinary team meeting (MDM)

**Table 6.1.3: Key Performance Indicators 2010-2013**

SBD KPIs	Target	2010	2011	2012	2013*
<b>URGENT ACCESS</b>	<b>&gt;95%</b>	<b>95.1%</b>	<b>98.7%</b>	<b>97.8%</b>	<b>98.0%</b>
Total number of urgent attendances; and of those		12,553	13,759	14,102	14,978
No. and % offered an appointment within 2 weeks		11,943	13,576	13,797	14,679
<b>NON URGENT ACCESS</b>	<b>&gt;95%</b>	<b>97.6%</b>	<b>95.5%</b>	<b>94.9%</b>	<b>95.6%</b>
Total number of non-urgent attendances; and of those		25,078	24,196	24,277	22,913
No. and % offered an appointment within 12 weeks		24,474 (97.6%)	23,103 (95.5%)	23,029 (94.9%)	21,896 (95.6%)
<b>Total referrals</b>		<b>37,611</b>	<b>37,955</b>	<b>38,329</b>	<b>37,891</b>
<b>MDM DISCUSSION</b>	<b>&gt;95%</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>	<b>100.0%</b>
Total no. of patients newly diagnosed in the cancer centre; and of those		2,012	2,145	2,130	2,109**
No. and % discussed at MDM.		2,012	2,145	2,129	2,109**

Source: NCCP. \*2013 data has not been validated. \*\*Does not include no. of cancers diagnosed Oct-Dec 2013 for Mater Hospital

A total of 37,891 women attended the Symptomatic Breast Disease Clinics in 2013. Of these 14,978 were deemed urgent and 14,679 (98%) were offered an appointment within two weeks of GP referral (Table 6.1.3). A further 22,913 were non urgent referrals and 21,896 (96%) of these were seen within the target of 12 weeks.

The Symptomatic Breast Disease Service in Ireland has developed significantly. The National Cancer Control Programme has been working in partnership with clinical, administrative and managerial staff in the cancer centres to consolidate the service into a standardised national programme, with comprehensive standards and targets. An annual report of KPIs for Symptomatic Breast Disease has been published on the NCCP website for 2010 and for 2011. A three year composite report was published in 2014 for the years 2010-2012. (TD2: SBD KPI report 2010-2012).

Each cancer centre reports on this set of Key Performance Indicators (KPIs), which are also published on the NCCP website. These KPIs are designed to assist patients, staff and the NCCP in assuring themselves that all designated cancer centres are adhering to the required standards of practice. Prompt access to cancer services has been one of the main deliverables for this service. The KPIs are presented and discussed at the annual NCCP multidisciplinary breast forum for audit, quality and risk.

Approximately one in 20 women presenting are found to have a primary diagnosis of breast cancer.

A review of KPIs was carried out by the Breast Clinical Leads group in 2011. A number of KPIs that were consistently being met and are now integrated as standard practice will no longer be routinely reported. The remaining 21 Breast KPIs will continue to be reported by all units.

The 2006 National Cancer Strategy recommended that “opportunistic testing of asymptomatic individuals for cancer is not recommended”.

The 2006 National Cancer Strategy stated that “opportunistic testing of asymptomatic individuals for cancer is not recommended”, which includes mammograms in asymptomatic women outside of the BreastCheck programme. Risk aversion and the cautious management of breast conditions, many of which are benign, are having an impact on the numbers referred to Symptomatic Breast Clinics and the volume of diagnostic imaging being performed.

Despite many challenges and an overall increase in numbers of patients attending the service, SBD centres continue to provide a high quality service. Priority is given to those with suspected cancers and these patients

**Table 6.1.4: Attendances at Symptomatic Breast Disease Units**

Year	Benign Cases	Breast Cancers Cases detected	Total Cases
2009	30,370	1,879	32,249
2010	35,619	2,012	37,631
2011	35,810	2,145	37,955
2012	36,249	2,130	38,379
2013	35,715	2,176	37,891

Source: NCCP 2014



are seen within two weeks of GP referral. Non urgent referrals are seen within 12 weeks where possible, however with increasing numbers of benign referrals, there are challenges meeting this target for all patients.

Additional resources were invested in Radiation Oncology and Medical Oncology in 2011 and these measures are beginning to show distinct improvements in these vital areas of patient care.

## 7. HIQA National Quality Review of Symptomatic Breast Disease Services

In 2009, the Health Information and Quality Authority (HIQA) carried out a national quality review of Symptomatic Breast Disease Services. Individual reports were published

for each breast unit in addition to an overall national report 'Report of the National Quality Review of Symptomatic Breast Disease Services in Ireland, February 2010'. The HIQA national report set out 18 recommendations on clinical governance, standards, audit, system assurance and the role of the Clinical Lead for Symptomatic Breast Disease services in each centre. The NCCP worked with each of the designated centres to implement the individual hospital recommendations and the overall national recommendations. Review meetings were held with hospitals quarterly and with HIQA twice yearly to monitor progress. The recommendations of the HIQA Quality Review are outlined below. The majority of recommendations have been completed, while others are ongoing.

	HIQA Recommendation	Status
1	The HSE should formally establish a national network of the SBD lead clinicians with a view to identifying and addressing mutual development and support needs.	✓
2	The HSE together with the designated centres should formally evaluate the implementation of Standard Operating Procedures on a phased and prioritised basis, to ensure that they are fully embedded and being applied consistently within and between designated centres.	Ongoing
3	The HSE should ensure that designated centres have robust governance arrangements in place, including a Service Level Agreement, to effectively manage relationships with third party providers. Such arrangements for the outsourcing of radiation oncology should be established promptly. These should cover the requirements of the Standards and in particular quality, safety and the formalised exchange of information.	✓
4	The HSE should put in place formal national clinical governance arrangements, to ensure that the eight centres build on robust local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purposes of clinical audit, sharing of good practice and problem solving.	✓
5	The HSE should put specific actions in place to ensure that its new directorate structure incorporates a clear mandate for describing and implementing the National Cancer Control Plan. In particular this should include clarity in the governance, accountability, responsibility, authority and resource allocation for the eight designated centres.	✓

	HIQA Recommendation	Status
6	The HSE should work with designated centres, to assess the organisational development needs of the newly established designated centres and introduce focused support as required.	Ongoing
7	The HSE together with the designated centres should carry out a risk assessment to identify areas in the designated centres where service continuity and sustainability, or the ongoing meeting of Standards, could be threatened by the absence of key staff and ensure that contingency plans are in place as needed.	Ongoing
8	The HSE should work with the designated centres, and the relevant training bodies, to develop a standardised framework for assuring the skills, education and training of staff in the centres are maintained at the necessary levels.	Ongoing
9	The HSE, with the designated centres, should establish effective ways of enhancing the continuity of patient care. This should include the introduction of the "Most Responsible Clinician" for patients within the SBD service. This should also be inclusive of aspects of care provided by third party providers.	✓
10	The HSE should require all centres to have in place robust arrangements for ensuring that all information relevant to patients' care is accessible as needed by patients and clinicians, irrespective of where the care is provided or the information is generated.	✓
11	The HSE should identify those designated centres where data management capability, and the use of data, are still in development and instigate ongoing evaluation and, where needed, provide focused support for those designated centres. This should include targeted support and development for SBD clinicians in the capture and use of data as an intrinsic facet of clinically effective care.	✓
12	The HSE together with the designated centres should coordinate, as part of its wider development of clinical audit systems, a review of referral and triage processes, aimed at understanding and addressing any unnecessary variations in referral or triaging practices between the designated centres and their referring clinicians.	✓
13	The HSE should coordinate, with the designated centres and the wider health system, the development of a differentiated service response that reflects the profile of patients being referred to the service, whereby patients with a lower risk of breast cancer are seen in a timely way and with the necessary clinical assessment.	Ongoing
14	The HSE together with the designated centres should develop mechanisms for monitoring the numbers of newly diagnosed patients seen and treated by individual clinicians with a view to developing benchmarks for the relevant clinical specialties.	✓

	HIQA Recommendation	Status
15	The HSE should develop, with the designated centres, a national clinical audit programme for SBD services that includes as a minimum: patients triaged as non-urgent and subsequently diagnosed with breast cancer, delayed diagnoses, longer term clinical outcome and survival rates. The national key performance indicator set should be reviewed regularly based on the outcomes of these audits.	✓
16	The HSE together with the designated centres should put in place arrangements to begin publicly reporting performance against the NCCP Key Performance Indicators during 2010.	✓
17	The HSE should undertake a formal evaluation of the change programme that has created the eight designated centres with a view to identifying lessons for future similar programmes of change. The changes that have been made in improving the symptomatic breast disease services should be used as a template to be adapted and modified for other services.	Ongoing
18	The HSE should nominate a national director to be responsible for developing and monitoring an implementation plan for these recommendations and should ensure that these actions are delegated as necessary. It should put in place arrangements for reporting progress with implementation to the HSE Board and the public.	✓

## 8. Establishment of a national governance model for Symptomatic Breast Disease

In May 2010, the NCCP held a Governance Forum for Symptomatic Breast Disease with the CEOs, clinicians and clinical directors of the designated cancer centres. This forum developed a national governance model for the SBD services, based on the recommendations of the National Quality Review of Symptomatic Breast Services (HIQA 2010). This governance model recommended the establishment of a national group of lead clinicians for Symptomatic Breast Disease and the establishment of a national Guideline Development Group for the development of clinical guidelines.

## 9. Establishment of a National Clinical Leads Network

The 2006 National Cancer Strategy recommended (no. 23) that “A lead clinician for each cancer centre should be appointed. In addition, a clinician should be appointed to lead the development of cancer care pathways for each major site-specific cancer in partnership with all stakeholders within the network”.

The HIQA report on the national quality review of Symptomatic Breast Disease services (2010) recommended that the HSE should formally establish a national network of SBD Lead clinicians with a view to identifying and addressing mutual development and support needs.

The SBD Clinical Leads group was established in July 2010 to ensure that the eight centres build on robust local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving. The group meets quarterly and the work is facilitated by an NCCP project manager.

The terms of reference for the clinical leads group are as follows:

- Contribute to the development and continuous improvement of SBD service.
- Share good practice and innovation in SBD service and ensure that non evidence based practice is discontinued.
- Inform decision making and standardisation of service delivery across the centres.
- Ensure adherence to National Standards and Key Performance Indicators.
- Review the quality and completeness of data, recommending corrective action where appropriate and necessary.
- Lead national multidisciplinary audit, quality and risk (AQR) meeting for SBD.
- Input into selection of Key Performance Indicators (KPIs) for Symptomatic Breast Disease Services.

The group has completed several significant projects in relation to standardisation of breast services, including:

- Protocol for follow-up after breast cancer
- Family history of breast cancer
- Management of interval cancers
- Review of Key Performance Indicators (KPIs)

- HR census of breast unit staffing
- Management of mastalgia (breast pain)
- Review of GP referral guidelines and referral form for breast disease

The Symptomatic Breast Disease services are now led by a lead clinician in each designated cancer centre and are supported by a multidisciplinary team of cancer specialists. Through this national network, best practice models are identified and shared, to ensure standardisation and service improvement nationally.

## 10. Annual Audit Quality and Risk Forum for Symptomatic Breast Disease

Based on the recommendations of the HIQA Quality review (2010), the NCCP established an annual audit quality and risk forum for the Symptomatic Breast Services. The purpose of the SBD forum is to:

- Provide an annual multidisciplinary forum for audit, quality and risk in the Symptomatic Breast Services.
- Build on local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving.
- Identify best practice models and ensure standardisation and service improvement nationally.
- Examine and agree referral criteria for the Symptomatic Breast Disease Units.

This is a decision making forum. Each year, the KPIs from each unit are presented and any variation is discussed at this forum. The first Breast Forum was held in October 2010 and they have been held annually since. The 5th annual NCCP Breast Forum was held in October 2014 in Limerick.

Key themes of the Breast Forum in previous years included:

2010	Follow up after breast cancer, family risk of breast cancer.
2011	Breast imaging, genetic testing, surgical management of the axilla, breast reconstruction and radiation treatment.
2012	Hereditary cancer programme, staging investigations, GP referrals, quality assurance in pathology.
2013	Quality Assurance for Symptomatic Breast Disease services, breast cancer clinical guidelines, neoadjuvant treatment, surgical margins, and specialist breast care nursing.

The forum also encompasses evidence based practice debates and multidisciplinary workshops for the purpose of problem solving and sharing of best practice models - each clinical discipline identifies and agrees key areas requiring standardisation and national protocols for service improvement.

## 11. National clinical guidelines for diagnosis, staging and treatment of breast cancers

The 2006 National Cancer Strategy recommended that "HIQA should establish site-specific multidisciplinary groups at a national level to develop guidelines for quality in major cancers".

The 2006 National Cancer Strategy recommended the development of evidence based guidelines and standards. The NCCP commenced the development of evidence based clinical guidelines for the diagnosis, staging and treatment of breast cancers in 2011. These guidelines include recommendations relating to the patient

pathway in the areas of pathology, radiology, surgery, medical oncology and radiation oncology. There are 29 clinical questions for breast cancer covered in this guideline. Nominations for each group were sought from the relevant clinical faculties. The breast clinical guideline was completed in December 2014 and is available on the NCCP website.

## 12. Revised national standards for Symptomatic Breast Disease

In June 2012, the HIQA published the National Standards for Safer Better Healthcare. These describe how a service provides high quality, safe and reliable care, centred on the service user and are structured around eight themes for quality and safety including: Person centred care and support, Effective care and support, Safe care and Support.

A framework on quality assurance for Symptomatic Breast services was developed by the NCCP in 2013, based on the HIQA National Standards for Safer Better Healthcare; 'Symptomatic Breast Service – Quality Assurance for Safer Better Healthcare, NCCP 2013' (TD 3).

In September 2013, the Health Information and Quality Authority recommended that the 2007 National Quality Assurance Standards for Symptomatic Breast Disease be subsumed into the National Standards for Safer Better Healthcare (HIQA 2012). In October 2013, this decision was endorsed by the Minister for Health. Monitoring of standards for Symptomatic Breast Disease Units by HIQA has now been subsumed into their monitoring programme for the National Standards for Safer Better Healthcare.

## 13. Audit and Research

An audit and research report on breast cancer referrals in Ireland is included in TD 11.

## 14. Workforce planning

The 2006 National Cancer Strategy recommended that “the HSE should develop a national cancer Workforce Plan designed to fully implement national cancer policy”

The projections from the NCRI show an increase in incidence and prevalence of breast cancer (TD 1). Based on demographic trends only, the NCRI predict an 84% increase in breast cancer incidence in females and a 107% increase in males by 2040.

The NCRI have also reported the number of breast cancers requiring treatment in 2010 and the estimated number of breast cancers requiring treatment in 2025, for the first year following patient diagnosis (NCRI 2014). These projections will form the basis for NCCP workforce planning for breast cancer.

A surgical oncology workforce planning project commenced in 2013 in the National Cancer Control Programme and will inform long term service planning. The NCCP developed a workforce plan for oncology for the HSE Medical Education and Training Unit (MET) in 2013 to inform the training and human resource requirements for oncology, including requirements for breast cancer in the areas of surgery, radiology, pathology, medical oncology and radiation oncology (a copy of this report is available).

## 15. Community Oncology

In parallel with the restructuring and centralisation of breast surgical services a range of initiatives were undertaken to strength and support the integration of the primary and secondary care interface. These include:

- Development of GP referral guidelines and standardised referral form (TD 4)
- Development of electronic GP referral systems
- Development of GP algorithm on mastalgia (breast pain)
- Development of patient booklet and smartphone App’ for mastalgia
- Establishment of a follow-up protocol for patients when their treatment is complete
- Development of information materials for GPs and patients on follow-up after breast cancer
- Development of an e-learning module for GPs on breast disease
- Training for GPs through CME, ICGP and hospital study days
- Training of hospital and community nurses on cancer prevention and treatment

**Table 6.1.5: Projected Breast Cancer Treatment numbers**

Female breast	2010	2025 projections (based on demography only)
Surgery	2,541	3,461
Chemotherapy	1,388	1,890
Radiotherapy	2,058	2,803

Source: NCRI 2014 – includes screen detected cancers.

- Prevention of secondary lymphoedema in cancer patients
- Cancer Survivorship initiatives

These initiatives and programmes are further discussed in the community oncology, Section 9.

## 16. Hereditary cancers / genetics / molecular

Work within the NCCP includes the following initiatives:

- Health Technology Assessment for women <50 at increased risk of breast cancer was undertaken by HIQA at the request of the NCCP
- Establishment of a Hereditary Cancer Programme
- Advice for GPs on referral of patients with family risk of breast cancer
- Working group to examine options for surveillance of women at increased risk of breast cancer
- Breast Cancer Family Risk forum 2014
- Provision of Oncotype DX testing

These are further described in the hereditary cancer (Section 10) and community oncology (Section 9) of this report.

## Challenges for Breast Cancer Services

- With the development of Hospital Groups, it is important that the autonomy of hospital groups does not compromise national cancer policy in terms of designated centres. Patients with breast cancer should continue to have their treatment in the appropriate designated sites, with the relevant multidisciplinary teams.
- The cessation of surgical services outside of the designated SBD Units, risk aversion and the cautious management of breast conditions, many of which are benign, are having an impact on the numbers referred to Symptomatic Breast Clinics and the volume of diagnostic imaging. Referrals to the Symptomatic Breast Disease Units in Ireland have increased from 23,575 in 2006 to 37,891 in 2013, without a corresponding increase in breast cancers detected. This increasing volume of referrals has resulted in increasing challenges for cancer centres in meeting the target waiting times for the non-urgent referrals.
- There has been some reluctance from some medical organisations to support the discharge of well women to their GP five years post cancer surgery.
- There is a lack of IT systems and data management staff to automatically capture the range of work in the breast service, particularly of multidisciplinary teams.
- The current HR environment with retirements, voluntary redundancy and recruitment moratoria has exacerbated the lack of clerical support, mammographers and theatre nurses in the breast service.
- Competing demands for acute hospital beds may impact on timely access for cancer patients. The NCCP plans to monitor access times for cancer patients for elective surgery.



- Management of women at increased risk of breast disease remains controversial. Following a HTA, HIQA made several recommendations in relation to surveillance of women at increased risk of breast cancer. The surveillance of women at moderate and at high risk of breast disease will place additional demands on the system if implemented. The level of evidence for cost and clinical effectiveness for the implementation of a surveillance system for the moderate risk group is weak.
- The increasing demand for predictive testing and for new medicines for the treatment of breast cancer has significant resource implications.
- The National Cancer Registry predictions of an increase in breast cancer incidence in females and a 107% increase in males by 2040 will have a significant impact on the existing services for breast cancer.
- There are opportunities to look at a diversity of roles in the Symptomatic Breast Clinics, such as Advanced Nurse Practitioner and GP clinics to manage selected non urgent referrals.
- Clear information for patients and for GPs on risks associated with family history of breast cancer assist the streamlining of the referral process.
- The development and implementation of the clinical guidelines for breast cancer will assist in standardisation of practice e.g. diagnostic imaging, surgical management of the axilla, surgical margins, rates of breast conservation surgery and reconstruction.
- The Health Information Bill, when enacted should provide provision for protected disclosure for audit.
- The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and activity there is not subject to NCCP scrutiny.

### Opportunities for Breast Cancer Services

- It is opportune to re-examine the scope and structure of the breast clinics in relation to suspected cancers and benign / non urgent referrals, to ensure that suspected cancers are seen quickly and non urgent referrals are seen in the most appropriate setting.
- The numbers of women attending breast rapid access clinics rose rapidly when the clinics were first established and although attendances have remained stable at 38,000 since 2010, the proportion of women who are diagnosed with cancer remains at just over 5% which is at the lower end of the range internationally. A variety of initiatives to optimise care in the community are being progressed to ensure appropriate referrals to specialist centres e.g. management of mastalgia, smartphone App', family risk and benign breast conditions. (Discussed under community oncology Section 9).

## 6.2 Prostate Cancer

### Epidemiology

There was an annual average of 3,267 prostate cancers diagnosed in Ireland 2009-2011, making prostate cancer the commonest invasive cancer in Ireland, excluding non-melanoma skin cancer. Prostate cancer accounts for 31.9% of all invasive cancers. In 2011, there were 563 deaths from prostate cancer, making it the 3<sup>rd</sup> most common cause of invasive cancer deaths. Between 1994 and 2011, there has been an annual increase in incidence rate of 5.3% per year; much of this increase can be attributed to an expansion of PSA testing. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of cancers and five-year relative survival for this cohort is 93% with a 95% confidence interval of between 92.2%-94.4% (Cancer Factsheet: Prostate NCRI 2013).

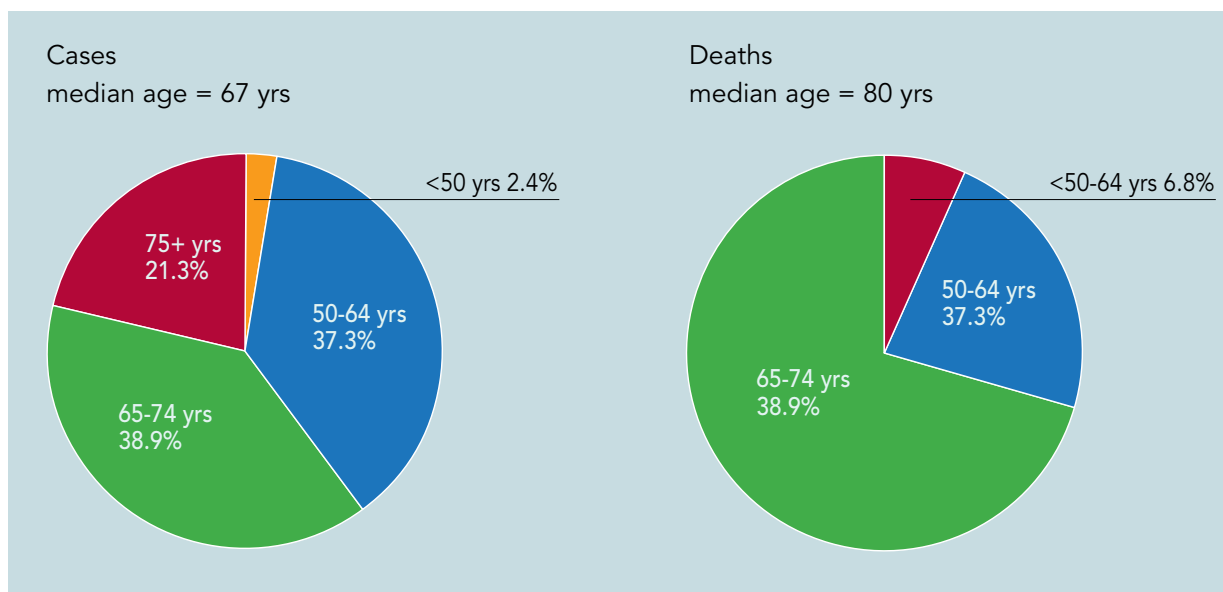
Recent cancer projections from the NCRI predict that the number of prostate cancers will increase by 104%-288% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

### Cancer strategy implementation – surgical centralisation

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that "curative surgical treatment of primary urological cancers will be provided in four centres" (Appendix 1).

In 2007, there were nine hospitals (five of them designated cancer centres) undertaking radical prostatectomy for prostate cancer. The NCCP undertook an examination of the activity in these hospitals, looking at volumes, bed utilisation, ITU usage and the geographical patterns of patient referral. Beaumont Hospital, St. James's Hospital, the Mater Hospital, St Vincent's University Hospital, Cork University Hospital and University College Hospital Galway were designated as the six surgical centres for prostate cancer. Rapid Access Prostate Cancer Clinics have been established in each of the eight designated cancer centres where patients are treated by cancer specialists in multidisciplinary teams.

Figure 6.2.1: Age profile at diagnosis & death



Source: NCRI, 2013

## Summary of achievements of the National Cancer Control Programme in relation to Prostate Cancer

### 1. Establishment of the National Cancer Control Programme Prostate Service & Rapid Access Clinics

Prostate Cancer has remained a major area of focus of the NCCP since its inception. Rapid Access Clinics (RACs) were established in each of the eight designated cancer centres, with GP referral guidelines and standardised referral forms. The first prostate rapid access clinics were opened in 2010 and by 2012 all eight clinics had opened. Referrals to the RACs have increased from 2,466 in 2011 to 2,870 in 2013.

### 2. NCCP framework to implement the National Cancer Strategy

Recommendation 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.
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The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 concluded that there was a need for four Centres nationally, one within each Network, for the curative surgical treatment of primary urological cancer (Appendix 1).

### 3. Centralisation of Primary Surgical Activity

In 2007, there were nine hospitals undertaking radical prostatectomy for prostate cancer and just five were designated cancer centres – Beaumont, Mater, St Vincent's, St James's and University College Hospital Galway. Between 2007 and 2013, radical prostate cancer surgery commenced in Cork University Hospital, with a major increase from 2012 onwards. However, the centralisation of radical prostatectomy has only risen by about 10% between 2007 and 2013. This is predominantly due to two large surgical services in the Adelaide, Meath and National Children's Hospital (Tallaght Hospital) and the Mercy University Hospital, Cork which have not yet transferred to neighbouring designated cancer centres (Table 6.2.1).

**Table 6.2.1: Resection of Prostate Tumours by Designation of Hospital and by Year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	256	254	260	303	350	341	290
Number of procedures undertaken in a cancer centre	45	58	44	65	45	76	80
Number of procedures undertaken in one of the six designated surgical centres for prostate cancer	156	139	150	186	241	247	199
% of procedures undertaken in one of the six designated surgical centres for prostate cancer	61%	55%	58%	61%	69%	72%	69%


Source: HIPE data, Healthcare Pricing Office 2014

#### 4. Development of NCCP GP Referral Guidelines and Referral Form for Prostate Cancer


Recommendation 24	The HSE should develop care pathways for cancer care to link primary care, services, hospital services and other relevant services.
Recommendation 25	Improved cancer information services should be available in primary care.

National GP Referral Guidelines for prostate cancer were developed to support the NCCP Rapid Access Prostate Clinics in conjunction with the national multidisciplinary prostate cancer teams and the Irish College of General Practitioners.

These were the first in a series of national GP referral guidelines to be developed. The evidence based guidelines were developed in consultation with all the relevant stakeholders. The guidelines however, do not override the individual responsibility of health professionals to make decisions appropriate to the circumstances of the individual patient. (TD 18)



## NATIONAL PROSTATE CANCER GP REFERRAL GUIDELINES



Rapid access clinics aim to improve access to investigations for prostate cancer in men aged from 50 to 70 (or from aged 40 if they have a first degree relative with prostate cancer). Prostate cancer will continue to be diagnosed in general urology clinics.

Prostate cancer is the leading cause of cancer in men (excluding skin cancer). Over 2,500 men are diagnosed with prostate cancer in Ireland each year. The cumulative risk of a man developing prostate cancer before the age of 50 is 1 in 485 and before the age of 70 is 1 in 13.

Data Source: National Cancer Registry, Ireland.

**Risk Factors:** Family history of prostate cancer, age (risk of prostate cancer increases after 50 years), and men of African ethnicity.

**Prostate Specific Antigen (PSA) Testing**

- PSA testing of asymptomatic men or PSA screening is not national policy
- Prostate assessment consists of a digital rectal examination (DRE) and a PSA test
- PSA testing should only be carried out after full advice and provision of information. (Patient information leaflet about prostate assessment is available from the National Cancer Control Programme on (01) 8287100 or can be downloaded by logging onto [www.cancercontrol.hse.ie](http://www.cancercontrol.hse.ie))
- All men with an abnormal DRE should be referred to a urologist regardless of PSA results

Patient Advice	Guidance on PSA Testing
<ul style="list-style-type: none"> <li>Prostate assessment involves a blood test and a rectal examination</li> <li>A normal assessment does not rule out cancer</li> <li>A biopsy can be uncomfortable. Side effects such as bleeding, infection or urinary retention may occur but less than 1% require hospital admission</li> </ul>	<ul style="list-style-type: none"> <li>Patients should be counselled before they have a PSA test</li> <li>Patients with an abnormal PSA result should have a repeat PSA at six weeks. If the patient also has an abnormal DRE, the PSA test does not need to be repeated and they should be referred directly</li> <li>Finasteride / dutasteride reduce PSA results by 50%, therefore the PSA result should be doubled in these patients</li> <li>DRE performed before the PSA does not raise the issue</li> </ul>

A Digital Rectal Examination (DRE) should be performed on every patient who is having a prostate assessment.

**GENERAL RECOMMENDATIONS**

A patient who presents with symptoms or signs suggestive of prostate cancer should be referred to a rapid access prostate assessment. Primary health care professionals should encourage all men over 50 years of age to measure their PSA from a blood sample taken with prostate cancer or those of African ethnicity to be aware of prostate health issues. In order to make this a prevention of disease.

To make a referral, FAX or POST - NATIONAL RAPID ACCESS PROSTATE CLINIC REFERRAL FORM or submit an electronic prostate cancer referral form via Healthlink. Electronic referral systems are currently being developed. go to the following website [www.healthlink.ie](http://www.healthlink.ie) for further updates.

Additional prostate cancer referral forms can be obtained by logging the National Cancer Control Programme on (01) 8287100 or by logging onto [www.cancercontrol.hse.ie](http://www.cancercontrol.hse.ie)

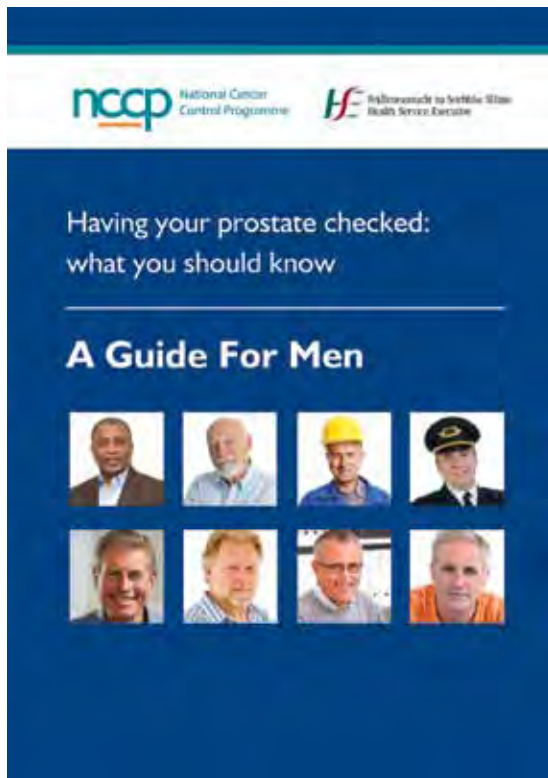
**NATIONAL RAPID ACCESS PROSTATE CLINICS (please refer to only one clinic)**

Beaumont Hospital, Dublin 8	Tel: (01) 809 3488	Fax: (01) 809 3488
Cork University Hospital	To open during 2011	
Garway University Hospital	Tel: (091) 542 053	Fax: (091) 542 092
Mid Western Regional Hospital, Limerick	Tel: (061) 565 637	Fax: (061) 482 572
Mater Hospital, Dublin 7	Tel: (01) 803 2644 / 2295	Fax: (01) 803 4030
St. James's Hospital, Dublin 8	Tel: (01) 416 2850	Fax: (01) 428 4090
St. Vincent's University Hospital, Dublin 4	Tel: (01) 221 3055	Fax: (01) 221 4318
Waterford Regional Hospital	To open during 2011	

This guideline represents the view of the NCCP which was formed as a result of after careful consideration of the evidence available. Health professionals are expected to take full and account when exercising their clinical judgement. The guideline does not override the individual responsibility of health professionals to make decisions appropriate to each patient. This guideline will be reviewed at the relevant intervals, and updates will be provided. For NCCP contact details or further guidelines, please call 111 (line opens 09:00-18:00).

### Development of information booklet for patients on 'Having your prostate checked'

Once the cancer centres had been designated, a patient information booklet was developed for men called 'Having your prostate checked: what you should know'. This booklet provides key information for patients on what to expect when having their prostate checked.



### Meeting the Needs of GPs

Education of GPs with respect to referral direction and timing can have an important bearing on the process and outcome of care that a patient may experience. The needs of GPs in relation to cancer were identified in the report 'Early Detection of Cancer, A Needs Assessment of General Practitioners' which was published in 2007 by the Irish Cancer Society ([www.cancer.ie](http://www.cancer.ie)) and the Irish College of General Practitioners ([www.icgp.ie](http://www.icgp.ie))

The common barriers that were identified included:

- Delay in patient presentation
- Lack of clear recommendations
- Inequity of access
- Long waiting lists and inadequate access for investigations
- Referral of patients who cannot pay privately
- Lack of direct access to hospital-based diagnostics
- Communication difficulty with referral to hospital services for investigation/assessment

The development of national GP referral guidelines, referral forms and electronic systems (developed in conjunction with the National Healthlink Project ([www.healthlink.ie](http://www.healthlink.ie))) are aimed at supporting GPs to recognise suspicious symptoms and expedite referral of patients to the rapid access clinics. It is hoped that these referral guidelines, standardised referral forms and electronic referral systems will increase the number of patients diagnosed at an earlier stage in order to maximise outcome and survival.

## 5. Development of Key Performance Indicators (KPIs)

Recommendation 55	The HSE should present a report on policy indicators each year to the National Cancer Forum.
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A suite of Key Performance Indicators (KPIs) for prostate cancer were developed in 2011, along with data definitions. Data collection of KPIs concerning the functioning of the Rapid Access Clinics commenced in 2012. A full suite of KPIs concerning access, multidisciplinary working, pathology reporting and quality of surgery were piloted in 2013 with national rollout to commence in 2014 (Table 6.2.2):

**Table 6.2.2: Key Performance Indicators**

Access	90% of referrals to the rapid access prostate clinic shall be offered an appointment within 20 working days of the date of receipt of a letter of referral in the cancer centre
Time to treatment – surgery	For 90% of patients diagnosed with a primary prostate cancer, the interval between the date of decision to treat and date of first surgical intervention where surgery is the first treatment, shall be less than or equal to 30 working day
Time to treatment – radiation oncology	90% of new patients with primary prostate cancer who undergo radical therapy will be treated within 15 working days of the date of ready to treat
Multidisciplinary discussion	All patients who are diagnosed with prostate cancer shall be discussed at MDM prior to their first therapeutic intervention
Timeliness of pathology reporting	The histology report following a first prostate biopsy should be available within 10 working days of the procedure being carried out in 80% of cases
Surgery	For patients who have a radical prostatectomy for prostate cancer and the specimen is classified as a pathological stage pT2, the positive margin status should not exceed 15%
	For patients who have a radical prostatectomy for prostate cancer and the specimen is classified as a pathological stage pT2, post-operative PSA at three months will be below detection levels in 90% of cases
	For patients who have a radical prostatectomy for prostate cancer and the specimen is classified as a pathological stage pT3, the positive margin status should not exceed 40%
	For patients who have a radical prostatectomy for prostate cancer and the specimen is classified as a pathological stage pT3, post-operative PSA at three months will be below detection levels in 70% of cases



A new KPI relating to the rate of urinary tract infections (UTI) and blood stream infections (BSI) will pilot in 2015 to monitor the new national policy on TRUS biopsies.

Each cancer centre reports on this set of Key Performance Indicators (KPIs), which are also published on the NCCP website. The KPIs are presented and discussed at the annual NCCP Prostate Cancer Quality and Audit Forum.

Prostate cancer services in Ireland have developed significantly. The National Cancer Control Programme has been working in partnership with clinical, administrative and managerial staff in the cancer centres to consolidate the service into a standardised national programme, with comprehensive standards and targets.

**Table 6.2.3: NCCP Rapid Access Prostate Clinics 2013**

INDICATOR	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Total
Patients referred to RAC shall be offered an appointment to attend within 20 working days of receipt of referral	52%	55%	55%	54%	56%	51%	59%	53%	52%	51%	59%	71%	55%
The no. of patients that attended a Prostate RAC within reporting calendar month	225	278	211	264	296	215	227	200	231	244	279	200	2870
The no. of patients that attended or received an appt. to attend RAC within 20 working days of receipt of referral in the cancer centre	117	153	115	143	165	109	133	105	121	124	165	141	1591
% new patients diagnosed. with PRIMARY prostate cancer	42%	33%	39%	32%	36%	33%	38%	28%	40%	39%	34%	40%	36%

Source: NCCP 2014



2,870 men attended the eight NCCP Rapid Access Prostate Clinics in 2013. Of these 1,591 were offered an appointment within 20 working days. On average, 36% of patients who attended the clinic were subsequently diagnosed with cancer in 2013. Access to clinics continues to be an issue with just 55% of patients who were referred being seen within the target time (Table 6.2.3).

Access to prostate RACs has deteriorated further in the first half of 2014.

Significant challenges exist within some of the prostate cancer Rapid Access Clinics in meeting the KPI targets. Galway, Limerick and Waterford Hospitals have continuously struggled to reach their KPIs. A contributory factor to the delays in accessing these clinics is a lack of consultant urologist posts locally.

Since January targets are not being met in some Dublin centres arising from cancellation of clinics over holiday periods and staffing challenges. There is an underlying vulnerability in the lack of surge capacity which is evident in many RACs. The NCCP has been assured that all referrals to these centres are triaged, urgent cases are prioritised and appointments offered to all appropriate patients in the first instance.

Recruitment is underway to appoint an additional consultant urologist in Galway and in June 2014 approval was given by the Director General of the HSE to appoint another cancer urologist at Cork University Hospital with a commitment also to the South East. Two new general urology posts have also been approved for the South East and the recruitment process is underway.

**Table 6.2.4: Rapid Access Prostate Clinics 2014**

INDICATOR	Jan	Feb	Mar	Apr	May	Total
Patients referred to RAC shall be offered an appointment to attend within 20 working days of receipt of referral	42%	44%	52%	38%	42%	44%
The number of patients that attended a Prostate RAC within reporting calendar month; of those	230	248	200	197	225	1100
The number of patients that attended or received an appointment to attend RAC within 20 working days of receipt of referral in the cancer centre	96	110	104	75	94	479
% new patients diagnosed with PRIMARY prostate cancer	37%	38%	43%	40%	38%	39%

Source: NCCP 2014

## 5. Establishment of a National Clinical Leads network for Prostate Cancer

Recommendation 23	A lead clinician for each Cancer Centres should be appointed. In addition, a clinician should be appointed to lead the development of cancer care pathways for each major site-specific cancer in partnership with all stakeholders within the network.
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The purpose of the national NCCP Prostate Cancer Clinical Lead Network is to ensure that the eight centres build on robust local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving.

The terms of reference for the clinical leads group are as follows:

- Contribute to the development and continuous improvement of the prostate cancer service.
- Share good practice and innovation in prostate cancer service and ensure that non evidence based practice is discontinued.
- Inform decision making and standardisation of service delivery across the centres.
- Ensure adherence to National Standards and Key Performance Indicators.
- Review the quality and completeness of data, recommending corrective action where appropriate and necessary.
- Lead national multidisciplinary audit, quality and risk (AQR) meeting for prostate cancer.
- Input into selection of Key Performance Indicators (KPIs) for Prostate Cancer Services.

The NCCP Prostate Cancer Clinical Leads group was established in 2011 and meets quarterly. The group has completed several key projects in relation to standardisation of PSA, developed a national policy on management of infection post TRUS prostate biopsy, functional outcome surveys submission to the Irish Medicines Board and European Medicines Agency to request that PSA home testing kits be banned and the development and review of KPIs.

The prostate cancer services are now led by a lead clinician in each designated cancer centre and are supported by a multidisciplinary team of cancer specialists. Through this national network, best practice models are identified and shared, to ensure standardisation and service improvement nationally.

## 6. Annual NCCP Prostate Cancer Quality and Audit Forum

The NCCP established an Annual Prostate Cancer Quality and Audit Forum for Prostate Cancer Services. The purpose of the forum is to provide an annual multidisciplinary forum for audit, quality and risk for Prostate Cancer Services.

This is a decision making forum. Each year, the KPIs from each unit are presented and any variation is discussed at this forum. The forum also encompasses multidisciplinary workshops for the purpose of problem solving and sharing of best practice models - each clinical discipline identifies and agrees key areas requiring standardisation and national protocols for service improvement.

The first Prostate Cancer Forum was held in Farmleigh in November 2012 and it has been held annually since.

Key themes of the previous fora included:

- 2012: Guest Speaker Professor Damian Greene, UK: Presented on setting up prostate cancer centre of excellence.
- 2013: Guest Speaker, Mr. Rick Popert, UK: Presented on Trans Perineal Prostate Biopsy.

## 7. National clinical guidelines for diagnosis, staging and treatment of prostate cancer.

The NCCP has commenced the development of evidence based clinical guidelines for the diagnosis, staging and treatment of prostate cancer. These guidelines will include recommendations relating to the patient pathway in the areas of pathology, radiology, surgery, medical oncology and radiation oncology. Nominations for each group were sought from the relevant clinical faculties. The prostate cancer clinical guideline is due for completion in 2014 and will be available on the NCCP website. Further information is available in Section 12.

## 8. NCCP PSA Standardisation Project Board 2013-2014

The NCCP sought to address the lack of standardisation of PSA measurements around the country as indicated in a recent publication in British Journal of Urology International (BJUI). It was proposed that harmonisation of PSA assays around the country will lead to better decision-making particularly for PSA results in the narrow 3-7 ug/L range where a decision to perform prostate biopsy may be taken and where it is thought that lack of standardisation may contribute to unnecessary biopsies.

The project board agreed to the establishment of a PSA Harmonisation Group which would further consider the issue and recommend the best approach to achieving optimal standardisation.

The project was divided into the following three phases:

**Phase 1: National Online Survey:** To collate data on the current practice in relation to pre-analytical, analytical and post-analytical aspects of PSA analysis and reporting in Irish laboratories, in particular in the NCCP designated cancer centres.

**Phase 2: Cross-Laboratory Review:** A questionnaire was circulated to the eight designated cancers and AMNCH and Mercy Hospital Cork.

### Phase 3: Internal Quality Control (IQC) and External Quality Assurance (EQA)

**sampling:** Phase three of the project involves running common IQC materials to facilitate intensive management of PSA measurement. Stability testing of PSA samples has also been completed as well as an audit of distribution timelines of PSA blood samples.

### Three NCCP PSA Harmonisation Workshops

were held during 2013 and 2014 to update laboratory personnel about the project.

### Limiting of Free to Total PSA Testing:

As part of the work of the NCCP PSA Standardisation Project Board, a decision was agreed in conjunction with the Irish College of General Practitioners to limit the use of Free to Total PSA testing to hospital based Consultant Urologists. The limiting of Free to Total PSA testing to Consultant Urologists will result in an estimated annual cost saving of one million euros.

## 9. Development National Policy for the 'National Policy on the Prevention and Management of Infection Post Trans Rectal Ultrasound (TRUS) Guided Prostate Biopsy'

A project team was established in May 2013 with agreed terms of reference:

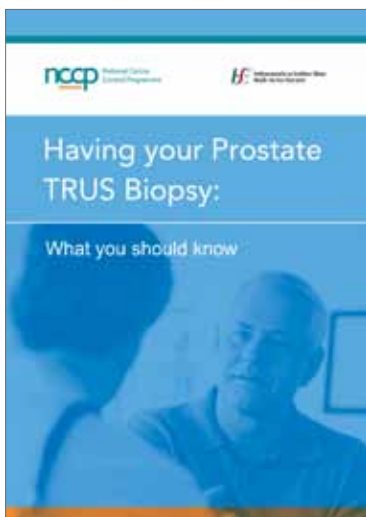
- a. To conduct an online survey of the eight designated NCCP prostate cancer centres, Mercy Hospital, Cork and Tallaght Hospital, Dublin to determine current national practice in relation to the prevention and management of infection post prostate biopsy.
- b. To conduct a literature search for the clinical questions raised by the board.

- c. To draft and agree a national prostate biopsy surveillance form and protocol, and circulate to relevant stakeholders for their review and feedback.
- d. To present the findings of the national survey at the NCCP Prostate Cancer Quality and Audit Forum meeting in Dublin Castle on the 8<sup>th</sup> November 2013.

The national policy for prevention and management of infection post TRUS guided biopsy has now been published and circulated to the designated cancer centres and all relevant national stakeholders. The guidelines are also available on the NCCP website. <http://www.hse.ie/eng/services/list/5/nccp/pubs/guidelines/guidelines.html>. A new key performance indicator is being piloted in Q4 of 2104 to monitor the implementation of the national policy.

**10. Development of information booklet for patients on 'Having your Prostate TRUS Biopsy: What you Should know'**

Another output of the NCCP Prostate TRUS Infection Project Board is the development of a patient information booklet for men called 'Having your Prostate TRUS Biopsy: What you should know'. This booklet provides key information for patients on what to expect when having their prostate TRUS biopsy. The NCCP was awarded the National Adult Literacy Agency Plain English mark for this booklet.



**11. Development of electronic GP referral systems for prostate, lung (and other) Cancers - Electronic referral: (2010-ongoing)**

The NCCP, in collaboration with a broad range of stakeholders has developed electronic referrals for breast, prostate and lung cancer. This award winning initiative commenced in 2008 and enables GPs to send a prompt referral to the relevant designated cancer centre. The referrals are available on-line and a breast, prostate and lung cancer referral form are available as an integrated referral form in GP practice management systems. Referrals are acknowledged and the cancer team sends a response to the GP with the date of the patients' appointment within five working days. The numbers of prostate cancer referrals have increased from 186\* in 2010 to 1,042 in 2013. This project was awarded an eGovernment award in 2012.

Further information is available in the community oncology Section 9 of this report.

\*only three hospitals were live in 2010.



## 12. Submission to the Irish Medicines Board and the European Medicines Agency to request the banning of PSA home testing kits

Recommendation 18	Population based prostate screening should not be introduced in Ireland at present. The Nation Cancer Forum should keep emerging international evidence on population screening for prostate cancer under review.
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The National Cancer Control Programme considers that the use of home self-test kits for Prostate Specific Antigen (PSA) constitutes an unnecessary risk to the health of men. For this reason the NCCP is calling for a ban on the importation, distribution, marketing and sale of such home self-test PSA kits. The NCCP have made a submission to the Irish Medicines Board and the European Medicines Agency to request the banning of PSA home testing kits.

## 13. Community Oncology

Additional achievements relating to prostate cancer have been achieved in Community Oncology and these are discussed in Section 9 of this report, including:

- Development of GP referral guidelines and standardised referral form for prostate (and other) cancers.
- Establishment of a follow-up protocol for patients when their treatment is complete.
- Development of an e-learning module for GPs on prostate cancer.
- Training for GPs through CME, ICGP and hospital study days.
- Ongoing development of information materials for GPs and for patients on follow-up.
- Training of hospital and community nurses on cancer prevention and treatment.

## Opportunities and Challenges

- Timely access to prostate rapid access clinics continues to be a challenge. Some of the difficulties relate to capacity, particularly in the West where there are large numbers of referrals. Surgeons from Galway and Cork travel to Limerick and Waterford respectively to run a weekly clinic in those hospitals. However, there is little or no surge capacity in the outlying hospitals if the surgeon is on leave or a clinic is cancelled.
- Completing the centralisation of prostate cancer surgery remains a challenge. Prostate cancer surgery continues to be undertaken in Tallaght & the Mercy hospitals where there has been a historically high volume of urology cancer surgical activity.
- In order to address increasing reports of cancellations of cancer surgeries, the NCCP intends to commence monitoring of waiting times for admission for elective cancer surgery in 2014.
- There is a lack of data management staff and IT systems to automatically capture the work, particularly of multidisciplinary teams.
- The current HR environment with retirements, voluntary redundancy and moratoria has exacerbated the lack of data management support, and theatre nurses in the prostate service.
- Robotic Surgery is one method of performing radical prostatectomy. HIQA undertook a request of the NCCP. The conclusion of the HTA was that robot-assisted keyhole surgery has benefits to patients compared to conventional open radical prostatectomy, but that the quality of the evidence to support clinical effectiveness was poor and the cost of its introduction would be significant.
- Potential innovation in diagnostics such as a move from TRUS prostate biopsies to Transperineal Prostate Biopsies would have a significant impact on resources such theatre and day-ward time, nursing and medical personnel.

- The development and implementation of the clinical guidelines for prostate cancer will assist in standardisation of practice e.g. diagnostic imaging, surgical management.
- PSA testing is best undertaken within NCCP guidelines. Home tests currently available risk patients undergoing unwarranted tests with their associated anxiety. The NCCP has made a submission to the Irish Medicines Board and the European Medicines Agency to request the banning of PSA home testing kits.
- Development of a national policy for the prevention and management of infection post transrectal ultrasound (TRUS) guided prostate biopsy will standardise anti-microbial prophylaxis for men undergoing TRUS and should result in a reduced rate of infections.
- NCCP PSA Standardisation seeks to address the lack of standardisation of PSA measurements around the country. It was proposed that harmonisation of PSA assays around the country will lead to better decision-making particularly for PSA results in the narrow 3-7 ug/L range where a decision to perform prostate biopsy may be taken and where it is thought that lack of standardisation may contribute to unnecessary biopsies.
- The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and their activity is not subject to NCCP scrutiny.

## 6.3 Lung Cancer

### Epidemiology

There was an annual average number of 2,165 lung cancers diagnosed 2009-2011 in Ireland, making lung cancer the 4<sup>th</sup> most common invasive cancer in Ireland, excluding non-melanoma skin cancer. In 2011, there were 1,858 deaths from lung cancer, making it the most common cause of invasive cancer deaths. Between 1994 and 2011, there has been an annual increase in incidence rate of 2.2% per year in females and an annual decrease of 0.8% in males. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of cancers and five-year relative survival for this cohort is 13.3% with a 95% confidence interval of between 12.2%-14.3% (Cancer Factsheet: Lung NCRI 2013).

Recent cancer projections from the NCRI predict that the decrease in incidence rate will be reversed in the future in men and that growth will accelerate in women. Models for lung cancer predict the number of cancers to increase by 88%-124% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

Over 90% of lung cancer in Ireland may be attributed to smoking tobacco and is therefore theoretically preventable. Other known risk factors are exposure to radon, asbestos and other occupational carcinogens. The prevalence of smoking in Ireland remains over 23%, with peak prevalence of 31% in the 25-34 year old age group.

The success rate for smoking cessation among established smokers is approximately 20% with pharmacological therapy. Some smokers who wish to quit will attempt many times before succeeding. This and the long lag time between beginning smoking and the development of lung cancer mean that lung cancer will continue to be a major cause of cancer mortality for the foreseeable future. Earlier diagnosis, efficient and correct diagnosis and staging, and modern multidisciplinary management lead to improved short and long term survival with good quality of life. Improvements in the delivery of care are necessary through earlier diagnosis, rapid access to diagnostic and staging procedures, and provision of co-ordinated multidisciplinary treatment.



## Summary of achievements of the National Cancer Control Programme in relation to Lung cancer

### 1. Establishment of the National Cancer Control Programme Lung Cancer Service

There is substantial body of evidence supporting the hypothesis that volume of service and surgeon specialisation makes a difference with respect to outcomes for lung cancer surgery. The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that "four (4) centres nationally will be required, for the curative surgical treatment of primary thoracic cancers".

In 2007, there were six hospitals (all of them designated cancer centres) undertaking excision of primary lung tumours. Following an NCCP review of activity, volumes, bed utilisation, ITU usage, surgical outcomes and

the geographical patterns of patient referral, a decision was made to centralise lung cancer surgery into four hospitals.

In 2008, the Mater Hospital, St James' Hospital, Cork University Hospital and University Hospital Galway were designated as the four surgical centres for primary lung cancer treatment. In 2007, 79% of all primary lung cancer surgery took place in one of these four centres and by 2013 that percentage had increased to 96%. Due to capacity issues in the Mater Hospital, a small number of resections are carried out in St Vincent's University Hospital (Table 6.3.1).

In 2009, the NCCP prioritised funding and additional staffing for lung cancer services to support the establishment of Lung Cancer Rapid Access Clinics in all eight designated cancer centres. The aim is of these clinics is to accelerate the diagnostic process for patients with highly suspicious signs and/or

**Table 6.3.1: Resection of Primary Lung Cancers in Irish Public Hospitals by Designation of Hospital and by Year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	241	272	282	297	321	401	385
Number of procedures undertaken in a cancer centre	241	272	282	297	321	401	385
% of procedures undertaken in a cancer centre	100%	100%	100%	100%	100%	100%	100%
Number of procedures undertaken in one the four designated cancer centres	191	221	254	277	308	389	370
% of procedures undertaken in one the four designated cancer centres	79%	81%	90%	93%	96%	97%	96%

Source: HIPE data, Healthcare Pricing Office, 2014 \*Data for 2013 is provisional



symptoms of lung cancer and improve access to treatment to optimise patient outcomes. Funding was provided for a considerable number of staff including respiratory physicians, pathology and radiology posts together with nursing, radiographer, medical laboratory scientist and administrative support. Funding was also provided for endoscopic ultrasound equipment. By March 2011, all designated centres had established a Rapid Access Lung Cancer Clinic and were returning monthly data on the clinic to the NCCP.

GP referral guidelines and standardised referral forms were developed in tandem with the establishment of the rapid access clinics. Patient information booklets have been developed for each of the rapid access clinics with key information for patients on what to expect at their appointment including what

tests they may undergo. These booklets also include details on who to contact in the clinic with queries or concerns.

These structures have provided a significant advancement towards the integrated delivery of cancer services. In 2013, 91% of patients were assessed in a rapid access clinic by a respiratory physician within 2 weeks of receipt of request from GP or Emergency Department for assessment (the target is 95%). (Table 6.3.2).

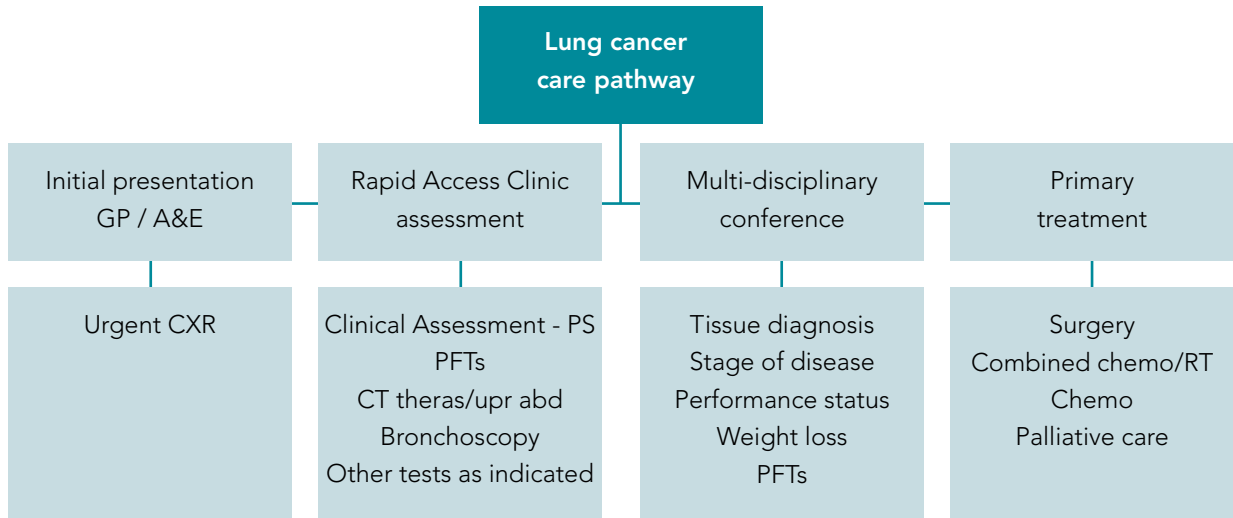
While 40% of patients with lung cancer are referred to a Rapid Access Clinic, other patients are diagnosed through other referral streams (acute hospital admission, referral to respiratory physicians). Such patients are discussed and their management planned at lung cancer MDTs (Figure 6.3.1).

**Table 6.3.2: Lung Rapid Access Clinics**

Attendances	2011	2012	2013*
All attendances	1,920	2,751	2,980
Number of primary cancers diagnosed	733	909	868
% of attendances who had a primary cancer diagnosed	38%	33%	30%

Source: NCCP 2014. \*2013 is provisional data

**Figure 6.3.1 Lung Cancer Care pathway**



**2. NCCP Rapid Access Lung Clinic Booklet wins Crystal Clear Award for Plain English**

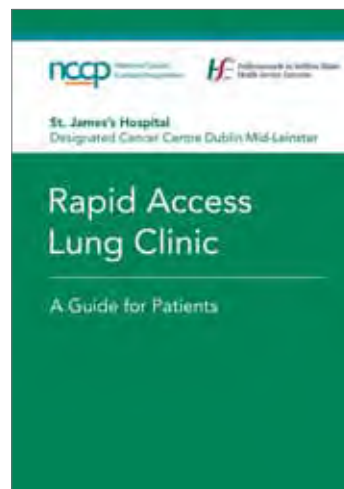
The NCCP won the 2012 Crystal Clear Award for 'Best Project in a Hospital' for development of eight NCCP Rapid Access Lung Clinic Patient Booklets.

This award has been developed to increase focus on health literacy in conjunction with the National Adult Literacy Agency (NALA). This booklet provides information on what to expect when you attend the Rapid Access Lung Cancer Clinics in the eight NCCP designated cancer centres. They also provide local information such as contact details for the lung cancer team.

**Best Project in a Hospital**

'NCCP Rapid Access Lung Clinic Patient Booklets' The National Cancer Control Programme (NCCP) developed the Rapid Access Lung Clinic patient booklet to provide information for patients about what to expect when they attend their Clinic. GPs can refer patients with suspected Lung Cancer to a Rapid Access Lung Clinic.

Early diagnosis of Lung Cancer increases the chance for a cure. The typical lung cancer patient is often from the lower socio – economic groups, and therefore may have low literacy levels. The deliverable of this project was to produce and distribute the patient booklets to the eight designated cancer centres around the country. The core information in all eight booklets is standardised, and there is hospital specific information in the individual booklets. This was to ensure that clear information is available to all patients irrespective of which hospital they attend. As well as informing the patients about their visit to the clinic, they include health promotion information, in particular a focus on encouraging patients to quit smoking.



### 3. Key Performance Indicators

A suite of Key Performance Indicators (KPIs) for lung disease was finalised in 2012, along with data definitions. These KPIs were piloted in 2013 and rolled out nationally in 2014.

**Table 6.3.3: Key Performance Indicators**

Referral	<i>95% of referrals to the rapid access lung clinic (RALC) shall be offered an appointment to be seen at clinic within 10 working days of the date of receipt of a letter of referral in the cancer centre</i>
Multidisciplinary discussion	<i>All patients with a diagnosis of primary lung cancer shall be discussed at a multidisciplinary meeting (MDM)</i>
	<i>For patients referred to the rapid access clinic and subsequently diagnosed with a primary lung cancer, the interval between the receipt of referral and first discussion at a multidisciplinary meeting (MDM) shall be monitored</i>
Diagnostics	<i>For patients diagnosed with a primary lung cancer, clinical TNM stage is recorded at MDM in 95% of cases</i>
Time to treatment – surgery	<i>Patients diagnosed with a primary lung cancer where surgery is the first treatment shall be offered an appointment for surgery within 30 working days of the date of the decision to operate by the multidisciplinary team</i>
Time to treatment – systemic therapy	<i>For patients receiving their first cycle of systemic therapy for lung cancer in the day ward setting, the timeline between the date of receipt of the finalised treatment plan in the day ward and the administration of the first cycle of intravenous systemic therapy will not exceed 15 working days</i>
Time to treatment – radiation oncology	<i>90% of new patients with a primary lung cancer who have radical therapy will be treated within 15 working days of date of being deemed ready to treat</i>
Time to treatment – small cell lung cancer	<i>Patients diagnosed with a small cell lung cancer have treatment initiated within 10 working days of the histological diagnosis</i>
Surgery	<i>For those patients with primary lung cancer who have a resection, pathological TNM stage is recorded</i>
	<i>Volume and type of surgical resections for primary lung cancer will be recorded</i>
	<i>For those patients with primary lung cancer who have a resection, intra-operative mediastinal lymph node staging is undertaken and recorded</i>

Source: NCCP 2014

Access to clinics is monitored on an ongoing basis (Table 6.3.4)

**Table 6.3.4: Indicator 2014**

		Jan	Feb	Mar	Apr	May	Total
Patients referred to RAC shall be offered an appointment to attend within 10 working days of receipt of referral (target is 95%)		90%	94%	87%	92%	86%	90%
The number of new patients that attended a Lung RAC within reporting calendar month; of those		271	285	273	246	245	1320
The number of new patients that attended or received an appointment to attend RAC within 10 working days of receipt of referral in the cancer centre		244	267	237	226	210	1184
The number of attendances (excluding DNAs) at lung rapid access clinics during the month:	New	271	285	273	246	245	1320
	Return	321	356	358	346	325	1706
	Total	592	641	631	592	570	3026
% new patients diagnosed with PRIMARY lung cancer		43%	34%	30%	36%	36%	36%
Number PRIMARY lung cancer diagnosed		116	97	83	89	88	473

Source: NCCP 2014

Data for the year 2014 suggest that the proportion seen within 10 working days of receipt of referral is remaining stable at about 90%. However, the target is 95%.

Each cancer centre reports on the Key Performance Indicators (KPIs), which are also published on the NCCP website. These KPIs are designed to assist patients, staff and the NCCP in assuring themselves that all designated cancer centres are adhering to the required standards of practice. Prompt access to cancer services has been one of the key deliverables for this service. The KPIs are presented and discussed at the annual NCCP multidisciplinary Lung audit and quality forum.

#### 4. Establishment of a National Clinical Leads Network for Lung Cancer Services

Each of the designated cancer centres has identified lead clinician for lung cancer supported by a multidisciplinary team of cancer specialists. Their role is to monitor key performance indicators within the hospital, standardise processes and promote models of good practice.

The Lung Cancer Leads group was established in 2011 and meet quarterly. This group of lead clinicians from the eight cancer centres now operates as a cohesive national clinical network for the purpose of clinical audit, sharing of best practice and problem solving. Through this national network, best practice models are identified and shared, to ensure standardisation and service improvement nationally.

The terms of reference for the clinical leads group are as follows:

- Contribute to the development and continuous improvement of lung cancer service.
- Share good practice and innovation in lung cancer services and ensure that non evidence based practice is discontinued.
- Inform decision making and standardisation of service delivery across the centres.
- Ensure adherence to National Standards and Key Performance Indicators.
- Review the quality and completeness of data, recommending corrective action where appropriate and necessary.
- Lead national multidisciplinary audit and quality meeting for lung cancer services.
- Input into selection of Key Performance Indicators (KPIs) for lung cancer services.

## 5. Lung Cancer Quality and Audit forum

An Inaugural National Lung Cancer Quality and Audit forum was held on May 10<sup>th</sup> 2013 and the second took place in May 2014. The purpose of this forum is to establish an annual multidisciplinary meeting focusing on quality and audit of lung cancer services around the country. The meeting builds on local clinical governance arrangements in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving. It also identifies best practice models and ensures standardisation nationally of lung cancer services. The format of the day includes presentations, workshops and discussion of key service issues and developments. Lung cancer screening was discussed in depth at 2014 meeting, the consensus from the Audit and Quality Forum was that a national lung cancer screening programme should not be established at this time.

## Challenges and Opportunities

- 2011 was the establishment year for the Rapid Access Lung Clinics. The growth in new attendances between 2012 (the first full year of activity) and 2013 was 5%. The number of returns visits to the clinics is also monitored to ensure that the clinics remain primarily diagnostic clinics as they were designed to be. There was a 20% increase in return patients between 2012 and 2013. This trend is of concern, as if it continues, it will limit the capacity of the clinic to function properly as a rapid diagnostic clinic.
- The proportion of patients attending who were diagnosed with primary lung cancer fell from 38% to 30% between 2011 and 2013. While this figure suggests a highly appropriate referral pattern, the trend will continue to be monitored.
- Six of the eight designated centres see over 95% of patients within two weeks of referral. Two centres have not achieved this. Cork University Hospital in particular has experienced challenges in providing timely access to CT scanning. While a second CT scanner has been commissioned, the recruitment of radiographers, a scarce grade, has also posed difficulties.
- The diagnostic processes in the RAC result in the diagnosis of a relatively high number of lung nodules. These require follow-up monitoring; how best to manage this with efficient use of resources is a matter of some discussion.
- The aim is to increase survival from lung cancer. Timely access to curative treatment for suitable patients is vital to achieve this. If there is undue delay to surgery, the disease can progress within a short time frame to becoming inoperable. The NCCP is planning to monitor time from decision to operate to date of surgery from 2014 onwards.

- Lung cancer is to a large extent a preventable disease, related primarily to smoking. Efforts to reduce levels of smoking initiation and to support smoking cessation continue to be strengthened. Levels of smoking among young women and in more deprived communities require particular attention to prevent widening inequality in relation to this disease.
- The emergence of e-cigarettes is a relatively recent phenomenon. There has been rapid market penetration despite unanswered questions about their safety, efficacy for harm reduction and cessation, and overall impact on public health. To minimise potential impacts on prevention and cessation and the undermining of existing tobacco control measures, there is a need to regulate the availability of these nicotine delivery devices. The HSE does not endorse the use of e-cigarettes.
- The ongoing debate and emerging evidence in relation to lung cancer screening will be monitored.
- The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and activity there is not subject to NCCP scrutiny.

## 6.4 Colorectal Cancer

### Epidemiology

There was an annual average 2,468 colorectal cancers diagnosed 2009-2011 in Ireland, making colorectal cancer the 3rd most common invasive cancer in Ireland, excluding non-melanoma skin cancer. In 2011, there were 1,040 deaths from colorectal cancer, making it the 2nd most common cause of invasive cancer deaths. Between 1994 and 2011, incidence rates have been stable. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of cancers and five-year relative survival for this cohort is 60.6% with a 95% confidence interval of between 59%-62.1% (Cancer Factsheet: Colorectal NCRI 2013).

Recent cancer projections from the NCRI predict that this stability in incidence rates will change in future with models for colon cancer predicting number of cancers to increase by 110%-138% between 2010 and 2040 and predictions for rectal cancer increasing by 89%-97% in the same time period (Cancer Projections for Ireland: 2015-2040. NCRI 2014. TD 1).

### Cancer strategy implementation – Surgical Centralisation

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that "the curative surgical treatment of primary colon cancers will be delivered at all Eight (8) Cancer Centres" but that "there is a need for four centres nationally for the curative surgical treatment of primary rectal cancers".

In 2007, there were 35 hospitals undertaking colectomies for colon cancer and 33 hospitals undertaking resections for rectal cancer. The NCCP undertook an examination of the activity in these hospitals, looking at volumes, bed utilisation, ITU usage and the geographical patterns of patient referral for colorectal resections. In consultation with clinical advisors, a decision was taken to audit the surgical management of rectal cancer in public hospitals in Ireland.

## Audit

In 2008, the RCSI in collaboration with the NCRI and funded by the NCCP undertook a retrospective audit of all rectal cancers that underwent surgery in 2007 in a public hospital in Ireland. Data were collated retrospectively on individual patients by the NCRI and RCSI staff on patient characteristics, multidisciplinary decision making, management plan for all patients, processes and outcomes of surgery and whether patients received chemotherapy or radiation treatment.

The major elements that were examined included hospital volumes, surgeon volumes, patterns of care, type of operation undertaken and surgical outcomes including negative margin resection rates, 30 day mortality, clinical leaks, return to theatre, length of stay, readmission rates and timing and use of radiotherapy.

Following the audit, the Irish Association of Coloproctology recommended that:

- Rectal cancer surgery should not be performed in hospitals where fewer than 20 rectal cancer surgeries are carried out annually.
- Rectal cancer surgery should be performed in all eight designated cancer centres with provisos in relation to number of operations, adherence to guidelines, surgeon training, nomination of a lead surgeon, discussion of patients at multidisciplinary team meetings and participation in audit.
- Rectal cancer surgery could be performed in a small number of high volume non-designated centres, with similar provisos as the cancer centres, on an interim basis.

Following consideration of the audit report, the NCCP decided that rectal surgery would be centralised to all eight of the cancer centres. For colon cancer, in view of the high proportion of such cancers that present outside cancer centres as emergencies and the importance of maintaining surgical competence in the provision of emergency care outside the cancer centres, it was decided not to actively centralise colon cancer surgery. It was recommended that all patients should be discussed at the cancer centre multidisciplinary meeting.

## Centralisation of Primary Surgical Activity

Although colon cancer has not been actively centralised, there has been some movement towards the cancer centres between 2007 and 2013 with about half of all cancers being surgically treated in a cancer centre compared to 41% in 2007 (Table 6.4.1). It is anticipated that this percentage will increase in coming years with the roll out of BowelScreen across the country and the establishment of hospital groups. Cancers diagnosed under the BowelScreen programme will be treated in one of the designated cancer centres.

There has been a moderate level of success in centralising rectal cancer to the eight cancer centres and Letterkenny, the proportion being treated in a cancer centre rising from 43% in 2007 to 77% in 2013 (Table 6.4.2). A further 23% of activity was performed in one of four hospitals – Tallaght Hospital, the Mercy University Hospital, Cork, Kerry General Hospital and Mayo General Hospital. Capacity and resource issues in the receiving cancer centres have delayed the transfer of these services.



**Table 6.4.1: Resection of Colon Cancers by Designation of Hospital and by Year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	906	903	958	895	822	901	830
Number of procedures undertaken in a cancer centre	371	382	462	445	445	434	417
% of procedures undertaken in a cancer centre	41%	42%	48%	50%	54%	48%	50%

Data Source; HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013

**Table 6.4.2: Resection of Rectal Cancers by Designation of Hospital and by year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	438	405	458	459	420	432	414
Number of procedures undertaken in a cancer centre	190	199	237	249	279	311	317
% of procedures undertaken in a cancer centre	43%	49%	52%	54%	66%	72%	77%

Data Source; HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013

### Leads Group

A national Rectal Cancer Clinical Leads group, comprising of the lead rectal cancer clinician from each of the eight cancer centres has been established. The role of the leads is to develop a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving.

## Key Performance Indicators

A suite of Key Performance Indicators (KPIs) for rectal cancer was developed in 2012, along with data definitions. This suite concerning access, multidisciplinary working, timeliness of interventions, staging, pathology reporting and quality of surgery was piloted in 2013 with national rollout in 2014 (Table 6.4.3).

**Table 6.4.3: Key Performance Indicators**

Activity	<i>Number of rectal cancer patients referred to the cancer centre</i>
Diagnostics	<i>Every patient should have a rigid sigmoidoscopy performed to determine the position of the tumour prior to any therapeutic intervention.</i>
Time to treatment – surgery	<i>For patients diagnosed with a primary rectal cancer, the interval between the discussion at the multidisciplinary meeting (MDM) and date of first surgical intervention where surgery is the first treatment shall be monitored.</i>
Time to treatment – radiation oncology	<i>90% of new patients with primary rectal cancer who undergo radical therapy will be treated within 15 working days of the date of ready to treat</i>
Time to treatment – systemic therapy	<i>90% of new patients with primary rectal cancer who require systemic therapy will be treated within 15 working days of the date of the finalised treatment plan</i>
Multidisciplinary discussion	<i>All patients who are diagnosed with rectal cancer shall be discussed at MDM prior to their first therapeutic intervention</i>
Staging	<i>For patients with a primary rectal cancer, clinical TNM stage is recorded at prior to commencement of treatment</i>
Surgery	<i>The proportion of patients with rectal cancer who undergo a radical surgical procedure that have an abdominoperineal resection (APR).</i>
	<i>Distal margin status will be documented for all patients who have a radical surgical procedure for rectal cancer</i>
	<i>Radial margin status will be documented for all patients who have a radical surgical procedure for rectal cancer</i>
	<i>The percentage of patients whose marginal status is clear will be documented for all patients who have a radical surgical procedure for rectal cancer</i>
	<i>Number of lymph nodes that are harvested from all newly diagnosed rectal cancer patients will be recorded</i>
	<i>The number of newly diagnosed rectal cancer patients who have to return to theatre for any surgical procedure during their hospital stay</i>
Radiotherapy	<i>The proportion of newly diagnosed rectal cancer patients who receive radiotherapy pre or post operatively</i>
Length of stay	<i>Following surgery for rectal cancer, the percentage of patients with unscheduled re-admission to hospital within 30 days of discharge following surgery</i>

## Opportunities and Challenges

- The national roll out of BowelScreen, the national colorectal screening programme will increase the caseload of adenomas and colorectal cancers in the cancer centres, particularly in the early years of the programme. This will require careful planning and management to ensure that patients are treated in a timely manner.
- The completion of the centralisation of rectal cancer surgery remains a challenge.
- Monitoring of the quality of colon cancer management has not commenced and will prove challenging because of the wider dispersal of cases around the hospital system.
- There is a lack of data management staff to enable ongoing collection of data to monitor the quality of the colorectal service.
- The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and activity there is not subject to NCCP scrutiny.

## 6.5 Oesophageal and Gastric Cancers

### Epidemiology

There was an annual average of 526 gastric cancers diagnosed 2009-2011 in Ireland, making gastric cancer the seventh (7<sup>th</sup>) most common invasive cancer in Ireland, excluding non-melanoma skin cancer. In 2011, there were 327 deaths from gastric cancer, making it the seventh (7<sup>th</sup>) most common cause of invasive cancer deaths. Between 1994 and 2011, there has been an annual decrease in incidence rates of 1.6% per year in both females and males. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of cancers and five-year relative survival for this cohort is 23.9% with a 95% confidence interval of between 21.2%-26.6% (Cancer Factsheet: Stomach NCRI 2013).

Recent cancer projections from the NCRI predict that this decrease in incidence rate will be reversed in the future with models for gastric cancer predicting number of cancers to increase by

29%-64% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

On average 384 oesophageal cancer cancers have been diagnosed annually between 2009 and 2011. This makes oesophageal cancer the fourteenth (14<sup>th</sup>) most common invasive cancer in Ireland, excluding non-melanoma skin cancer. In 2011, there were 359 deaths and oesophageal cancer was ranked as the sixth (6<sup>th</sup>) highest cause of invasive cancer death. Between 1994 and 2011, there has been an annual decrease in incidence rates of 1% per year in females and an annual increase of 0.2% per year in males. For the 2008-2010 cohort, the five-year relative survival is estimated as being 15.1% with a 95% confidence interval of between 12.6%-17.8% (Cancer Factsheet: Oesophagus NCRI 2013).

Recent cancer projections for oesophageal cancer predict that this cancer will increase by 116%-134% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

### Cancer strategy implementation – surgical centralisation

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 was the first outline of an implementation plan for the 'A Strategy for Cancer Control in Ireland 2006' (Appendix 1). The Working Group concluded that "there is a need for two centres nationally for the curative surgical treatment of primary upper gastrointestinal cancers".

In 2007, there were nine hospitals (four of them designated cancer centres) undertaking oesophagectomies for upper gastrointestinal cancer and 28 hospitals (including all of the designated cancer centres) undertaking gastrectomies for gastric cancer. The NCCP undertook an examination of the activity in these hospitals, looking at volumes, bed utilisation, ITU usage and the geographical patterns of patient referral for both oesophageal and gastric resections. Cognisant of the strong association between volume and outcomes for oesophageal resections and in consultation with clinical advisors, it was agreed to designate four hospital units to

undertake the primary surgical management of oesophageal cancer. A more in-depth audit of these hospitals was to be undertaken prior to final determination of surgical centres.

In 2010, Beaumont Hospital, St James's Hospital, University Hospital Galway and Cork University Hospital were pre-designated as the four candidate units subject to audit of performance and safety. At present surgical activity in Cork is undertaken in the Mercy University Hospital; it is however planned to transfer this surgical work to the designated cancer centre in Cork University Hospital.

## Audit

In 2011, a retrospective audit of all oesophageal and junctional cancers that underwent surgery between 2008 and 2010 was undertaken in the four candidate oesophageal cancer surgical centres and James Connolly Memorial Hospital (Dublin), utilising the methodology adopted by the National Oesophago-Gastric Audit in England and Wales. Data were collated retrospectively on individual patients by the participating centres on patient characteristics, pre-treatment tumour stage, the staging process, the patient management plan, the processes and outcomes of surgery and whether patients received chemotherapy or radiation treatment. Data analysis was undertaken by the NCCP.

The major elements that were examined included hospital volumes, type of staging investigations carried out, documentation of pre-operative staging, patterns of care, type of operation undertaken and surgical outcomes including in-hospital mortality, anastomotic leaks, haemorrhage, acute renal failure, wound infection and cardiac and respiratory complications. Other outcomes examined included unplanned return to theatre rates, pathological margins and lymph node yields.

The main conclusions of this audit were that there was evidence of a volume/outcome differential with the highest volume centre having better surgical outcomes in terms of in-hospital mortality, reduced post-operative complications and fewer unplanned return to theatre. However, all four units achieved

an international standard compatible with the volume of patients treated in the centre.

Following consideration of the audit report, in 2012, the NCCP designated St James's Hospital as the National Centre for Oesophageal and Gastric Cancer with Beaumont Hospital, University Hospital Galway and Cork University Hospital designated as the three satellite centres for oesophageal cancer surgery.

The four surgical units all continue to contribute to a national database, based in St James's Hospital, which enables ongoing detailed audit of the management and outcomes of upper gastrointestinal cancers.

## Clinical Leads Group

In 2011, the clinical lead surgeons of the four hospitals formed a Clinical Leads Group chaired by the national clinical lead. The terms of reference for the clinical leads group are as follows:

- Contribute to the development and continuous improvement of upper gastrointestinal cancer surgical service.
- Share good practice and innovation in upper gastrointestinal cancer surgical service delivery and ensure that non evidence based practice is discontinued.
- Inform decision making and standardisation of service delivery across the centres.
- Ensure adherence to National Standards and Key Performance Indicators.
- Review the quality and completeness of data, recommending corrective action where appropriate and necessary.
- Lead national multidisciplinary audit, quality and risk (AQR) meeting for upper gastrointestinal cancer surgical service.
- Input into selection of Key Performance Indicators (KPIs) upper gastrointestinal cancer surgical service.

## Key Performance Indicators

The four clinical lead surgeons of the candidate hospitals for the surgical management of oesophageal cancer agreed a number of Key Performance Indicators which were identified as being an appropriate part of the quality monitoring programme that the NCCP in conjunction with the lead clinicians was putting in place. As well as monitoring activity in the national centre and its three satellite units, agreement was reached to monitor other quality parameters such as access, staging, multidisciplinary discussion, timely treatment, surgical outcomes and use of resources (Table 6.5.1).

**Table 6.5.1: Key Performance Indicators**

Access	<i>New patients referred with a histology report that indicated an oesophago-gastric cancer shall be offered an appointment at the oesophago-gastric cancer centre within 10 working days of the date of receipt of the referral letter in the centre</i>
Staging	<i>Patients newly diagnosed with an oesophageal or G-O junction cancer will have a PET-CT scan where it is clinically indicated within 15 working days of the date of diagnosis at the cancer centre</i>
	<i>Patients newly diagnosed with a malignant neoplasm of the oesophagus or G-O junction or malignant neoplasm of the stomach with predicted early cancer (T1 or T2) should undergo endoscopic ultrasound.</i>
Surgery	<i>Patients newly diagnosed with a malignant neoplasm of the oesophagus, G-O junction or rest of the stomach, with predicted high grade dysplasia (HGD) or T1a cancer should undergo endoscopic mucosal resection.</i>
Multidisciplinary discussion	<i>For patients with a newly diagnosed oesophago-gastric cancer, the interval between the date of diagnosis and the date of discussion at a multidisciplinary meeting (MDM) shall not exceed 25 working days.</i>
Time to treatment – systemic therapy	<i>Initial systemic/combination therapy in a curative setting will be carried out promptly.</i>
Time to treatment – radiation therapy	<i>Initial radiation therapy in a curative setting will be carried out promptly.</i>
Time to treatment – surgery	<i>Surgical intervention, where surgery is the first treatment, will be carried out within 15 working days of the MDM decision in 90% of cases.</i>
	<i>Surgical intervention, following neoadjuvant treatment, will be carried out within 40 working days of completion of neoadjuvant treatment in 90% of cases</i>
Surgery	<i>75% of patients will have a complete resection (R0).</i>
	<i>75% of patients will have 15 or more lymph nodes removed.</i>
Use of Resources	<i>Following surgery, patients will be discharged within 21 calendar days after the date of the surgical procedure.</i>
	<i>Following surgery, &lt;15% percentage of patients will be re-admitted to hospital within 30 days of discharge following surgery.</i>

The KPI suite of indicators was agreed in 2011 and the suite was piloted nationally in 2012. A full report of the pilot of the Key Performance Indicators for that year is found in TD 5 but some highlights include:

- In 2012, over 600 patients were referred to one of the four centres.
- Overall 58% of patients referred to the designated surgical centres were treated with curative intent.
- 91% of patients referred to the designated cancer centre with a histology report that indicated an oesophago-gastric cancer were offered an appointment at the oesophago-gastric cancer centre within 10 working days of the date of receipt of the referral letter in the centre.
- 79% of patients newly diagnosed with an oesophageal or G-O junction cancer and assessed at the oesophago-gastric cancer centre regarding suitability for treatment with curative intent had a PET-CT scan where it was clinically indicated within 15 working days of the date of diagnosis at the cancer centre.
- 84% of patients newly diagnosed with a malignant neoplasm of the oesophagus or G-O junction and 72% of patients newly diagnosed with a malignant neoplasm of the stomach with predicted early cancer (T1 or T2) underwent endoscopic ultrasound.
- 84% of patients with a newly diagnosed oesophago-gastric cancer were discussed at a multidisciplinary meeting (MDM) within 25 working days of the date of the initial diagnosis.

- The target for timely surgery was changed to 20 working days as it was deemed to be a more achievable target without compromising patient outcomes.
- For patients who underwent surgery, the target for a complete resection was exceeded for both oesophageal and gastric cancers.
- For patients who underwent surgery, the target for lymphadenectomy was exceeded for oesophageal cancer and was 74% for gastric cancer (target is 75%).
- Examining length of stay following surgery, it was identified that there was room for improvement, particularly for oesophageal surgery.
- Readmission rates following surgery were low.

### Centralisation of Primary Surgical Activity

Although the four surgical centres for upper gastrointestinal cancers were not formally designated until 2012, it is clear from Table 6.5.2 that patients began to be referred to one of the eight designated cancer centres shortly after the establishment of the NCCP. A higher proportion of patients who required oesophageal resections were attending designated cancer centres in 2007 (65%). This has risen to 78% in 2013. The Mercy University Hospital still has surgical activity ongoing there, pending transfer of the service to Cork University Hospital and there is some surgery taking place in Tallaght Hospital – which accounts for the procedures outside of cancer centres.

**Table 6.5.2: Oesophageal Resections for Upper Gastro-Intestinal Cancers by Designation of Hospital and by Year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	132	133	141	142	155	127	120
Number of procedures undertaken in a cancer centre	85	97	104	104	114	96	93
% of procedures undertaken in a cancer centre	65%	73%	74%	73%	74%	76%	78%
Number of procedures undertaken in a designated surgical unit	79	93	100	103	113	96	93
% of procedures undertaken in a designated surgical unit	60%	69%	71%	73%	73%	76%	78%

Data Source; HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013

Gastric cancer surgery was more widely dispersed in 2007, with just 43% of activity being performed in one of the four designated surgical units and 56% of activity occurring in any of the eight cancer centres. In 2013, this has increased to 60% and 66% respectively (Table 6.5.3).

**Table 6.5.3: Gastric Resection for Gastric Cancers by Designation of Hospital and by Year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	144	154	167	182	143	149	131
Number of procedures undertaken in a cancer centre	81	99	98	125	90	90	87
% of procedures undertaken in a cancer centre	56%	64%	59%	69%	63%	60%	66%
Number of procedures undertaken in a designated surgical unit	62	83	80	107	76	80	79
% of procedures undertaken in a designated surgical unit	43%	54%	48%	59%	53%	54%	60%

Data Source; HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013



## Challenges and Opportunities

- Completing the centralisation of oesophageal surgery remains a challenge as capacity within the receiving centres is constrained. The NCCP has entered into discussions with the Acute Hospital Directorate and individual hospitals to expedite the transfer of upper GI cancer surgery from the Mercy into the designated cancer centre in Cork University Hospital and to cease the remaining surgical activity in Tallaght Hospital (Dublin).
- The NCCP in conjunction with the national clinical lead needs to formalise a strategy for the surgical management of gastric cancers particularly in terms of volume and distribution.
- For oesophageal cancers, there are plans in place to expand the programme to encompass early mucosal endoscopic lesions.
- The establishment of a national clinical database provides a unique opportunity for detailed national audit over and above the collation of the KPIs. It enables local and national research and facilitates patient access to international clinical trials.
- The Clinical Surgical Leads Group does not have a NCCP project manager assigned to it. This makes co-ordination of the group somewhat haphazard and has led to delays in the group processes.
- The NCCP has a remit for developing cancer services and monitoring volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and activity there is not subject to NCCP scrutiny.

## 6.6 Pancreatic Cancer

### Epidemiology

An average of 478 pancreatic cancers were diagnosed annually 2009-2011 in Ireland, making pancreatic cancer the eleventh (11<sup>th</sup>) most common invasive cancer in Ireland, excluding non-melanoma skin cancer. In 2011, there were 478 deaths from pancreatic cancer, making it the fifth (5<sup>th</sup>) most common cause of invasive cancer deaths. Between 1994 and 2011, there has been an annual increase in incidence rate of 0.4% per year in females and 0.9% per year in males. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of cancers and five-year relative survival for this cohort is 7.0% with a 95% confidence interval of between 5.4%-8.8% (Cancer Factsheet: Pancreas NCRI 2013).

Recent cancer projections from the NCRI predict the number of pancreatic cancers to increase by 147% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

### Cancer Strategy Implementation – Surgical Centralisation

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that curative pancreatic surgical treatment should be concentrated in one national centre (Appendix 1). The decision to centralise pancreatic all surgery was based on actual activity data prior to 2007.

Pancreatic cancer surgery in Ireland was relatively widely dispersed with no one particular high volume hospital. In 2008, there were nine hospitals (six of them designated cancer centres) undertaking excision of pancreatic tumours. Preparatory work and consultation with clinical leadership commenced in 2008/2009 and a process was undertaken in 2009 to identify the preferred location for a national centre - this resulted in St. Vincent's University Hospital (SVUH), Dublin being designated the National Centre in late 2010.

During 2010, the NCCP reviewed the data in relation to the surgical units that provided pancreatic cancer surgery at that time. Based on this review it was proposed that a satellite unit be established in the Mercy University Hospital pending transfer of the service to the designated cancer centre in Cork University Hospital.

As obtaining pre-operative histology is not always possible a decision was taken to centralise the surgical treatment of all pancreatic tumours suspected of being malignant as well as those with proven malignancy. All cancer surgeries were concentrated in the new national centre (incorporating the Cork satellite service), with patients continuing to undergo diagnostic and staging investigation and non surgical management in other hospitals and designated cancer centres.

Significant additional funding was transferred to St. Vincent's University Hospital in 2010 to support the centralisation of pancreatic cancer surgery. Casemix costings for the surgical episode of care were transferred from those hospitals that had previously carried out resections, with funding for work up, diagnostics and non-surgical treatments remaining in the referring hospitals. Some surgeons who previously undertook pancreatic surgery in other Dublin hospitals had their contracts adjusted to enable them to operate in St. Vincent's Hospital.

Members of the national surgical team for pancreatic cancer in consultation with their colleagues nationally agreed patient pathways, referral criteria and patient information for pancreatic cancer surgery. A National Pancreatic Imaging Network was also established to agree standards for diagnostic imaging prior to referral to the national pancreatic centre in SVUH.

It was deemed essential that Pancreatic Cancer surgery transfer from the Mercy University Hospital to the designated cancer centre at Cork University Hospital (CUH). This took place in July 2012.

## Governance

A series of arrangements, including governance, multidisciplinary team and clinical effectiveness arrangements, were put in place in order to establish this single national service in SVUH with a satellite unit in CUH. These included:

- Designation of one National Clinical Lead for the National Surgical Centre for Pancreatic cancer
- Practitioners operating at CUH to participate and be subject to all elements of the audit and quality processes of the national programme
- An oversight group to be established to monitor implementation consisting of representatives from both sites and the NCCP
- A single national set of referral, diagnostic and treatment guidelines, protocols and audit parameters to be implemented at the National Centre and the Satellite centre

The main objectives of the Pancreatic Cancer Oversight Committee are to:

- Establish a joint multidisciplinary meeting
- Develop clinical guidelines and standards
- Develop and implement key performance indicators for Pancreatic Cancer Surgical Services
- Review patient pathways and referral protocols
- Agree clinical and corporate governance mechanisms

This Committee agreed and piloted a suite of Key Performance Indicators which have now been adopted nationally. The first Audit and Quality Forum for Pancreatic Cancer was held in 2014. This included presentation and discussion of audit data from 2012 and activity data from 2013.

In 2013, 91% of all resections of pancreatic tumours took place in the National Surgical Centre including its satellite in Cork University Hospital and 93% of activity took place in a cancer centre (Table 6.6.1).

**Table 6.6.1: Resection of Pancreatic Tumours by designation of hospital and by year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	76	89	79	90	77	95	86
Number of procedures undertaken in a cancer centre	45	58	44	65	45	76	80
% of procedures undertaken in a cancer centre	59%	65%	56%	72%	59%	80%	93%
Number of procedures undertaken in the National Surgical Centre for Pancreatic Cancer	9	11	16	51	40	71	78
% of procedures undertaken in the National Surgical Centre for Pancreatic Cancer	12%	12%	20%	57%	52%	75%	91%

Data Source; HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013

### Key Performance Indicators

The establishment of a suite of Key Performance Indicators (KPIs) was an essential part of the quality monitoring programme established by the NCCP. A suite of KPI indicators was agreed in 2011 and piloted nationally in 2012. As well as monitoring activity in the national centre and its satellite unit, agreement was reached to monitor other quality parameters such as diagnostics, multidisciplinary discussion, timely treatment, surgical outcomes and use of resources (Table 6.6.2).

**Table 6.6.2: Key Performance Indicators**

Diagnostics	<i>Number of newly diagnosed proven or suspected pancreatic cancer patients referred from other hospitals who require a repeat triphasic CT following initial MDT discussion at the NSCPC.</i>
Multidisciplinary discussion	<i>For patients with newly diagnosed proven or suspected pancreatic cancer, the interval between referral to the NSCPC and discussion at multidisciplinary conference (MDM) shall not exceed 10 working days.</i>
Time to treatment – systemic therapy	<i>Neo-adjuvant systemic therapy will be carried out within 15 working days of the finalised treatment plan.</i>
Time to treatment – surgery	<i>Surgical intervention in new patients with proven or suspected pancreatic cancer, where surgery is the first treatment, will be carried out within 20 working days of the MDM decision.</i>

Surgery	<i>The number of patients with operable pancreatic cancer who do not undergo surgical resection and have a have documented valid reason why not.</i>
	<i>If the patient with pancreatic cancer has surgery, then the margin-negative resection rate (<math>R_0</math>) should be measured.</i>
	<i>If a patient has a Whipples (pancreaticoduodenectomy) for pancreatic cancer, then the regional lymph node dissection should encompass 10 or more lymph nodes.</i>
Use of Resources	<i>Length of inpatient hospital stay of patients who undergo a Whipple (pancreaticoduodenectomy) or distal pancreatectomy procedure.</i>
	<i>Number of patients following a Whipple (pancreaticoduodenectomy) or distal pancreatectomy procedure who are readmitted to hospital within 30 days of discharge following surgical procedure.</i>

A full report of the pilot of the Key Performance Indicators for 2012 is found in TD 6, but some highlights include:

- In 2012, almost 600 patients were referred to the National Surgical Centre for Pancreatic Cancer (NSCPC).
- Forty four percent or 260 patients were diagnosed with pancreatic cancer and 96 of these patients underwent either a Whipple's procedure or a distal pancreatectomy in either St. Vincent's University Hospital or in the Cork centre.
- This indicates that 260 out of 478 or 54% of patients diagnosed with pancreatic cancer in Ireland were referred to the NSCPC in that year.
- Eighty four percent of referrals were discussed at a multidisciplinary meeting (MDM) within 10 working days of receipt of referral and 20% of referrals required a repeat triphasic CT following the MDM discussion, which indicates that there is room for improvement in the referral process.
- Seventy one percent of those deemed to have an operable tumour went on to surgery within 20 working days of the decision to operate.

- Of those with pancreatic cancer, almost 70% had an  $R_0$  resection and almost 89% had at least 10 lymph nodes removed.
- The 30 day in-hospital mortality rate following a Whipple procedure was 2.8%.
- Parameters looking at use of resources indicate a continuous shortening of length of stay in 2012 with few hospital readmissions.

All of these parameters are within international standards.

### **Annual audit quality and risk forum for pancreatic cancer**

In line with the management of other cancers and based on the recommendations of the HIQA Quality Review (2010), the NCCP established an annual audit quality and risk forum for pancreatic cancer. The purpose of the forum is to:

- Provide an annual multidisciplinary forum for audit, quality and risk in pancreatic cancer services.
- Build on local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving.

- Identify best practice models and ensure standardisation and service improvement nationally.
- Examine and monitor referral criteria to the National Surgical Centre for Pancreatic Cancer.

The inaugural forum for pancreatic cancer was held in the NCCP Offices in February 2014.

### Challenges and Opportunities

- Completing the centralisation of pancreatic tumour surgery remains a challenge as capacity within the receiving centres continues to be a limiting factor.
- Establishment of a joint multidisciplinary team meeting between St. Vincent's University Hospital and Cork University Hospital is still outstanding.
- There are opportunities for both units delivering pancreatic surgical services to work together to develop and standardise in-hospital clinical management pathways, and to work with community oncology in developing patient information.
- The centralisation of surgical services and data capture offers an opportunity to establish a national clinical database, which would provide a unique opportunity for detailed national audit over and above the collation of the KPIs, enable local and national research and facilitate patient access to international clinical trials.
- Both centres continue to cite challenges in ensuring adequate work up and staging of patients prior to referrals to the national centre for surgery.
- The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and activity there is not subject to NCCP scrutiny

## 6.7 Neuro-Oncology: Cancers of the Brain and Central Nervous System

### Epidemiology

An annual average of 345 cancers of the brain and central nervous system (including benign intracranial and intraspinal tumours) were diagnosed nationally 2009-2011 in Ireland. These cancers account for 1.8% of all invasive cancers excluding non-melanoma skin cancer and are the thirteenth (13<sup>th</sup>) most common category of cancer in Ireland. In 2011, there were 262 deaths from brain and central nervous system cancer, making it the ninth (9<sup>th</sup>) most common cause of invasive cancer deaths. Between 1994 and 2011, there has been no change in incidence rates of these tumours. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of cancers and five-year relative survival for this cohort has remained unchanged since 1994 at 20% with a 95% confidence interval of between 17.12%-23.1% (Cancer Factsheet: Brain and Central Nervous System NCRI 2013).

Recent cancer projections from the NCRI predict that the incidence rate will increase in the future with models for brain and central nervous system cancer predicting the number of cancers to increase by 46%-95% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

### Cancer strategy implementation – Surgical Centralisation

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that "the curative surgical treatment of primary brain and other central nervous system (CNS) cancers will be provided at one national centre" (Appendix 1).

In 2007, there were two hospitals undertaking the primary surgical treatment of brain and CNS tumours – Beaumont and Cork University Hospitals. The NCCP undertook an examination of the activity in these hospitals, looking at volumes, bed utilisation, ITU usage and the geographical

patterns of patient referral for brain and central nervous system resections. Following this review and in consultation with clinical advisors, a decision was taken to establish a national neuro-oncology service on two sites for adults - the national site in Beaumont, with a satellite unit in Cork.

## Annual Report

The first annual report on the national neuro-oncology service was published in 2012 and encompassed both adult and paediatric tumours. The full report is found in TD 7 but some highlights include:

- 822 neuro-oncology operations performed with 751 adult procedures and 71 paediatric procedures.
- Of the adult procedures, 680 or 91% were intracranial procedures and 71 (9%) were spinal.
- 552 (74%) of all of the adult procedures were performed in Beaumont and 199 (26%) were undertaken in Cork.
- 89% of intracranial procedures and 87% of spinal procedures were on primary tumours, the remainder were on metastases.
- Glioma was the commonest adult intracranial primary tumour that an operation was performed upon (324 or 54% of all operations on primary tumours).

Of those gliomas, 191 were WHO Grade 4.

- Looking at those who were operated on for metastases, 25 (32%) of the primary cancers were lung in origin.
- Expansion of awake craniotomies in Beaumont and Cork University Hospital.
- Introduction of immunofluorescence-guided surgery.
- Development of fully refurbished suite of laboratories specifically for the molecular genetic analysis of brain tumour in Beaumont.

## Key Performance Indicators

In 2014 a number of Key Performance Indicators were developed which will be part of an ongoing quality monitoring programme.

## Challenges and Opportunities

- Improvements to the service in recent years include the opening of the new Intracranial Stereotactic Radiosurgery Service at the St Luke's Radiation Oncology Unit at Beaumont Hospital in May of 2013. In the initial year it is expected that up to 50 patients will benefit increasing to around 200 annually over the coming years as the service develops.
- Data management staff are not available to the National Neuro-Oncology Service which will pose a challenge to the collation of a suite of Key Performance Indicators.
- The expansion of awake craniotomies has resulted in an increased requirement for the expertise of Speech and Language therapists. This is currently being met on an ad hoc basis in Beaumont Hospital.
- There is currently no administrative support to the multidisciplinary team meeting in Beaumont which is a challenge to support this essential component of cancer care.
- There is inadequate specialist community rehabilitation staff to support patients upon discharge.
- The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and activity there is not subject to NCCP scrutiny.

## 6.8 Gynaecology Cancer

### Epidemiology

Gynaecological cancers can be broadly subdivided into uterine body, ovarian, cervical and other rarer cancers such as cancers of the vulva, vagina and placenta.

### Uterine Cancer (Corpus Uteri)

There was an annual average of 400 uterine cancers (corpus uteri) diagnosed 2009-2011 in Ireland, making uterine cancer the 5th most common invasive cancer in women in Ireland, excluding non-melanoma skin cancer. In 2011, there were 83 deaths from uterine cancer, making it the 15th most common cause of invasive cancer deaths in women. Between 1994 and 2011, incidence rates have increased by 2.4% per year. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of uterine cancers and five-year relative survival for this cohort is 78.4% with a 95% confidence interval of between 75%-81.5% (Cancer Factsheet: Corpus Uteri NCRI 2013).

Recent cancer projections from the NCRI predict that this increase in incidence rates will continue in future with models predicting number of uterine cancers to increase by 62%-90% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

### Ovarian Cancer

For ovarian cancer, there was an annual average of 344 cancers diagnosed 2009-2011 in Ireland, making ovarian cancer the 6th most common invasive cancer in women in Ireland, excluding non-melanoma skin cancer. In 2011, there were 278 deaths from ovarian cancer, making it the 4th most common cause of invasive cancer deaths in women. Between 1994 and 2011, incidence rates have demonstrated a slight decrease of

0.8% per year, though this decrease was not statistically significant. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of ovarian cancers and five-year relative survival for this cohort is 39.4% with a 95% confidence interval of between 36.0%-42.8% (Cancer Factsheet: Ovarian NCRI 2013).

Recent cancer projections from the NCRI predict a moderate increase in incidence rate in future with models for ovarian cancer predicting number of cancers to increase by 34%-44% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

### Cervical Cancer

There was an annual average of 328 cervical cancers diagnosed 2009-2011 in Ireland, making cervical cancer the 7th most common invasive cancer in women in Ireland, excluding non-melanoma skin cancer. In addition, there has been an average of 2,847 cervical carcinomas in situ diagnosed every year. In 2011, there were 78 deaths from cervical cancer, making it the 12th most common cause of invasive cancer deaths in women. Between 1994 and 2011, incidence rates have increased by 2.1% per year for invasive cancers and 7% per year for in situ cancers, the latter increase particularly reflecting the national roll out of the cervical screening programme. The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of invasive cervical cancers and five-year relative survival for this cohort is 72.2% with a 95% confidence interval of between 68.7%-75.4% (Cancer Factsheet: Cervical NCRI 2013).

Recent cancer projections from the NCRI predict that this increase in incidence rates will continue in future with models for cervical cancer predicting number of cancers to increase by 77%-88% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).



## NCCP and Gynaecological Cancers

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that "the curative surgical treatment of primary gynaecological cancers will be delivered at four centres nationally" (Appendix 1).

In 2007, there were 27 hospitals undertaking surgery for cervical, ovarian or uterine cancers. The NCCP undertook an examination of the activity in these hospitals, looking at volumes, bed utilisation, ITU usage and the geographical patterns of patient referral for gynaecological resections. In consultation with clinical advisors, a decision was taken early in 2012 to centralise surgical gynaecology oncology services into 7 designated cancer centres: Mater Hospital, St James Hospital, St Vincent's Hospital in Dublin; Cork University Hospital, University Hospital Limerick, University Hospital Galway and Waterford Regional Hospital outside Dublin.

Complex gynaecological cancer surgery will be carried out in St James's Hospital and the Mater Hospital.

## Establishment of a National Clinical Leads network for Surgical Gynaecology Oncology

The Surgical Gynaecology Oncology Clinical Leads group was established in January of 2012. The purpose of the National Leads group is to ensure that the seven centres build on robust local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving. This group meets on a quarterly basis and is supported by a project manager from the NCCP.

The terms of reference for the clinical leads group are as follows:

- Contribute to the development and continuous improvement of surgical gynaecological services.
- Share good practice and innovation in surgical gynaecological services and ensure that non evidence based practice is discontinued.
- Inform decision making and standardisation of service delivery across the centres.
- Develop and ensure adherence to National Standards and Key Performance Indicators.
- Review the quality and completeness of data, recommending corrective action where appropriate and necessary.
- Lead national multidisciplinary audit, quality and risk (AQR) meeting.
- Input into selection of Key Performance Indicators (KPIs) for Gynaecology Oncology Services.

## Gynae Oncology Standards

The following standards have been set by the NCCP and Leads Group in Surgical Gynaecology Oncology:

- All patients diagnosed with or with a strong suspicion of having a cancer (with an ovarian mass) should be referred to a Gynae Oncologist pre-operatively.
- All radical gynaecological surgery will be performed by Gynae oncology surgeons only, including laparoscopic and robotic surgery if appropriate.
- Low grade cases of uterine cancer with no evidence of myometrial invasion on MRI do not require surgery under a Gynae Oncologist.

All patients will be discussed at MDM, and recommendations recorded in the patients' chart.

## Centralisation of Primary Surgical Activity

There has been a moderate level of success in centralising uterine and ovarian cancer to the eight cancer centres since the decision was made in early 2012 (Table 6.8.1 and 6.8.2). The proportion of women being treated in a cancer centre rose from 68% in 2009 to 79% in 2013 for uterine cancer (Table 6.8.1) and from 68% in 2009 to 87% in 2013

for ovarian cancer (Table 6.8.2). Colposcopy services for cervical cancer are not being centralised and about 30% of radical surgery for cervical cancer is still being conducted outside of the cancer centres with no significant change in the proportion since 2009 (Table 6.8.3).

**Table 6.8.1: Resection of Uterine Cancers by Designation of Hospital and by Year, 2009-2013**

	2009	2010	2011	2012	2013*
Total number of procedures	325	290	264	272	276
Number of procedures undertaken in a cancer centre	222	193	175	192	219
% of procedures undertaken in a cancer centre	68%	67%	66%	71%	79%

Data Source: HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013

**Table 6.8.2: Resection of Ovarian Cancers by Designation of Hospital and by Year, 2009-2013**

	2009	2010	2011	2012	2013*
Total number of procedures	229	185	174	219	149
Number of procedures undertaken in a cancer centre	157	138	118	173	130
% of procedures undertaken in a cancer centre	68%	75%	68%	79%	87%

Data Source: HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013

**Table 6.8.3: Resection of Cervical Cancers by Designation of Hospital and by Year, 2009-2013**

	2009	2010	2011	2012	2013*
Total number of procedures	171	151	152	121	90
Number of procedures undertaken in a cancer centre	117	107	98	79	62
% of procedures undertaken in a cancer centre	68%	71%	64%	65%	69%

Data Source: HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013

## **Development of Key Performance Indicators (KPIs) for Surgical Gynaecology Oncology**

A suite of Key Performance Indicators (KPIs) for Surgical Gynaecology Oncology are currently being developed by the NCCP in co-operation with the Leads Group for Gynaecology Oncology. It is expected that these will be agreed by the end of 2014 and will be piloted in 2015.

## **Commencement of national Clinical Guidelines for Diagnosis, Staging and Treatment**

The 2006 National Cancer Strategy recommended the development of evidence based guidelines and standards. The NCCP has commenced the development of evidence based clinical guidelines for Gynaecology Services. These guidelines will include recommendations relating to the patient pathway in the different Gynaecology areas. The following subgroups have been identified: Cervical Cancer, Ovarian Cancer, Vulval Cancer, Endometrial Cancer, Uterine and Fallopian Cancer and Gestational Trophoblastic Disease.

The Gestational Trophoblastic Disease subgroup was the first to start and this guideline is due for completion in 2014 and will be available on the NCCP website following stakeholder review.

## **Annual Quality Safety and Risk meeting**

The first Surgical Gynaecology Meeting will take place in 2015 when KPI data becomes available. The purpose of this forum will be to:

- Provide an annual multidisciplinary forum for audit, quality and risk.
- Build on local clinical governance arrangements, in order to operate as a cohesive national clinical network for the purpose of clinical audit, sharing of good practice and problem solving.
- Identify best practice models and ensure standardisation and service improvement nationally.

## **Community Oncology**

(These initiatives are further discussed in the Community Oncology Section 9 of this report)

- The Development of Ovarian Cancer GP referral guidelines and a standardised referral form are being progressed by the Community Oncology division of the NCCP in co-operation with the Leads Group in Surgical Gynaecology.
- Following completion of these guidelines electronic GP referral forms may be developed.
- Access to diagnostic tests needs to be strengthened and developed throughout the country in line with the implementation of the guidelines.

## 6.9 Neuroendocrine Cancer

### Epidemiology

Neuroendocrine tumours arise from cells of the endocrine (hormonal) and neural (nervous) system. These cells can be found throughout the body but neuroendocrine tumours are most frequently diagnosed in the digestive tract and the lungs. Many are benign, but some are malignant.

Neuroendocrine tumours are defined as per the RARECARE definitions (TD 8). Table 6.9.1 outlines the number of cases recorded by the National Cancer Registry every year. Table 6.9.2 is an estimate of the current number of prevalent cases.

**Table 6.9.1: Neuroendocrine Cancers in Ireland: Total Cases Diagnosed per Year, 1994-2011**

Year of diagnosis	By tumour behaviour			By site		
	Borderline/uncertain	Invasive	Total	Gastro- entero-pancreatic*	Other	Total
1994	26	283	309	55	254	<b>309</b>
1995	25	301	326	60	266	<b>326</b>
1996	23	277	300	46	254	<b>300</b>
1997	33	296	329	71	258	<b>329</b>
1998	24	318	342	57	285	<b>342</b>
1999	22	343	365	72	293	<b>365</b>
2000	21	350	371	72	299	<b>371</b>
2001	37	349	386	98	288	<b>386</b>
2002	29	351	380	76	304	<b>380</b>
2003	25	374	399	79	320	<b>399</b>
2004	31	388	419	85	334	<b>419</b>
2005	27	425	452	94	358	<b>452</b>
2006	29	449	478	105	373	<b>478</b>
2007	40	487	527	124	403	<b>527</b>
2008	36	493	529	128	401	<b>529</b>
2009	40	563	603	154	449	<b>603</b>
2010	38	535	573	166	407	<b>573</b>
<b>2011 **</b>	<b>33</b>	<b>486</b>	<b>519</b>	<b>147</b>	<b>372</b>	<b>519</b>

Source: NCRI 2012

\* gastroenteropancreatic defined as all tumours located in the digestive system (ICD10: C15 – C26 inclusive) \*\* data for 2011 is not yet complete

**Table 6.9.2: Prevalence of Neuroendocrine Cancers in Ireland**

Gastroenteropancreatic*	1,009
Other	1,016
Total	2,025

Source: NCRI 2012. Total prevalence (17 year: 1994-2010) = number of patients diagnosed between 1994 & 2010 that were still alive on 31/12/2010

While the incidence of the disease in Ireland is on a par with other countries (around four per 100,000 per year), since 1994 there has been a steady increase in numbers being diagnosed. A total of 55 gastro-entero-pancreatic cases were diagnosed in 1994, while in 2010, 166 cases were reported representing an annual percentage increase of eight per cent.

### Hospital Activity

As demonstrated in Table 6.9.3, about half of all intestinal neuroendocrine tumours are currently treated in a cancer centre.

### Cancer strategy implementation

In 2013, the NCCP established a neuroendocrine network which is aimed at establishing an integrated and coordinated national approach to handling the diagnosis and treatment of gastroenteropancreatic Neuroendocrine Tumours (NETS) in Ireland. The priority is to increase collaboration between specialists treating such tumours.

The National Programme aims to build a network involving the designated cancer centres in Dublin, Cork and Galway. This will improve service levels for Irish patients with increased exposure to new treatments and approaches, inclusion in drug and other trials, as well as other benefits. A minority of patients may still be referred for treatment abroad in rare circumstances and it is anticipated that lung NETS will still be managed by the specialist lung oncology centres.

The National Clinical Lead for Neuroendocrine Tumours leads a weekly dedicated multidisciplinary outpatients NET clinic in St Vincent’s University Hospital. Input is also provided by specialists with endocrinology and pancreatic/hepatobiliary surgical expertise. Plans are well underway to set up a special clinic for patients and families with hereditary neuroendocrine tumours and it is expected that a national MDT will be operational later in 2014. Strong links have also been established with the NET patient support group.

**Table 6.9.3: Distribution of Gastroenteropancreatic Neuroendocrine Tumours by Hospital of Treatment**

	Total Cases Attending The Hospital						Had Tumour Directed Surgery					
	2006	2007	2008	2009	2010	Annual Average	2006	2007	2008	2009	2010	Annual Average
Cancer Centre	60	76	73	76	103	<b>77.6</b>	21	35	39	35	45	<b>35</b>
Other Hospital	63	69	75	99	87	<b>78.6</b>	32	30	41	53	45	<b>40.2</b>

Data Source; HIPE Portal, Healthcare Pricing Office

## 6.10 Sarcomas

### Epidemiology

Between 1994 and 2012, there were 671 cases of invasive primary bone cancer diagnosed in Ireland, an annual average of 35 cases per year. Approximately 85% of these cancers are sarcomas. In addition to the bone tumours, there were on average 42 cancers of connective tissue registered every year between 2009 and 2011. These are rare tumours and due to the small numbers involved it is difficult to establish any trend in incidence. There were seven deaths in 2011 from a primary bone cancer and 22 deaths from a soft tissue cancer. (Cancer Trends No 22: Primary bone cancer, NCRI 2014). Because soft tissue sarcomas can occur in any anatomical site, they may be assigned to the code of the site organ rather than to the connective tissue code. For this reason, it has been shown internationally that registry data can underestimate soft tissue sarcomas by as much as 50%.

The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of primary bone cancers and five-year relative survival for this cohort is 57.3% with a 95% confidence interval of between 45.4%-69.0% (<http://www.ncri.ie/data/survival-statistics> downloaded May 2014). For soft tissue sarcomas, the five-year relative survival for the equivalent cohort is 64.4% with a 95% confidence interval of between 57.7%-71.0% (<http://www.ncri.ie/data/survival-statistics> downloaded May 2014).

### Hospital Activity

The NCCP undertook a review of the hospital activity associated with the treatment of sarcoma in 2012. The main findings were:

- There are approximately 1,000 patient discharges from public hospitals every year following treatment for bone cancer.
- Approximately one quarter of these patients are children.
- Looking specifically at surgical treatment of bone tumours of the limb (C40), Cappagh and St Vincent's Hospitals and Beaumont

Hospital are the main providers for the adult population and Cappagh and Crumlin Hospitals are the main providers for children with these cancers. St. Vincent's University Hospital is the largest service provider for surgical procedures for these types of tumours.

- For surgical treatment of bony sites other than limbs, St James's Hospital is the main service provider.
- There are on average 2,248 discharges recorded on the HIPE system every year following treatment of a soft tissue tumour.

### NCCP Plans

The NCCP has convened two national meetings to discuss and agree a process to develop pathways for the management of suspected sarcoma diagnosis. Agreement was reached at the meeting that the surgical management of these sarcomas is to be within designated cancer centres with other cancer care delivered locally. Treatment planning should be agreed in a designated centre by a multidisciplinary team.

It is intended to develop pathways to ensure that patients with suspected sarcomas are referred for diagnosis and treatment to a cancer centre. While additional considerations will be required to agree the treatment location of certain sarcomas, it has been agreed that the treatment of Musculo-skeletal sarcomas will be centralised in St. Vincent's University Hospital and Cappagh Hospitals. Chest wall and gastrointestinal stromal tumors (GIST) will be treated in St. James's Hospital.

The NCCP has yet to agree an implementation plan with local clinicians and hospital managers on the reconfiguration of services and clinical pathways to enact these proposals.

The Inaugural Meeting of the Irish Sarcoma Group (ISG) has been scheduled for the end of November 2014.

## 6.11 Head and Neck Cancers

### Epidemiology

Between 1994 and 2009, there were 411 cases of invasive head and neck cancer diagnosed in Ireland every year. The most common cancer site was the larynx, with 127 cases registered every year, followed by tongue cancer at 62 cases per year (Cancer Trends No 10: Head and Neck cancer, NCRI 2011). Incidence rates have been increasing by 7.9% per year for females and 5.2% per year for males since 2001.

The most recent relative survival estimates are a hybrid estimate for the 2008-2010 cohort of head and neck cancers and five-year relative survival for this cohort is 47.9% with a 95% confidence interval of between 42.8%-52.9% (<http://www.ncri.ie/data/survival-statistics> downloaded May 2014).

Recent cancer projections from the NCRI predict that incidence rates will continue to increase with models for head and neck cancer predicting the number of cancers to increase by 60%-114% between 2010 and 2040 (Cancer Projections for Ireland: 2015-2040. NCRI 2014).

### Cancer Strategy Implementation – Surgical Centralisation

The document 'Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres' published by the HSE in 2007 recommended that "the curative surgical treatment of head and neck cancers will be delivered in one national centre" (Appendix 1).

### Hospital Activity

In 2013, the NCCP undertook a review of the hospital activity associated with the treatment of head and neck cancers between 2008 and 2012. The main findings were:

- There are approximately 2,027 patient discharges from public hospitals every year following treatment for head and neck cancer.
- Surgical procedures were carried out in over 30 hospitals.
- Over 68% of those discharges were from a cancer centre.
- A further 11% of discharges were from the South Infirmary University Hospital, Cork.
- Looking specifically at surgical treatment, 68% of procedures were undertaken in a cancer centre. Twenty percent of activity was undertaken in the South Infirmary University Hospital, Cork.

### Centralisation of Primary Surgical Activity

As head and neck cancers have not been actively centralised, there has been no change in the distribution of the surgical treatment of head and neck cancers between 2007 and 2013 (Table 6.11.1).

**Table 6.11.1: Resection of Head and Neck Cancers by Designation of Hospital and by Year, 2007-2013**

	2007	2008	2009	2010	2011	2012	2013*
Total number of procedures	391	386	409	446	423	425	438
Number of procedures undertaken in a cancer centre	270	250	280	308	280	284	307
% of procedures undertaken in a cancer centre	69%	65%	69%	69%	66%	67%	70%

Data Source; HIPE Portal, Healthcare Pricing Office. \*Data is provisional for 2013



## Plans for Head and Neck Consolidation

In November of 2013, the NCCP convened a national meeting of all relevant stakeholders and clinical experts to develop a national approach for head and neck cancer surgery. Priorities were agreed in the areas of surgery, primary care pathways, radiology, pathology, workforce planning, multidisciplinary care and performance monitoring. Work is an advanced stage in relation to primary care pathways and surgical planning.

Complex head and neck cancers are to be centralised into designated centres where there is access to the full multidisciplinary team which includes head and neck surgeons, radiation oncologist, medical oncologist, pathologists and radiologists with special interest in head and neck cancers, cancer nurse specialists, data managers as well as speech therapists and dieticians. Access to restorative dentistry, plastic surgery and endocrinology are also required.

It has been agreed that head and neck sarcomas, rare, biologically challenging and hypo-pharyngeal head and neck cancers should be treated in one national centre. A minimum case volume of twelve cases per surgeon will be the initial standard increasing to 24 cases over time. Work is currently underway to develop a structure for a consolidated service.

# National Radiation Oncology Programme

Recommendation 30

The 2006 National Cancer Strategy recommended that “The National Network for Radiation Oncology Services should be established by the HSE in accordance with the timelines set by Government”.

In July 2005, the Minister for Health and Children announced the Government’s approval for a national network for radiation oncology to be put in place by 2011. The original intention was for a capital investment of over €400m (predominantly funded through a Public Private Partnership (PPP)) resulting in 23 additional linear accelerators to bring the national total to 36. The Network was to consist of:

## National Radiotherapy Strategy

For the past number of years, the expansion of radiation therapy facilities has been progressed under *The Report on the Development of Radiation Oncology Services in Ireland*, (known as the Hollywood Report) which was published in 2003 (TD 12).

The report outlined the significant deficit that existed at that time in relation to meeting the radiation oncology needs of cancer patients. Modern estimates suggest that between 55% and 60% of patients will require access to radiation oncology services during their cancer illness. In contrast, at that time, approximately 20% of cancer patients in Ireland had radiation therapy as part of their primary treatment and approximately 39% of patients with invasive cancer had radiation therapy at some point during their illness.

Four large centres, two in the Dublin Region (in St. James’ Hospital and Beaumont Hospital), one in Cork University Hospital and one in Galway University hospital:

- A single Eastern Region treatment centre serving the southern part of the region and adjacent catchment areas, ultimately providing a 13-14 linear accelerator capacity with appropriate clinical and non-clinical staff.
- A single Eastern Region treatment centre serving the northern part of the region and adjacent catchment areas, ultimately providing an 8-9 linear accelerator capacity with appropriate clinical and non-clinical staff.

A treatment centre located at Cork University Hospital (CUH) was ultimately to provide an 8-9 linear accelerator capacity with appropriate clinical and non-clinical staff.

The treatment centre located at University College Hospital Galway (UCHGI) was ultimately to provide a 6 linear accelerator capacity with appropriate clinical and non-clinical staff.

The report also recommended the development of two integrated satellite centres in Waterford and Limerick each with two Linear Accelerators. These satellites were to link with the large centres in Cork and Galway respectively. In addition the report recommended that arrangements be put in place with the Northern Ireland health authorities for services for patients in the North West of Ireland to be referred for treatment initially in Belfast City Hospital with further work to pursue the joint provision of a satellite centre for the North West linked to Belfast. A recommendation was also included that the continuity of expertise and ethos in St. Luke's Hospital be maintained for the services.

These recommendations were implemented on a phased basis. Phase 1 of the National Programme for Radiation Oncology (NPRO), involved the provision of new radiation oncology centres on the grounds of St. James's and Beaumont Hospital Campuses both with four linear accelerators and two CT simulators. These new facilities were opened and operational in early 2011. The existing radiotherapy centre at St Luke's and the new centres at Beaumont and St James's together form the St Luke's Radiation Oncology Network (SLRON) which operates across the three sites.

SLRON now operates as a single network with patients and staff moving between the centres as required. Services are delivered across the three sites on a 4-4-4 model (i.e. four linear accelerators operational on each site) with all patients booked through a central booking office. This ensures patients equity of access to the next available appointment, subject to site specific tumours and consultant availability.

Phase 2 of the national plan involved the design and construction of new departments in CUH and UHG. Funding for Cork and Galway has been fully provided for in the 2012-2016 HSE Capital Plan. Funding for Phase 2 expansion in Dublin (envisaged to be about €132k in the longer term) has yet to be agreed.

Under the original plan, the capital investment for Phase 2 was to be provided through a combination of exchequer and public private partnership (PPP) funding. However, in view of the economic outlook in Ireland, the Department of Health decided in 2012 to fund all expansion via traditional means from within the HSE Capital Plan.

The NPRO was drafted with a view to providing sufficient capacity in the public system to treat all patients in the Republic of Ireland. However in the intervening years radiotherapy facilities were built in the private sector and the HSE has since entered into Service Level Agreements for the provision of radiotherapy by private sector providers in both Waterford and Limerick.

In Waterford the Whitfield Hospital operated by UPMC (University of Pittsburgh Medical Centre) provides radiotherapy to patients from the South East while the Mater Private Hospital currently operates a facility on the grounds of University Hospital Limerick for patients from the Mid West. Both facilities have two linear accelerators and provide approximately one linear accelerator of capacity to the HSE. Future capacity projections for public radiotherapy facilities have for the medium term included the continuation of this level of activity in these private facilities.

There are also private radiotherapy facilities in Dublin (St. Vincent's Private Hospital, the Mater Private Hospital, The Hermitage and Beacon Hospitals). All of these units have two linear accelerators and operate independently of the NCCP.

In 2013 as part of the considerations on expansion plans for Phase 2 in Dublin, the Minister for Health commissioned Trinity College Dublin to undertake a study on the costs of radiation oncology provision through the public and private sectors in Ireland. The report found that public providers offer significant cost advantages over private providers particularly as capacity utilisation increases.

## National Plan for Radiation Oncology Phase 2 in Cork and Galway

There are currently four linear accelerators in Cork University Hospital and three in University College Hospital Galway. Funding for Phase 2 of the National Plan for Radiation Oncology provides for one additional linear accelerator (and a spare bunker) in Cork as well as the replacement of the current four linear accelerators over the period from 2013-2017 at a projected cost of €52m. In Cork considerable enabling works are required to decant the identified site and commission a purpose built unit. The preliminary site work associated has commenced and it is envisaged that this project will be completed in late 2017.

In Galway one additional linear accelerator (and a spare bunker) will also be provided, and the three existing linacs replaced. The work is scheduled to be completed in 2018 at a cost of €48m. Significant enabling works are also required.

The new radiotherapy units in Cork and Galway are significant new capital builds encompassing additional linear accelerators capacity as well as all related onsite facilities including dedicated clinic space, planning facilities and support staff offices. Contingency plans are being developed in each unit in the event of a shortfall in capacity, pending completion of the new expanded facilities.

## Capacity Planning for Dublin

Based on the flow of patients, the St. Luke's Radiation Oncology Network (SLRON) currently treats approximately 55% of all radiotherapy patients nationally.

Capacity planning for the Dublin Region has been revised to reflect the amended National Cancer Registry of Ireland (NCRI) cancer projections (2014) (TD 1). Planning has been based upon the following assumptions:

- 60% of all cancer patients are expected to receive radiotherapy;
- 55% of all radiotherapy patients nationally are treated in Dublin; and
- 65% will be treated through public provision in the Greater Dublin area.

## Dublin Expansion

The medium to longer term plan for Dublin involves the provision of seven additional linear accelerators at St. James's and four additional linear accelerators at Beaumont Hospital to give a total of 19 linear accelerators over time. Four of the linear accelerators at St. James's would replace those at St. Luke's which it is intended will ultimately cease to operate as a radiation oncology treatment facility.

The indicative cost for this is €120m (€75m at St James's and €45m at Beaumont). The capital allocation for the pre-construction phase in 2014/15 for Beaumont would total €5m, with construction through to 2016/18 costing €40m and the facilities being operational from early 2019. This required funding is not available from within the current HSE capital plan and discussions are ongoing with HSE Estates and the Dept. of Health to agree and fund expansion to accommodate the demand for treatment in the Dublin region.

**Table 7.1: Requirement for Linear Accelerators in Dublin up to 2030**

Linac requirement	Current	2015	2016	2017	2018	2019	2020	2025	2030
65% Public provision	12	14	14	14	15	15	15	17	19

In June of 2014 ministerial agreement was reached to fund the refurbishment of three existing bunkers in St. Luke's hospital to accommodate two/three new linear accelerators. The approval for this expansion which is funded from the existing HSE capital plan has been welcomed as capacity will be reached in the St. Luke's network by the end of 2015. The continuation of services in St. Luke's Hospital will provide the interim treatment capacity required, pending agreement on a longer term expansion plan. The current priority for the NCCP is the development of additional radiation oncology capacity at Beaumont Hospital. Funding for the design and planning of expansion in the Beaumont hospital site is being sought from within the existing HSE capital plan to enable construction to commence in 2017. Construction work on the development of the new National Paediatric Hospital on the site of St. James's will delay expansion of the radiotherapy facility until at least 2020. Funding for the long term expansion in Dublin has yet to be secured.

The revised plans for additional capacity at St. Luke's and the continued delivery of radiotherapy will defer the full transfer of radiation oncology services to the Beaumont and James's campuses and the cessation of services on the St. Luke's site. The continuation of the service over three sites will pose a continued staffing challenge for the network.

Allied to the opening of the radiotherapy facilities on the grounds of Beaumont and St. James's Hospitals, 12 dedicated inpatient radiotherapy beds have opened in each of the host hospitals; St. James's (February 2014) and Beaumont Hospitals (2012). There has been a commensurate reduction in radiotherapy beds in St. Luke's hospital.

During the period 2010-2012, a total of 54 additional staffing posts were provided to the SLRON network. These posts were primarily radiation therapists, physicists and clinical engineers and were required to support patients across the network. Some of these posts (including dietetics and nursing staff) will form part of the complement in the host hospital, and provide service to radiation patients in the inpatient beds and the new centres. Additional consultant radiation oncologist posts have also been added in recent years, bringing the current total in the St Luke's Network to 16.

### Access to Radiotherapy

Prior to the opening of the new radiotherapy facilities on the grounds of St James's and Beaumont Hospitals there had been a significant challenge to ensure timely access to radiotherapy in Dublin. These delays have improved considerably with the opening of the new radiation oncology centres on the grounds of St. James's and Beaumont Hospitals.

**Table 7.2: Average Waiting Times (Weeks) for Treatment**

	2007	2013
Breast	10	2
Prostate	21	2
H&N	5	2.5
Rectum	4	2
Cervix	5	2

The increase in linear accelerator capacity in Dublin from 2008-2013 has also resulted in an 80% reduction in treatment of patients treated on an out-of-hours basis (i.e. after 10pm). St. Luke's Hospital has moved from treating approximately 750 patients on an out-of-hours basis per year to 150 in 2013. This improvement has not only resulted in a better service to patients but has also yielded financial savings of €1.2m to the network.

Timely access to radiotherapy is a key performance indicator (KPI) for all radiotherapy units. Since 2012 the NCCP has published radiotherapy waiting times for public patients in all centres (SLRON, Cork, UCHG, Waterford and Limerick). Originally data was only reported on the number and percentage of patients undergoing radiotherapy treatment for breast, lung, rectal or prostate cancer who commenced treatment within 15 working days of being deemed ready to treat by the Radiation Oncologist. Since 2013 waiting times for all patients undergoing radical treatment are monitored by the NCCP each month.

There has been a notable improvement in the number and percentage of patients undergoing radical radiotherapy treatment who commenced treatment within 15 working days of being deemed ready to treat by a consultant radiation oncologist. The most recent figures for Quarter 1 in 2014 indicated that 91.6% of patients are treated within the target of 15 working days. This reflects a sustained improvement on access in the past two years.

## New Technology

There has been a significant investment in new technologies for radiotherapy, all of which are designed to enable patients to receive more effective and precise treatment, frequently over a shorter time period. All radiotherapy centres in Ireland offer external beam radiotherapy and brachytherapy. Intensity modulated and image guided radiotherapy is available for specific tumour types in all radiotherapy centres.

The SLRON centres in St. James's and Beaumont Hospital sites are both equipped with MRI scanners and with rapid arc capabilities and St James's Centre treated the first patient in Ireland with RapidArc™ technology in December 2011.

## Brachytherapy

A national prostate brachytherapy (radioactive seed implant) training programme was introduced across all public units in 2012. Led by Prof. Frank Sullivan from UCHG and applying recently published UK and Ireland Prostate QA guidelines, four consultants were trained initially and, training was provided to two further radiation oncologists in 2014. Over 180 patients were implanted in 2013 and an ongoing quality assurance programme is underway. The treatment is a day case procedure, as opposed to the traditional seven and half weeks of external beam radiotherapy. It is expected that approximately 200 men will be provided with this treatment in 2014, and that the patient numbers will grow significantly in future years.

**Table 7.3: % Undergoing Radical Treatment Who Commenced Treatment within 15 Working Days**

Year	Q1	Q2	Q3	Q4
2012	79.6%	77%	77.3%	81%
2013	82.0%	77.9%	78.4%	84.2%
2014	91.6%			



An ocular brachytherapy programme for the treatment of ocular melanoma was opened in St. Luke's Hospital, Rathgar in 2010 with dedicated surgical and nursing support provided by the Royal Victoria Eye and Ear Hospital and image-guided gynaecological brachytherapy commenced in Cork University Hospital in 2013.

### Stereotactic Surgery

Following a significant equipment upgrade, funded by the charity Friends of St. Luke's Hospital a new intracranial stereotactic radiotherapy/radiosurgery service opened in the SLRON unit at Beaumont hospital in August 2013. All patients requiring this treatment are jointly managed by site-specialised radiation oncologists and neurosurgeons.

The extracranial stereotactic service (SABR: Stereotactic Ablative Radiotherapy) commenced in the SLRON unit at St James's in March 2014, with the initial focus on treating early stage non-small cell lung cancers with curative intent. This service will be gradually extended with the result that patients no longer have to travel abroad under the HSE Treatment Abroad Scheme or depend upon the service being contracted from the private sector.

A new more efficient, modern and fractionated programme for Total Body Irradiation (TBI) patients was developed in 2013 and the programme was transferred from St Luke's Hospital to SLRON at St James's in association with the national bone marrow transplant unit which is based in St James's Hospital.

### Governance

Prior to the 1st of January 2014 St. Luke's Radiation Oncology Network (SLRON) was under the direct governance of the HSE National Cancer Control Programme. The Network has since transferred to the Dublin Midlands Hospital Group of the HSE. The radiotherapy units in Galway and Cork are under the direct management of the hospitals.

The National Radiation Oncology Planning and Implementation Committee was established in 2012 to "Provide support, advice and guidance to the Director of the NCCP on radiation oncology services to ensure timely and equitable access to radiation oncology services of the highest international standard". It comprises of professional leads, as well as clinical and managerial representation from the public radiotherapy units in Dublin, Cork and Galway (Terms of reference and membership are available). The group is currently progressing the development of national clinical radiotherapy guidelines and is overseeing the development of local and national contingency plans in the event of unavailability of capacity or machine failure for a protracted period of time.

Patients in the South East of the country may be referred to the UPMC Whitfield Cancer Centre for radiation oncology. The HSE has a service level agreement (SLA) with Whitfield for the provision of services to public patients referred through the designated cancer centre at Waterford Regional Hospital.

Similarly patients in the Mid West are referred to the Mater Private facility on the grounds of the Mid Western Regional Hospital in Limerick under a SLA. The SLA covers quality & clinical governance, access, the patient referral process, patient discharge, patient-centred care, interdisciplinary communication, adverse incident reporting, data requirements and a review process and dispute resolution. Regular meetings are held between both operators and the HSE to discuss performance matters.

Although UPMS has divested its ownership and management responsibilities at Beacon Hospital in Dublin, it has confirmed to the NCCP in April 2014 that it intends to continue to operate the radiotherapy facility in Waterford.



## Quality Key Performance Indicators

All radiotherapy units nationally report the number of patients (excluding palliative patients) who completed radical radiotherapy treatment in the preceding quarter. During 2013 a total of 3,951 patients completed their care in public radiotherapy facilities.

Radiotherapy units also report on the number and % of patients undergoing radical radiotherapy treatment who commenced treatment within 15 working days of being deemed ready to treat by the radiation oncologist (palliative care patients not included). The target is that 90% of patients are treated within this 15 day period. During 2013 an average of 81% of patients (3,181) were treated within this timeframe. For the first quarter of 2014 over 90% of patients are being treated within the target timeframe.

In 2011 SLRON has established a Quality Assurance in Radiotherapy (QART) Committee which is responsible for coordinating, overseeing and integrating quality assurance and continuous quality improvement initiatives across St Luke's Radiation Oncology Network (SLRON) and to advise nationally if required. The QART committee has developed a quality and audit system for the network which provides assurance that the specified requirements relating to the quality of patient care are satisfied and that the appropriate quality control mechanisms and procedures are in place. This has included the development of clinical protocols and an on line documentation system which is in line with international best practice. The SLRON clinical guidelines are currently being reviewed by Cork and Galway with the intention of endorsing and adopting these for national use. This is being progressed under the auspices of the National Radiation Oncology Planning and Implementation Committee (NROPIC). Once agreed these guidelines will form the basis of future contracted services and of clinical audit.

National radiotherapy meetings are held annually to discuss key performance indicators, advances in technology and clinical services as well as and new service developments.

## Progress on Cross Border Provision of Radiation Oncology Services

Agreement with Belfast City Hospital for the provision of radiation oncology services to patients from Donegal, particularly those with breast or prostate cancer, was reached in 2006. A very small number of patients continue to avail of this service annually.

Access for patients from the North West to radiotherapy will be improved under a North/South agreement to refer cancer patients from Co. Donegal to the new unit in Altnagelvin which is scheduled to open in 2016. The HSE will provide both a capital contribution and ongoing revenue funding. The new unit will also treat patients needing palliative radiotherapy and will provide a much reduced travel time.

## Research & Development

Current research in SLRON is included in the areas of clinical trials, translational research and developmental research. St Luke's Institute of Cancer Research (SLICR) provides funding to the Clinical Trials Unit (CTU) in SLRON from funding SLICR receives from the Friends of St Luke's, the Health Research Board and the St Luke's Cancer Research Fund. In 2013 SLRON recruited 103 patients to clinical trials, the highest accruals to cancer treatment trials of all HRB funded sites. SLRON also attained the highest credits of all HRB funded sites during 2013. The work of the CTU is multidisciplinary and involves clinicians, radiation therapists, physicists, nurses, statistician and administrative staff. The list of trials open to patient accrual in SLRON during 2013 and due to start in 2014 is included in TD 9.

There are two academic chairs at present (UCD & TCD), and there are strong academic links to the Faculty in the RCSI.

Three Translational research studies in the areas of Rectal Prostate and Pancreatic cancer also started in 2013 in collaboration with RCSI, UCD and DCU. The trials have provided five publications, five publications in progress and nine conference presentations during 2013.

Other areas of research and development involve the range of links which exist with Trinity College, University College Dublin and RCSI. These include PhD and MSc programmes, TCD Division of Radiation Therapy and the Institute of Molecular Medicine Cancer Research Laboratory also in TCD, UCD Conway Institute, SpR training programmes and nursing degree and education programmes.

There is a strong programme of PhD research in the physics department of SLRON together with UCD and DIT. There are at present four PhD students and a postdoctoral researcher working in areas contributing to clinical work in stereotactic and intensity modulated radiotherapy, the promising clinical field of Adaptive Radiotherapy, radiobiology of high dose treatments in lung and a national dosimetric audit system. Funding for the PhD research has come from SLICR, the Dublin Graduate Physics Programme and the NCCP medical physics training programme.

Cork University Hospital has recently secured funding for a full time radiation therapist post to support the Oncology Clinical Trials Unit. This will allow the department to establish radiotherapy trials which, to date, have not been achievable.

The radiation oncology department in Galway University Hospital is closely involved with the Prostate Cancer Institute at NUI Galway. With the planned expansion of the unit, it is anticipated that there will be increased involvement in research projects and improved co-ordination with the NUIG.

## Challenges for Radiation Oncology

The main challenge for radiotherapy relates to the significant capital costs of development and the long lead in time to build and then commission new equipment (this can be up to four years). Securing a timely decision to allow for completion of developments in line with projected demands remains a concern for the Dublin region.

Agreement and funding of the longer term expansion for the remainder of Phase 2 expansion in Dublin (indicative cost of €120m) has yet to be secured.

In the event that the radiotherapy service at the UPMC Whitfield Cancer Centre or the Mater Centre in Limerick was discontinued the existing public facilities in Dublin, Cork or Galway are not in a position to absorb the public demand (or a proportion of the private patients from either of these centres). In addition to limited linac capacity in the existing public system there would be patient access/satisfaction issues around travel times as well as revenue costs for additional in-patient and hostel beds, diagnostics and chemotherapy. In terms of contingency planning for this scenario there are a limited number of alternative scenarios available to the HSE for the delivery of this care.

The existing linacs in Cork and Galway are almost at full capacity and there may be challenges accommodating demand pending completion of the new facilities. Contingency plans are currently under development in all radiotherapy centres nationally in the event of a machine breakdown. In the absence of local alternatives some contingency plans may include transfer of patients off site for treatment.

The recently agreed expansion of St. Luke's will result in the continued delivery of radiotherapy across three sites in Dublin. This poses a challenge for clinical staff and medical cover.

Significant numbers of highly trained staff are required to run a radiotherapy unit. In recent years the availability of suitably trained physics staff has posed a challenge in commissioning new equipment. While a training programme (accredited by the Commission on Accreditation of Medical Physics Educational Programs (CAMPEP) has been developed between the radiotherapy units in SLRON and UCHG availability of qualified staffing remains a challenge.

The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and activity there is not subject to NCCP scrutiny

## Opportunities

Should the UPMC Whitfield Cancer Centre come to market the HSE/DOHC could consider a purchase or lease arrangement, retaining existing staff and protecting the clinical service, as well as gaining an opportunity to review revenue costs in order to secure the continuation of local treatment for patients from the South East.

## Activity Tables

The following tables outline radiotherapy activity in SLRON, UCHG and CUH from 2008 to 2013. Total body irradiation and stereotactic treatment are not available in UCHG or CUH. Data are also presented on public patients treated in Whitfield Radiotherapy and Limerick (Mater Private) Units.

**Table 7.1: Radiation Activity 2009-2013**

Radiotherapy Annual Activity SLRON 2008-2013						
Total Number of Patients (New Starts)	2008	2009	2010	2011	2012	2013
St Luke's Hospital	3366	3462	3685	2970	2331	1651
Beaumont Centre	-	-	-	449	935	1187
St James Centre	-	-	-	342	823	1160
Total	3366	3462	3685	3761	4089	3998
Radical Patient Numbers	2008	2009	2010	2011	2012	2013
St Luke's Hosp	2040	2217	2564	2011	1604	1139
Beaumont Centre	-	-	-	320	686	834
St James Centre	-	-	-	267	601	800
Total	2040	2217	2567	2598	2891	2773
Palliative Patient Numbers	2008	2009	2010	2011	2012	2013
St Luke's Hosp	1326	1245	1121	959	727	512
Beaumont Centre	-	-	-	129	249	353
St James Centre	-	-	-	75	222	360
Total	1326 (39%)	1245 (36%)	1121 (30%)	1163 (31%)	1198 (29%)	1225 (31%)

Radiotherapy Annual Activity SLRON 2008-2013						
<b>Brachytherapy Activity (SLH)</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Gynae Patients	173	153	159	158	142	166
Ocular Patients	-	-	8	26	38	42
Prostate Patients	-	-	-	-	22	30
Total Brachy Patients	173	153	167	184	202	238
<b>Number of Total Body Irradiation (TBI) Patients</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
St Luke's Hospital	29	32	48	28	27	16
St James Centre	-	-	-	-	-	25
Total	29	32	48	28	27	41
<b>Number of Stereotactic Patients</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
St Luke's Hospital	12	12	15	14	27	11
Beaumont Centre	-	-	-	-	-	25
Total	12	12	15	14	27	36
<b>Percentage of Patients treated using IMRT Technique (Step &amp; Shoot and RapidArc)</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
St Luke's Hospital	1%	2%	4%	7%	19%	30%
Beaumont Centre	-	-	-	-	11%	37%
St James Centre	-	-	-	-	10%	27%
Total	1%	2%	4%	7%	15%	31%

Table 7.2: Radiotherapy Annual Activity for UCHG Hospital 2008-2013

<b>Total Number of Patients (New Starts)</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total	1287	1393	1320	1303	1358	1262
<b>Radical Patient Numbers</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total	862	977	924	904	998	860
<b>Palliative Patient Numbers</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total	425	416	396	399	360	402
	33%	30%	30%	31%	27%	32%
<b>Brachytherapy Activity</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Gynae Patients	74	81	59	67	51	55
Ocular Patients	0	0	0	0	0	0
Prostate Patients	38	71	78	94	111	94
Total Brachy Patients	112	152	137	161	162	149
<b>Percentage of Patients treated using IMRT Technique (Step&amp;Shot and RapidArc)</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total	0	5%	8%	8%	13%	11%

<b>Table 7.3: Radiotherapy Annual Activity for Cork University Hospital 2008-2013</b>						
<b>Total Number of Patients (New Starts)</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total	1246	1261	1412	1339	1276	1277
<b>Radical Patient Numbers</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total	1041	1226	1308	1321	1123	1139
<b>Palliative Patient Numbers</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Palliative courses	359	317	412	383	424	438
Single sessions	185	157	193	161	150	143
<b>Brachytherapy Activity</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Gynae Patients	-	-	-	-	-	56
Prostate Patients	-	-	-	-	-	31
Total Brachy Patients	-	-	-	-	-	87
<b>Percentage of Patients treated using IMRT Technique</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total	-	-	-	-	-	7

**Table 7.4: Radiotherapy Annual Activity Whitfield Radiotherapy Unit Public Patients 2008-2013**

	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total Number of Patients (New Starts)	480	553	481	543	541	554
Total Radical Patient Numbers	244	313	263	307	317	297
Palliative Patient Numbers Total	236	240	218	236	224	252
Palliative patients as % of Total Pts.	49%	43%	45%	43%	41%	46%

**Table 7.5: Radiotherapy Annual Activity Limerick (Mater Private) Public Patients 2008-2013**

	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>
Total Number of Patients (New Starts)	338	315	308	416	397	369
Total Radical Patient Numbers	287	222	233	302	292	250
Palliative Patient Numbers Total	51	93	75	114	105	119
Palliative patients as % of Total Pts.	15%	29%	24%	27%	26%	32%

Key performance indicators for radiation therapy are included in TD 19

# Medical Oncology & Haemato-Oncology Programme

The 2006 National Cancer Strategy did not make any direct recommendation in relation to medical oncology or haematology.

Recommendation 49	HIQA should establish a Cancer Health Technology Assessment Panel.
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are 34 consultant medical oncology posts and 58 consultant haematology posts. There are at least a further four medical oncology specialists and at least two haematology specialists working exclusively in the private sector. However, the number of medical oncology and haematology consultants in Ireland still falls far short of international norms based on population and cancer incidence.<sup>7</sup>

## Introduction

The 2006 National Cancer Strategy contained little in the way of recommendations relating directly to medical oncology and haemato-oncology services. At the time of the publication of the 2006 National Cancer Strategy, the specialties of medical oncology and haemato-oncology were growing. In 2000, there were 13 consultant medical oncology posts in Ireland and 22 consultant haematology posts<sup>5</sup> in the public health system. By 2005, this had increased to 23 consultant medical oncology posts and 40 haematology posts<sup>6</sup>. Currently there

## Medical Oncology & Haemato-oncology Services

The last ten years have witnessed a huge increase in the complexity and volume of chemotherapy. Data suggests that the number of patients receiving chemotherapy has increased substantially. The growth in both incidence of cancer and prevalence of patients on active treatment with new drugs drives growth of volume and complexity of work.

5 Comhairle na nOspidéal, Consultant Staffing, January 2000. Available [www.lenus.ie](http://www.lenus.ie).

6 Note: haematology posts referred to here cover all areas of haematology, including, for example, blood and clotting disorders, transfusion medicine, paediatric haematology etc. There is no approved sub-specialty of haemato-oncology in Ireland.

7 (Unpublished) Internal NCCP working document on medical oncology manpower planning, Dr. Maccon Keane.; The shortage of medical oncologists: The Australian Medical Oncologist Workforce Study, MJA 196(1) 2012.



Medical oncology and haemato-oncology services are provided in 25 acute adult hospitals and one paediatric hospital in Ireland. These services operate mainly on a hub and spoke model, with the oncologist and haematologists based at a designated cancer centre, travelling to provide agreed services to satellite centres. Complex chemotherapy and services are provided at designated cancer centres and complex haemato-oncology services are provided at specialist centres where there is access to in-patient beds.

There is wide variation in the management of oral chemotherapy with the majority of patients receiving prescriptions for dispensing in their local retail pharmacy business.

### **Impact of Hospital Groups on Medical Oncology and Haemato-Oncology Services**

The organisation of cancer services in eight cancer networks was an important outcome of the 2006 National Cancer Strategy. The Report on the Establishment of Hospital Groups as a transition to Independent

Hospital Trusts, known as the Higgins Report ([health.gov.ie/wp-content/uploads/2014/03/IndHospTrusts.pdf](http://health.gov.ie/wp-content/uploads/2014/03/IndHospTrusts.pdf)) sets out the planned structure of hospital groups, in anticipation of the establishment of hospital trusts. A criterion for each group was the inclusion in each of an NCCP-designated cancer centre and the report stated that the recommendations contained in the report "are not in conflict with existing NCCP arrangements and do not propose to dismantle any of the existing NCCP centres or radiation oncology services".

The structure of the hospital groups has a varying impact on the existing structure of medical oncology and haemato-oncology services.

- In the Dublin Northeast Group, there are existing linkages (on the basis of shared consultant posts and linked services) between Beaumont/Connolly and Beaumont/Drogheda, which fall within the hospital group

structure. However, there is an existing link between the Mater and Cavan hospitals, with the Mater Hospital acting as the hub for services in Cavan, an arrangement which is now outside of the new hospital group structure.

- In the Dublin Midlands Group, there are existing links between Tallaght and Naas hospitals, which are unaffected by the hospital group structure. There are shared consultant medical oncology posts between Tallaght and St. Vincent's hospitals but the services provided are separate so this is not a major cause for concern in relation to continuity of patient care. Medical oncology and haematology services at St. James's Hospital and Tullamore Hospital are largely unaffected, except in relation to the traditional referring patterns to these hospitals. Within the Midland Hospitals, clinics are provided by the Tullamore-based haematologists to Mullingar and Portlaoise, both of which are now in a different hospital group. There are also concerns regarding the impact of the hospital group structure on existing diagnostic service provision for currently linked hospitals.
- Existing shared posts and services in Dublin East will be largely unaffected, with the exception of the Mater/Cavan link mentioned above. The other significant change in this area is the new association of Kilkenny and Wexford with the cancer centres in the Dublin East Group (i.e. St. Vincent's & Mater Hospitals).
- In the South/South West Group, the change to existing links between the hospitals in the Southeast (Waterford / Kilkenny / Wexford) is a significant one and excellent links between these services have been built up over several years. These associations also reflect the traditional routes of patients for treatment. The Higgins Report states that: "Waterford Regional Hospital will continue to be an NCCP centre, retaining its current population referral base for cancer patients. Joint

consultant appointments, such as general surgery shared with Wexford, across the groups will continue to support the specialist cancer services it provides.”

- The links in place between hospitals in the West/North West hospitals do not pose any significant issues in relation to the new hospital group structure.
- The cancer services provided in the Midwest region will be unaffected by the new hospital group structure.
- The Higgins Report did not address services at St. Luke’s Hospital Rathgar.

### **Establishment of national NCCP programmes for medical oncology and haemato-oncology**

The NCCP formally established national programmes for medical oncology and haemato-oncology programmes in late 2012. A consultant medical oncologist was appointed national lead for the programme while clinical advice on haemato-oncology is provided by the Chair of the Irish Haematology Society. The programmes are supported by a Chief Pharmacist and a Programme Manager.

Approximately 33,000 people receive treatment with cancer drugs each year, both oral drugs delivered in the community and delivered by injection in hospital settings. NCRI predicts that the number of new patients receiving chemotherapy will increase by 42%-48% in the period 2010 to 2025. The total number of patients per year being treated is expected to grow even faster as new drugs and longer duration of treatment drives demand for services.

The medical oncology and haemato-oncology programmes aim to ensure that the needs of the anticipated increased incidence in cancer diagnosis, prevalence of cancer and requirements for treatment continue to be met. These programmes provide a framework for national

oversight and audit of drug use, adherence to protocols and drug spend. The programmes incorporate a number of evolving, inter-related work streams. Current areas of focus are listed below and are discussed in more detail in the sections that follow:

- Development of chemotherapy protocols
- Enhancement of patient safety and quality
- Technology Review Committee
- Oncology Drugs Management System (for new cancer drugs)
- Funding programme for growth in cancer drugs
- The development of a business case for a national Medical Oncology Clinical Information System
- Diagnostic molecular testing
- The development of key performance indicators for medical oncology and haemato-oncology services
- Clinical Trials
- Workforce planning for medical oncology and haemato-oncology
- Increased availability of information about the work of the programmes, principally through the development of the NCCP website

## Chemotherapy protocols

Adherence to protocols is a key patient safety and quality measure in the use of chemotherapy for the treatment of cancer. NCCP has commenced a major programme of drug protocol development, which will eventually cover over 300 cancer drug protocols. Since 2012, protocols for 23 different indications have been completed and made available on the NCCP website, at [www.hse.ie/nccpchemoprotocols](http://www.hse.ie/nccpchemoprotocols). The process of protocol development involves the review of international evidence and consultation with medical oncologists and haematologists in Ireland. The Irish Society for Medical Oncologists (ISMO) and the Irish Haematology Society (IHS) are responsible for contributing to and signing off the content of the protocols for relevant drugs.

## Patient Safety and Quality

In January 2014, NCCP published its Oncology Medication Safety Review Report<sup>8</sup>. The report presented the findings of the review which was conducted across the 26 hospitals in Ireland involved in the administration of systemic cancer therapy in adults and children. The aim of the review was to assess the oncology medication policies and practices in day units nationally, from a patient safety perspective. The report made a total of 93 recommendations, all of which were cross-referenced with the HIQA Safer Better Healthcare Standards<sup>9</sup>.

The NCCP is now focussed on the implementation of the report's recommendations. A national implementation steering group is in place and an action plan has been produced to guide implementation at national and local level. All hospitals are required to report regularly to NCCP on implementation of the recommendations. Work has commenced on the development of national policies and procedures to address areas raised by the report.

The Oncology Medication Safety Review revealed that approximately half of the 26 hospitals involved in providing chemotherapy services had a written patient consent process in place. In 2013, NCCP developed a national consent process and template consent form for systemic therapy. All hospitals are required to include the minimum parameters set out in the NCCP template into their local consent processes.

## Technology Review Committee

In 2011 the NCCP established a Technology Review Committee which is responsible for reviewing proposals received from industry or expert groups in Ireland for funding of new drugs, or expanded indications for existing drugs or related predictive laboratory tests. The Committee incorporates the consideration of clinical benefit, pharmacoeconomic evaluation from the National Centre for Pharmacoeconomics, value for money and National Clinical Practice Guidelines in its review processes.

The committee comprises nominees from the Irish Society of Medical Oncologists (ISMO), the Irish Haematology Society (IHS), HIQA, the National Centre for Pharmacoeconomics (NCPE), a pathologist, a public health specialist and pharmacy expertise. The committee reports to the Director of the National Cancer Control Programme and makes recommendations on the priority for consideration or implementation of a new treatment or test. The recommendations are based on the degree of clinical effectiveness, the acute and chronic toxicity and the cost effectiveness of the proposed technology.

A positive recommendation from the Technology Review Committee is brought to the HSE Drugs Committee. HSE/Department of Health management makes the final decision for funding on all new drugs and technologies.

8 [www.hse.ie/nccpconsafetyreview](http://www.hse.ie/nccpconsafetyreview)

9 HIQA. National Standards for Safer Better Healthcare. 2012.

Since 2012, 11 new cancer drugs and one diagnostic test (OncotypeDX) have been recommended for approval for funding in Ireland through this process. These drugs are Abiraterone (Zygiga®), Axitinib (Inlyta®), Bosutinib (Bosulif®), Cabazitaxel (Jevtana®), Decitabine (Dacogen®), Eribulin (Halaven®), Ipilimumab (Yervoy®), Mifamurtide (Mepact®), Ruxolitinib (Jakavi®) Pertuzumab (Perjeta®) and Vemurafenib (Zelboraf®). Updates on the list of drugs approved are available at [www.hse.ie/nccpdrugprogramme](http://www.hse.ie/nccpdrugprogramme).

NCCP is fully engaged with the National Centre for Pharmacoeconomics (NCPe) and the HSE Corporate Pharmaceutical Unit (CPU) on rapid reviews, health technology assessments (HTAs) and company price negotiations. NCCP is also engaged in the horizon scanning process with drug companies in relation to expected new cancer drugs.

### **Oncology Drugs Management System**

The demand for the introduction of new cancer drugs is growing internationally and Ireland is no different. These drugs are expensive and their introduction presents a particular challenge during difficult budgetary circumstances. Several new cancer drugs have been introduced in Ireland and their effectiveness will be reviewed as sufficient data becomes available.

The HSE has put a robust assessment process in place for new medicines, including cancer medicines, through the HSE Drugs Committee. The intention of this process is to ensure that the HSE can provide access to as many new and existing medicines as possible, at sustainable prices and from within the resources available.

As each new drug is approved by the HSE Drugs Committee, a protocol is developed and made available to ensure standardisation in the use of the drug.

In order to provide a mechanism for reimbursement of costs associated with newly approved cancer drugs, the NCCP collaborated with the Primary Care Reimbursement Service (PCRS) to develop the Oncology Drug Management System (ODMS). This system consists of a web portal which is accessible by approved users in the hospitals involved in providing chemotherapy services. To date (July 2014), this system relates to reimbursement for six newly approved high-cost cancer drugs delivered by injection in hospital settings, namely, Cabazitaxel (Jevtana®), Decitabine (Dacogen®), Eribulin (Halaven®), Ipilimumab (Yervoy®), Mifamurtide (Mepact®) and Pertuzumab (Perjeta®).

Hospitals are required to input data into the Oncology Drug Management System to claim reimbursement from the NCCP for approved drugs. Use of the drugs must be in line with the nationally agreed protocol for the drug. The process of reimbursement for new cancer drugs facilitates the implementation of the Government's policy on money following the patient.

The information provided on the use of new drugs will allow the NCCP to audit the use of these drugs in line with protocols and to assess their effectiveness over time and it will allow for research into patient outcomes and cost benefits realisation.

The NCCP maintains an oversight role, primarily to monitor the rate of growth and spending on listed drugs in addition to monitoring compliance with the approved indications. The collection of data through this system also provides for audits to be carried out to ensure quality and adherence to protocols.

The NCCP is currently working on an IT solution which will allow for the direct extract of data from hospital systems, without the need for manual entry. This work is ongoing.

## Funding for growth in cancer drugs

Many patients receive cancer drugs with curative intent. In situations where a patient's cancer is not considered curable, it is treated as a chronic disease, with patients often remaining on ongoing treatment with cancer drugs. Advances in new technologies are producing targeted therapies for specific cancers and the number of drugs being approved for use is growing steadily.

As the demand for cancer drug treatment grows, increasing pressure is being placed on hospitals to meet this demand. Hospital based cancer drugs account for approximately 50% of overall cancer drug expenditure. The cost of hospital cancer drugs has been rising significantly in recent years. This is expected to continue to increase along with complexity of chemotherapy provision due to the following factors:

- Predicted increase in cancer incidence due to population growth and ageing
- Steady improvements in treatment outcome
- Acceleration in the rate of introduction of new drugs
- More patients being treated closer to home

## National Medical Oncology Clinical Information System

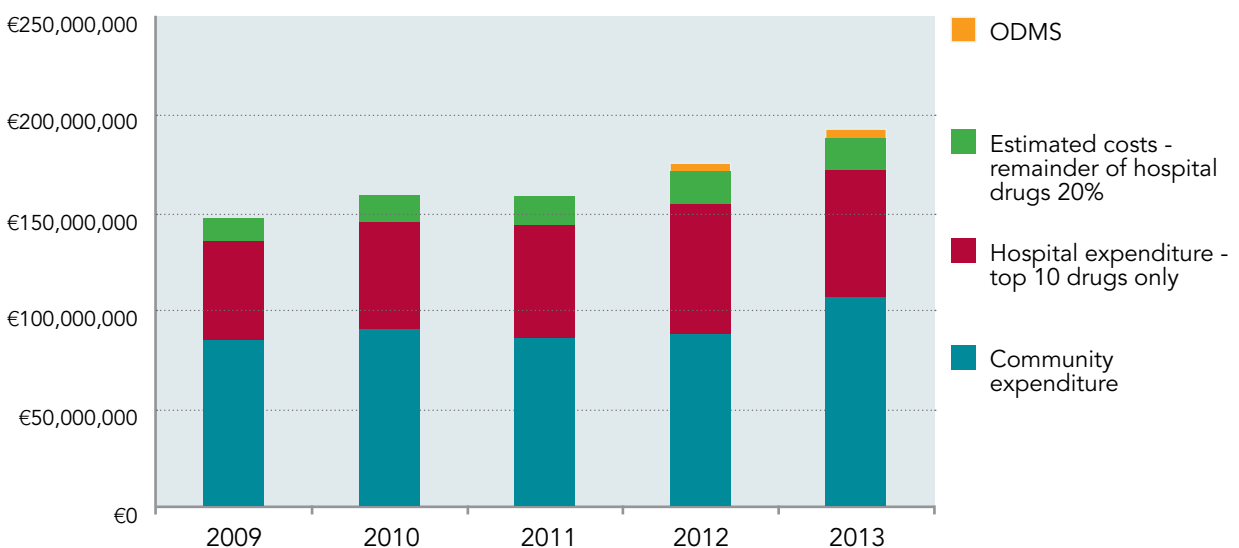
The 2006 National Cancer Strategy recommended the development of information systems and information technology to support the management and delivery of cancer services.

In late 2013, NCCP established a steering group to develop a business case for a national medical oncology clinical information system. The objective of the steering group is to develop a framework for the procurement and implementation of a Medical Oncology Clinical Information System (MOCIS) for the optimal and safe delivery of systemic cancer treatment, including e-prescribing and e-administration of chemotherapy, for the treatment of cancer, in publicly funded hospitals.

## Diagnostic molecular Testing

Increasingly, medicines are being developed which are targeted towards specific patient groups and their cancer type. Suitability for these medicines necessitates a range of molecular testing to identify those patients likely to respond. Numerous molecular biology findings have potential therapeutic impact and are potential contributors to changes in clinical practice. Some mutations

**Figure 8.1: Cost of Medicines Used in the Treatment of Cancer in Ireland 2009 - 2013**



have been shown to predict dramatic responses to certain treatments. In contrast other mutations confer a negative effect.

Prior to 2012, many of the newer molecular tests (e.g. KRAS, EGFR) were undertaken in the UK funded by the pharmaceutical industry. The pharma companies subsequently provided start up funding to three Irish laboratories to enable them to undertake testing locally. The support funding was withdrawn once testing became established and the funding requirements have since been transferred to the HSE/NCCP.

The Faculty of Pathology, at the request of the NCCP, developed guidelines for predictive cancer molecular diagnostic services in Ireland in 2011. The guidelines refer to laboratory accreditation, participation in molecular QA programmes, key performance indicators for test quality and reporting, minimum volume requirements and cost effectiveness/value for money.

The priority for the NCCP is to deliver a quality assured service of high volume and technical expertise which provides value for money and meets demands. There are considerable economic and quality indications to support centralisation of testing in one (or no more than two centres). Given the potential cost implication to the NCCP, it is critical that there is minimal to no redundancy of expertise or infrastructure across multiple laboratories. The NCCP is now funding two laboratories (RCSI/Beaumont Hospital and St. James's Hospital) to undertake public RAS, EGFR, BRAF and ALK cancer molecular testing nationally. University College Hospital Galway has also recently commenced a molecular testing service which is funded locally.

The NCCP is currently in consultation with the Faculty of Pathology to develop a sustainable plan for molecular testing. The Faculty has established a committee which will provide guidance and advice to the HSE in relation to molecular testing; this work is expected to be completed in the autumn of 2014.

## Cytogenetics testing

A national cytogenetics service is available in Ireland provided by the National Centre for Medical Genetics. As a result of funding and resource limitations many samples are sent to the UK for testing, often using the hospital's internal funding. Discussions are ongoing with the Irish Haematology Society to determine how best to identify and progress requirements for cytogenetics testing. Further information on cytogenetics activity, challenges and updates is available at <http://www.genetics.ie/documents/5-year-NCMG-report-2007-2011.pdf>.

## Key performance indicators

A suite of KPIs in medical oncology and haemato-oncology were developed by clinicians to monitor access to, and quality of, services and to address areas such as waiting time for consultation and treatment, attendance at MDMs and triple signature of prescriptions.

The first national KPI was introduced in 2012 across the 25 adult acute hospitals providing cancer treatment and addressed a key service access area relating to the waiting time for receipt of treatment:

"For patients receiving their first cycle of intravenous systemic therapy in the day ward setting, the timeline between the date of receipt of the finalised treatment plan in the day ward and the administration of the first cycle of intravenous systemic therapy will not exceed 15 working days."

All but one hospital have been reporting on this KPI regularly and work is continuing to ensure 100% compliance. Data for 2013<sup>10</sup> show that many hospitals are reaching the target of receipt of treatment within 15 days of finalisation of the treatment plan. Of the designated cancer centres, in five of the six centres that reported, 89%-100% of patients received treatment within the target time. Of 15 out of 17 satellite centres that reported, between 91% and 100% of patients received treatment within the target timeframe.

10 NCCP Cancer Intelligence, December 2013.

**Table 8.1: KPI for Time to Treatment - 2013 Data**

Year to date	Average number of patients receiving first dose of new systemic therapy regimen in the day ward setting every month*	% commenced treatment within target timeframe
Beaumont Hospital	No data received	
Mater Hospital	26.1	90%
St. Vincent's Hospital	No data received	
St. James's Hospital	53.2	100%
Cork University Hospital	32.1	68%
Limerick University Hospital	27.8	89%
Waterford Regional Hospital	18.4	94%
Galway University Hospital	34.5	87%
Connolly Hospital	No data received	
St. Luke's Rathgar	19.4	100%
Tallaght Hospital	24.4	100%
OLLH Drogheda	20.0	91%
Cavan General Hospital	7.0	98%
Naas Hospital	3.6	98%
Tullamore Hospital	19.2	97%
St. Luke's Kilkenny	9.0	92%
South Tipperary Hospital	7.2	94%
Wexford General Hospital	4.7	80%
Mercy Hospital	14.3	64%
South Infirmar Victoria Hospital	18.4	100%
Kerry General Hospital	20.2	100%
Sligo General Hospital	18.6	100%
Mayo General Hospital	19.3	93%
Portiuncula Hospital	7.7	86%
Letterkenny General Hospital	16.3	Insufficient data

Source: NCCP Cancer Intelligence, May 2014.

\*Note: These data relate only to patients receiving their first dose of a new treatment regimen in the day ward. NCCP does not collect key performance data on all chemotherapy administrations.



A pilot project is currently underway in relation to the implementation of the remaining KPIs in the agreed suite. Work is underway to develop a solution which would minimise additional manual collection of data. Implementation of this approach will be contingent on the outcome of the pilot and IT developments.

## Information & Communications

As the medical oncology and haemato-oncology programmes have developed, every effort has been made to make information available to all relevant stakeholders in a timely and accessible fashion. Our approach includes:

- Regular updates, through the National Director, to HSE management and leadership.
- Regular updates to hospital CEOs / management on drugs, programmes and initiatives.
- Regularly updated sections on the NCCP website for patients/public and health professionals.
- Appointment of hospital liaison people for specific projects, to ensure direct links with NCCP.
- A national annual multidisciplinary medical oncology and haemato-oncology meeting to discuss areas of strategic development.
- Informal links with clinicians, oncology nurses and pharmacists on the range of activities within the medical oncology and haemato-oncology programmes.

## Clinical Trials

Cancer clinical trials are essential for continued progress towards even more effective treatments and care for patients with cancer. Trials often involve local collaboration (with other academic groups or hospitals) or national/international collaboration (with research organisations or biotech/pharmaceutical industry). In 2013, more than 1,600 patients were on cancer clinical trials in Ireland<sup>11</sup>. Clinical trial studies are run by a team of consultants (medical oncology, haematology, radiation oncology, surgery, paediatric oncology etc.), supported by clinical research nurses and pharmacists and others where feasible (e.g. clinical research radiographers, data managers, clinical pharmacology, clinical trials radiology service and administrative staff).

NCCP strongly supports the provision of clinical trials in Irish public hospitals. Clinical trial activity is not affected by NCCP funding streams. The lack of data management staff has been raised by hospitals as a significant barrier to progressing clinical trials.

## Workforce planning

Cancer services are provided by a range of health professionals who work within a climate of increasing patient numbers and treatment complexities and decreasing resources. The health professionals who provide cancer services are highly trained and qualified and this level of training has a lead-in time of several years. The lack of a multidisciplinary workforce planning model and the inability of the current funding system to allow for meaningful multi-year workforce planning make the process of planning the workforce requirements extremely challenging.

11 ICORG: All-Ireland Cooperative Oncology Research Group. [www.icorg.ie](http://www.icorg.ie). Accessed March 11th 2014.

## Consultant Posts

Since 2007, when the National Cancer Control Programme was established, nine additional consultant medical oncologist posts have been approved, in addition to five replacement posts. The NCCP provides advice on the structure of these posts and in several cases, the posts include a designated contractual commitment to NCCP.

In the same period, twelve additional consultant haematology posts have been approved (although not all of these have a significant cancer component), in addition to 10 replacement posts. In the case of any posts which have a considerable cancer commitment, NCCP provides advice on the structuring of the posts.

While the number of consultant posts has increased, Ireland compares poorly against international norms for consultant staffing in medical oncology and haematology.<sup>12</sup> Based on international staffing levels, it is suggested that 60-80 consultant medical oncologists and approximately 75 consultant haematologists would be required<sup>13</sup>. There are currently 34 medical oncology and 58 consultant haematology posts in publicly funded hospitals in Ireland.

There remain several areas of particular concern in terms of consultant staffing. In medical oncology, there is one single-handed service, which is not recommended in terms of patient safety or workload for the consultant involved. In haematology, there are a number of single-handed consultant services. Additionally, there are a number of larger services which are under considerable pressure owing to significantly increased workload. In some cases, this situation is heightened where delays have been experienced in replacing consultants who have retired or resigned from post.

On a number of occasions the NCCP has repeatedly sought funding and approval for the appointment of additional consultant oncology posts in its annual Service Plan submissions. Current pressures are in the Midlands, St. James's / Tallaght, Cork, Galway and the Southeast. To date, these requests have not been funded.

A higher specialist training programme in medical oncology commenced around the time that the 2006 National Cancer Strategy was published, producing a pipeline for specialists in medical oncology to contribute to the growing role of the specialty in the treatment of cancer. However, some hospitals have reported difficulties in recruiting to permanent consultant posts, despite a significant number of specialists emerging each year from the State-funded higher specialist training programmes. Each year, 2-4 medical oncology specialists complete training, along with approximately 5 specialists in haematology.

At the request of the HSE's Medical Education & Training Unit, the NCCP made a submission in late 2013 in relation to expected training requirements in cancer-related specialties, including medical oncology and haemato-oncology. This submission highlighted the growing pressures on existing services and staffing levels and advocated for an increase in consultant posts in medical oncology and haematology.

Workforce requirements for nursing, pharmacy, allied health professionals, data management and clinical trials staff are handled directly by hospitals but NCCP provides advice on these areas, as appropriate.

12 (Unpublished) Internal NCCP working document on medical oncology manpower planning, Dr. Maccon Keane

13 (Unpublished) NCCP Submission to HSE Medical Education & Training Unit, November 2013.

## Oncology Nursing

There have been many positive developments in oncology nursing in Ireland over the past decade most notably the introduction of specialist roles, Clinical Nurse Specialist and Advanced Nurse Practitioners, as well as initiatives such as nurse led clinics and nurse prescribing all of which have enhanced patient care.

The NCCP and the HSE Office of the Director of Nursing and Midwifery Services (ONMSD) developed a partnership to identify and advise on priorities for cancer nursing nationally. This resulted in the establishment of the Strategic Nursing Reference Group in 2008 which developed a Strategy and Educational Framework for Nurses Caring for People with Cancer in Ireland. The 2006 National Cancer Strategy prioritised nineteen recommendations under the themes of *patient centred cancer care, leadership in cancer nursing, cancer education, knowledge skills and experience of the nurse delivering evidence based practice and cancer research*.

The education framework has been prioritised which will enable all nurses (generalist and specialist) to participate in cancer control. It will ensure the professional development of nurses in cancer control is consistent with the national framework for the profession and cancer care. The role of nurses and the competencies they require have been defined to meet the objectives of the 2006 National Cancer Strategy.

The 2006 National Cancer Strategy and Educational Framework will facilitate and guide the development of new roles, multidisciplinary working and will positively impact on the quality and safety of care delivered by nurses to patients and their carers in Ireland.

The introduction of defined nursing competencies and the introduction of the cancer module at undergraduate level will better prepare nurses to meet the needs of their patients. Further information is available in the Community oncology Section 6 of this report.

## Achievements

- Development of 23 indication specific cancer drug protocols since 2012, which are available on the NCCP website, at [www.hse.ie/nccpchemoprotocols](http://www.hse.ie/nccpchemoprotocols). Several more protocols are in development.
- Completion of the oncology drug medication safety review, development of an implementation action plan and commencement of implementation of the recommendations.
- Introduction of a national patient consent process for systemic therapy.
- Implementation of the oncology drugs management system for six drugs (to date) which were newly approved for funding. Reimbursement of costs for these drugs in conjunction with the PCRS.
- Implementation of the “Money Follows the Patient” model of funding utilising the Oncology Drug Management System.
- Introduction of national patient information for collection of data for the oncology drugs management programme.
- The completion of a baseline survey of current haemato-oncology services in Ireland.
- First annual multidisciplinary medical oncology & haemato-oncology meeting held in early 2014.
- The implementation of a national key performance indicator for medical oncology and haemato-oncology, relating to the time from approval of the patient’s treatment plan to receipt of treatment and a reported compliance of 90% to 100% for most hospitals. Additional KPIs are currently in pilot stage.
- Recognition by the Department of Social Protection of the cancer drugs management programme for the collection of the PPSN.
- Recognition of the NCCP as a health information resource by HIQA.

## Strengths

- Strong support amongst enthusiastic and committed stakeholders for the work of the programmes, particularly clinicians, oncology nurses and hospital management.
- Equitable provision of services and funding of new drugs and growth in drug costs.

## Challenges

- Demographics – the ageing population will increase the incidence of cancer. The number of newly diagnosed cancers is increasing by 4.5% annually and the National Cancer Registry estimate that new cases of cancer will increase by 84% for females and 104% for males by 2040. Most of these patients will require treatment with chemotherapy.
- Lack of IT and data management systems to support optimal delivery of care and planning of services.
- Uncertainty regarding availability of ongoing funding for cancer drugs and inability to plan services accordingly.
- Development and approval of a business case for the introduction of a national medical oncology clinical information system.
- The impact of the HSE recruitment moratorium on all staff involved in the provision of cancer services, including medical, nursing, pharmacy and data collection.
- Lack of multi-annual multidisciplinary workforce planning to address the burgeoning growth in cancer incidence.
- National coordinated and resourced approach to cytogenetics testing.
- The rapid evolution of personalised medicine and its impact on resources.

## Opportunities

- Implementation of a money follows the patient approach.
- Alignment of medical oncology and haemato-oncology programmes to a commissioning of services approach.
- Legislative developments – Health Identifiers Bill and Health Information Bill.
- Clinical review of funded cancer drugs and audit of cancer drug use and spending.
- Standardisation of haemato-oncology MDMs.

# Community Oncology Programme

## Introduction

The Community Oncology programme was set up in 2008 with the overall aim of supporting primary care professionals in the provision of cancer services with better integration of care. It set out to address the recommendations of the 2006 National Cancer Strategy. In this regard it has built solid relationships with both statutory and voluntary bodies and had many successes in relation to:

- Developing evidence based pathways of care for common cancers in collaboration with the Irish College of General Practitioners (ICGP) and specialist services
- Building capacity and enhancing knowledge of cancer among health professionals who work in community settings by developing specific training programmes for doctors, nurses and allied health professionals
- Embarking on innovative technological initiatives e.g. electronic cancer referral, e-learning and an App for patients
- Implementing cancer prevention initiatives especially in relation to smoking cessation
- Commencing a survivorship care programme to support patients, families and health professionals
- Providing evidence based information for the public and health professionals

In this chapter, we will present the key recommendations from the 2006 National Cancer Strategy and briefly outline the ways in which the Community Oncology programme has addressed these recommendations. Supplementary information on the community oncology programme is available in a separate report.

## Cancer Prevention

The 2006 National Cancer Strategy had 11 recommendations related to cancer prevention:

No. 2 The recommendations of the review of the National Health Promotion Strategy should be implemented across all sectors.

No. 3 Compliance with all provisions of the Public Health (Tobacco) Acts, 2002 and 2004 should be monitored.

No. 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.

No. 5 Nicotine replacement therapy should be made available free of charge to all medical card holders.

No. 6 The Report of the Strategic Task force on Alcohol, 2002 should be implemented in full.

No. 7 The recommendations of the Report of the National Task Force on Obesity, 2005 should be implemented in full. In particular there is a need for measures that raise awareness of the links between diet and cancer.

No. 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.

No. 9 The recommendations of The Report of the National Task Force on Obesity in relation to physical activity should be implemented in full.

No. 10 In conjunction with campaigns to promote safe sun practices and to reduce exposure to ultraviolet radiation, regulation of sun bed use, including restriction to use by adults only should be put in place.

No. 11 The public should be made aware that radon measurements can be undertaken by the Radiological Protection Institute of Ireland. Consideration should be given to providing financial support for testing in high-radon areas and for any necessary remedial work, on a means tested basis.

No. 12 The HSE should put in place arrangements to monitor inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes.

The NCCP Community Oncology Division collaborates with the HSE Directorates, in particular Health and Wellbeing (and its predecessor the HSE Population Health Division of the HSE), on a number of cancer prevention initiatives. While the focus involves a joint approach to lifestyle risk factors that are common to many chronic diseases, smoking cessation has been a priority. This has included work programmes with the Office of Tobacco Control and the HSE Tobacco Control Implementation Framework group on:

- Training of health personnel in Brief Interventions for smoking cessation

- E-learning in smoking cessation for GPs and Allied Health Professionals
- Development of smoking cessation advice for patients e.g. pre-surgery and after a diagnosis of cancer
- Research on the impact of brief interventions and counselling on quit rates
- Development of a national pharmacotherapy smoking cessation algorithm

The appointment of a part-time Health Promotion Officer has also facilitated NCCP involvement in health promotion initiatives including:

- Training of nursing personnel on lifestyle measures for cancer prevention, including the role of motivational interviewing techniques
- Collaboration with HSE led initiatives on obesity, physical activity, alcohol and nutrition
- Training supports for community pharmacists in relation to cancer prevention
- Submission of a Position Paper to the Department of Health on the evidence of the risks of sunbeds, which contributed to the introduction of legislation in 2014

Information on cancer prevention has been developed for patients and the public in leaflet, wallet card and electronic form. These have been widely distributed in a number of healthcare settings and during NCCP educational courses. They are available to download from the NCCP website and include:

- ABCs for being cancer aware
- Quit before your surgery and get better faster
- Smoking cessation after a cancer diagnosis
- Testicular cancer awareness

Additional lifestyle advice is provided on the NCCP website.

The NCCP has undertaken a number of joint initiatives with the wider health sector and academic bodies. The role of the Community Oncology programme includes advocating for disease prevention, developing prevention strategies and implementing cancer prevention initiatives. We have collaborated with the Irish College of General Practitioners (ICGP), Royal College of Physicians (RCPI), Royal College of Surgeons (RCSI), Irish Cancer Society (ICS) and other cancer charities. Specific outputs in relation to cancer prevention include the RCPI policy on alcohol, the RCPI policy on obesity, collaboration with the ICS on skin cancer prevention and the ICGP on smoking cessation e-learning.

Community oncology has acted as a resource in relation to expert advice on the aetiology of various cancers. This has included provision of advice on environmental risks (real or perceived), e.g. water fluoridation, responding to consultations (e.g. the National Radon Strategy) and contributing to the broader disease prevention efforts.

The national approach to disease prevention, particularly in relation to lifestyle risk factors, is the Healthy Ireland strategy.<sup>14</sup>

## Supporting GPs and Primary Care

The 2006 National Cancer Strategy recommended that:

- No. 24 The HSE should develop care pathways for cancer care to link primary care services, hospital services and other relevant services.
- No. 25 Improved cancer information services should be available to primary care.
- No. 26 The HSE should develop programmes that support primary care professionals in the provision of cancer services.
- No. 47 General practitioners should have comprehensive information that enables informed referral and other management decisions.
- No. 48 Information systems and information technology should be developed by the HSE to support the management and delivery of cancer services.

In 2009, the NCCP appointed a GP advisor to develop links between Community Oncology and the Irish College of General Practitioners (ICGP) and to identify new means of collaboration and support for GP colleagues. A large component of this work is collaboration on GP guidelines and referral pathways. The GP advisor also plays an essential role in the implementation of all NCCP guidance – linking with GP study days hosted by hospitals, attending GP Continuing Medication Education (CME) groups and conferences, while also feeding back concerns or suggestions from

14 Healthy Ireland. A Framework for Improved Health and Wellbeing 2013-2025 <http://www.hse.ie/eng/health/hl/hi/>



the GP community to the NCCP. Novel ways of providing education and information for GPs include e-learning, which has been used to develop modules on breast disease and breast cancer, prostate cancer and smoking cessation, in conjunction with the ICGP.

One of the key aims of the National Cancer Strategy is early referral of patients with clinical findings suggestive of cancer. The need for clear recommendations on the investigation and referral of patients presenting to their GP with possible signs of cancer has been well recognised.<sup>15</sup> The Community Oncology programme has to date developed GP referral guidelines for suspected breast (2009), lung (2010), prostate cancer (2011) melanoma (2011) and ovary (2014 - expected) cancers. These guidelines take account of existing published evidence-based referral guidelines and are applicable to the Irish healthcare setting and service configuration. A GP referral tool-kit is being developed to assist GPs in recognising urgent clinical features of less common cancers, e.g. head and neck.

While the primary focus is on when to urgently refer a patient, information is also included on actions that should appropriately be taken in primary care (e.g. referral for an urgent Chest X Ray) or indeed, practices that should be discouraged in primary care (e.g. aspiration of a breast lump, excision of a pigmented lesion). A standardised referral form was also developed in tandem with each guideline. The forms were designed to actively seek the information required for triage, plus other clinical information of relevance if patients were to undergo certain investigations on the day of clinic attendance, e.g. anticoagulant use. In addition, the dependencies of other HSE services are addressed before a guideline can be released. For example, an assessment of CA125 and ultrasound services has been carried out prior to the implementation of the ovarian cancer referral guideline.

The process of development of the guidelines and forms is outlined in detail in the supplementary information on the community oncology programme. The development and consultation process provided an opportunity to make links

with both primary and secondary care and opened communication as to the challenges faced in different parts of the service. Completed guidelines and forms have been circulated to each GP nationally and copies are available on the NCCP website, to which the ICGP, Healthlink and other websites can direct GPs. The agreed national referral forms for breast, lung, prostate and melanoma have also been developed into electronic formats, in collaboration with the General Practice Information Technology (GPIT group) and HSE ICT Directorate.

## Use of Information Technology

The 2006 National Cancer Strategy included recommendations that:

- No. 26 The HSE should develop programmes that support primary care professionals in the provision of cancer services.
- No. 47 General practitioners should have comprehensive information that enables informed referral and other management decisions.
- No. 48 Information systems and information technology should be developed by the HSE to support the management and delivery of cancer services.

A number of innovative community oncology projects have harnessed new capabilities in information technology, for the betterment of cancer services.

An excellent example of this is the development of an electronic referral system for GPs. This award-winning project (2012 Winners: Ireland eGovernment Awards <http://irishgovernmentawards.ie/>) has taken agreed national standardised referral forms for breast, lung, prostate cancer and melanoma and developed electronic versions in association with Healthlink, an electronic messaging system, and the four ICGP accredited software systems.

15 H Daly, C Collins Barriers to Early Diagnosis of Cancer in Primary Care: A Needs Assessment of GPs *Ir Med J.* 2007 Nov-Dec;100(10):624-6

The NCCP Electronic Cancer Referral Project commenced in 2008, with the objective of developing an online system for GPs to refer patients directly to the cancer centre. This ensures rapid referral of patients with suspected cancer in a secure manner. Once the GP sends an electronic cancer referral, an immediate acknowledgment is given. In addition the cancer teams send a response to the GP, with the date of the patient's appointment within five working days. It builds on existing technologies already deployed in GPs' surgeries and the wider Health Service, namely the Healthlink infrastructure ([www.healthlink.ie](http://www.healthlink.ie)) and accredited GP practice management systems. Details of the system development are included in the supplementary information on community oncology (TD 17).

Referrals are currently available as an online referral form (Healthlink Online) from the GP directly to the cancer teams, or an integrated referral form for ICGP accredited GP practice management systems. which also goes directly to the cancer teams. Work has commenced on the development of an integrated web services browser, which will facilitate the creation of additional electronic cancer referrals forms in a more seamless manner, via the National General Electronic Referral Project. The NCCP electronic referral model has been adopted to develop a platform for a National General Electronic Referral Form.

The number of electronic cancer referrals (Breast, Prostate and Lung Cancer) is increasing each year, with 2,070 referrals in 2010 (first year of go live), 4,360 electronic referrals in 2011. In 2013 there were 13,361 electronic referrals which was a 44% increase in referrals from 2012. Currently 35% of all breast, prostate and lung cancer referrals are sent electronically nationwide. Melanoma electronic referral commenced as a pilot exercise in 2014 and will be available nationally by the end of the year.

**Demonstration of effectiveness and success:**

The number of electronic cancer referrals (Breast, Prostate and Lung Cancer) has increased by 795% for the five years 2010 to 2014. Table 9.1 provides further details.

**Table 9.1: Electronic Cancer Referrals (Breast, Prostate and Lung – with the inclusion of Pigmented Lesion for 2014)**

Year	Number of Electronic Referrals
2010	2,070
2011	4,360
2012	9,303
2013	13,381
2014*	16,453

*Data Source: National Healthlink Project, NCCP*

The NCCP Electronic Cancer Referral Project is a good example of how different agencies can work together to pool their resources to achieve innovation and better quality healthcare.

Another innovative use of technology has been the development of a smartphone App, with information for patients on breast pain and an interactive patient diary. While breast pain is not a symptom concerning for breast cancer, it was recognised as a major cause for referral to symptomatic breast clinics (14.5% of all GP referrals in a one month study in 2011) and a source of anxiety for patients. The information and completed diary are designed to support GPs in their reassurance of young women with benign bilateral cyclical breast pain. Additional means of harnessing technology have included the use of e-learning to improve the reach of existing educational programmes (e.g. with the ICGP) and of the website as an information resource for health care professionals, patients and the public.

## Nursing Developments

The 2006 National Cancer Strategy recommended that:

- No. 25 Improved cancer information services should be available to primary care.
- No. 26 The HSE should develop programmes that support primary care professionals in the provision of cancer services.
- No. 50 The HSE should develop a National Cancer Workforce Plan designed to fully implement national cancer policy.[The 2006 National Cancer Strategy noted the need for “a focus on the development of cancer nursing roles that reflects recent successful developments in oncology nursing and maximises the potential role that nurses can play in all aspects of cancer care”.]

‘A Strategy and Educational Framework for Nurses Caring for People with Cancer in Ireland’<sup>16</sup> was launched in May 2012 and is for all nurses caring for people with cancer in Ireland. It was developed in conjunction with the Office of the Nursing and Midwifery Services Director (ONMSD) and following comprehensive consultation with nurses in Ireland. It aims to guide and support nurses in the provision of quality cancer care to people with cancer in Ireland, specifically by:

- Enabling all nurses to participate in cancer control whether specialist or generalist and irrespective of where they work
- Ensuring the professional development of nurses in cancer control is consistent with the national framework for the profession and cancer care
- Defining the role of nurses and the competencies they require to meet the objectives of the 2006 National Cancer Strategy

- Proposing a formal structure whereby nurses who care for people with cancer are represented at policy making level and have leadership roles that ensure the maximum contribution of nursing to evidence based cancer care

Its recommendations cover themes of patient centred cancer care, leadership in cancer nursing, cancer education, skills, knowledge and experience of the nurse and delivering evidence based practice and cancer nursing research. The 2006 National Cancer Strategy implementation group has overseen the following developments to date:

- A formal partnership has been established between the NCCP and the Office of the Nursing and Midwifery Services Director (ONMSD)
- Three nurse education programmes have been developed to address the needs of various nursing groups (further detail below)
- There has been collaboration with services and academic institutions such as NUIG and NMBI (Nursing and Midwifery Board of Ireland) in relation to programme developments
- Approval of a Health Research Board (HRB) Nursing Development Research grant

Future plans include national roll out of the three education programmes; development of a nursing leadership programme to meet the needs of nurses working in cancer care; to continue to promote cancer nursing research initiatives and to better integrate nursing care between specialist hospital oncology services and primary care services.

16 NCCP (2012) A strategy and educational framework for nurses caring for people with Cancer in Ireland <http://hdl.handle.net/10147/233454>

## **NCCP Cancer Nursing Education Programmes**

The nursing programmes developed to date to meet the educational needs of nurses caring for people with cancer in Ireland, in line with the 2012 strategy are:

- Cancer Education Programme for Registered Nurses Working in Primary Care (a two day programme)
- Education Programme for nurses working in an inpatient setting (a three day programme)
- Community Oncology Nursing Programme (a comprehensive six-month skills based programme which has university accreditation)

### **1. Cancer Education Programme for Registered Nurses Working in Primary Care**

The need for this programme was identified following research with nurses who work in the primary health care setting, showing they would benefit from participating in a short cancer programme that incorporated prevention, identification of symptoms suggestive of cancer, referral pathways, treatment and post acute care. Its implementation is supported by the Nursing Midwifery Planning Development Units (NMPDU) and the Centres of Nurse Midwifery Education (CNME). An Bord Altranais (now Nursing and Midwifery Board of Ireland, NMBI) approved the course as a Category 1 programme.

The programme covers four themes:

- Prevention – including motivational interviewing and cancer screening programmes
- Presentation of the patient in primary care, guidelines for referral
- Treatment of common cancers – breast, lung, prostate and skin
- Post acute care, survivorship and psycho-oncology

The programme has been delivered in specialist cancer centres to almost 700 primary care nurses since 2011, using video links to maximise participation. The evaluation of the programme has been very positive and has also informed a revision of the curriculum. An E-learning version of this programme is now under development to facilitate nurses who cannot attend in person.

### **2. Education Programme for Registered Nurses Working in an Inpatient Setting**

Every nurse at some stage of their career cares for patients diagnosed with cancer. This Continuing Professional Development (CPD) programme is to facilitate nurses who work in acute hospitals, care of the elderly units, nursing homes and community based hospitals / hospices to enhance their knowledge, skills and competence in cancer care.

The curriculum has been finalised for this three-day programme and it is due to commence during 2014. It is proposed to develop it to a Higher Education and Training Awards Council (HETAC) level 8 and to have it accredited as a category 2 programme by NMBI.

### **3. Community Oncology Nursing Programme**

Traditionally cancer patients who are receiving systemic chemotherapy receive all their care in an acute cancer unit. This often results in patients having to travel long distances to hospital for short procedures e.g. disconnection and flushing of venous lines. This Community Oncology Nursing Programme was developed to facilitate community nurses to provide shared nursing care to acute oncology patients at home.

These public health nurses undertake a nursing education programme which equips them with the required knowledge and skills to safely and competently provide care at home, to patients undergoing systemic cancer therapy. Theoretical and skills based training is delivered over six months. The programme commenced in 2010 in response to a clinical and patient need. It has been evaluated and deemed very successful, resulting in substantial hospital avoidance by patients who

could receive their care at home. A critical success factor was the national and local leadership. The project was awarded the UK Quality in Care Excellence in Oncology award 2012. The Programme has received university accreditation and will be delivered in multiple locations around the country.

## Survivorship

The 2006 National Cancer Strategy described cancer control as “a whole population approach to cancer care with a strong emphasis on integration and holistic care including survivorship, support services and palliative care” and specifically recommended:

- No. 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.
- No. 38 A partnership framework should be developed between the HSE and the voluntary sector.
- No. 39 A code of practice should be developed for self-help groups, support groups and support centres.

The term “cancer survivor” was used in the 2006 National Cancer Strategy and the predicted growth in cancer survivors was noted, particularly in relation to women who have had breast cancer. Many of the themes and recommendations of the 2006 National Cancer Strategy are relevant to cancer survivors – e.g. the need for integrated care and smooth patient pathways, information needs across the spectrum of health care professionals as well as for the patient themselves and the need for psychological support. Progress has been made in terms of long-term follow up of women with breast cancer with a policy which addresses information needs on keeping well and arrangements for ongoing mammography surveillance by hospitals.

The focus on psycho-oncology needs led to research on current availability of services and a report on proposed models of care. Following on from the publication of the 2006 National Cancer Strategy, the Irish Cancer Society established an affiliation project and developed a code of practice for cancer support services, to which the NCCP contributed.<sup>17</sup>

The complexity of survivors’ needs have been better described in recent years, with more evidence on long-term side effects and medical, psychological and social needs. The NCCP has therefore recently adopted a strategic approach to cancer survivorship and commenced the development of a patient survivorship programme. Its aim is to improve the quality of survivorship care in Ireland for cancer patients and their families.

The main goal for the NCCP Survivorship Programme is to empower patients to achieve their best possible health while living with and beyond a diagnosis of cancer. This involves providing information, guidance and support to survivors and families in relation to healthy lifestyle, disease prevention and control in order to aim for a good quality of life and prolonged survival.

One of the key priorities of a Survivorship Programme is for people with a history of cancer to become partners with the health service in their post-acute care and to be empowered in this regard.

The development of a Patient Treatment Summary and Care Plan is internationally recommended and a logical first step towards a sustainable Survivorship Programme.

The NCCP, in collaboration with specialist services, GPs and patients has developed a Patient Treatment Summary and Care Plan. This provides information on the patient’s medical history, treatment, specialist providers and ongoing disease specific surveillance requirements. In addition it highlights the importance of them taking charge of their preventive health care, how to recognise potential disease recurrence or long term complications of disease/treatment. It provides links to useful websites e.g. in psycho-oncology.

17 The Irish Cancer Society’s code of practice for cancer support services: [http://www.cancer.ie/sites/default/files/content-attachments/ics\\_support\\_groups\\_guidelines\\_2011.pdf](http://www.cancer.ie/sites/default/files/content-attachments/ics_support_groups_guidelines_2011.pdf)

This Patient Treatment Summary and Care Plan is currently being piloted in one specialist cancer centre, prior to national roll-out.

## Meeting the Information Needs of Professionals and the Public

The 2006 National Cancer Strategy recommended that:

- Improved cancer information services should be available to primary care.
- The HSE should develop programmes that support primary care professionals in the provision of cancer services.
- HIQA should ensure that the public has access to high-quality up-to-date information about all aspects of cancer.
- General practitioners should have comprehensive information that enables informed referral and other management decisions.

The Community Oncology Programme has developed a suite of information materials for health care professionals in the community and primary care and to support patients and the public. A complete list of materials produced to date is provided in the supplementary information on community oncology (TD17). The process of GP referral guidelines has already been outlined, including the emphasis placed on appraising current evidence, consultation with all stakeholders and supporting implementation. Similarly, the community oncology resource booklet has been invaluable for those public health nurses supporting patients in the community, has won a number of awards and been adopted for use in other countries.

A similar in-depth process has been applied in the development of material for patients or the public. At the time of the writing of the 2006 National Cancer Strategy, it was envisaged that this role would be fulfilled by HIQA. Nonetheless, the recommendations of the 2006 National Cancer Strategy have been followed in terms of consultation with voluntary groups and attention to detail in ensuring information is “accessible and

understood by those of different standards and cultures”. Members of the team have received training by the National Adult Literacy Agency (NALA) and materials intended for the public are approved by NALA prior to publication. There is wide multidisciplinary team input to materials that are intended for patients attending a service and inclusion of practical information tailored to individual hospitals. Voluntary groups are consulted in regards to the appropriateness and acceptability of material. The patient booklet prepared for those attending a rapid access lung clinic appointment (Lung Cancer Rapid Access Clinic- what you should know) was awarded the Crystal Clear Award in 2012, for excellence in plain English communication.

Information materials have also been prepared to support cancer prevention and early detection of symptoms among the general public. A working group was established in 2013 following the expressed need by various health professionals for resources for use with the general public and patients to increase awareness of testicular cancer, the early warning signs of cancer in general and to convey the benefits of quitting smoking prior to cancer treatment and surgery.

- Screening Promotion Officers in the NCCP identified an opportunity to promote awareness of the early warning signs of cancer with various groups including minority ethnic groups.
- Health Promotion Officers in the HSE expressed a need for resources to use with smokers undergoing cancer treatment and also undergoing surgery.
- Pharmacists identified an opportunity to target young men regarding awareness of testicular cancer via their female partners attending for contraception.

Materials for the public are made available in hard copy in GP surgeries or pharmacies as appropriate and are also accessible on the NCCP website, [www.cancercontrol.hse.ie](http://www.cancercontrol.hse.ie).



## Research & Audit

The 2006 National Cancer Strategy noted that “cancer research is an essential component in the development, implementation and evaluation of a national cancer control programme”.

The need for high quality research in all aspects of cancer care is a stated aim of the 2006 National Cancer Strategy. The National Cancer Forum identified research as an essential component in the development, implementation and evaluation of a National Cancer Control Programme. The scope of cancer research includes subjects in which Community Oncology can make a contribution. This includes areas of epidemiology, prevention, audit and health services research. The Community Oncology programme recognises the importance of research and establishing an evidence base for new developments and initiatives. The division has health professionals from diverse backgrounds including the disciplines of public health medicine, general practice, psychology, nursing, health promotion, laboratory science and health management. This diversity of disciplines creates fertile ground for health service research and brings a number of perspectives to the work we undertake.

Collaboration is an integral part of the work of the Community Oncology Division. The division actively seeks to be part of networks in the wider health service and academic institutions and has participated as collaborators as a health service partner in large scale and small scale research projects that are relevant to cancer control and services. The National Cancer Control Programme is fortunate to be able to take a national view of cancer services, policy and prevention. This facilitates the implementation and scaling up of any research results that would be beneficial to cancer services in Ireland. In developing the evidence base, either as a principal investigator or as a health service partner, the NCCP can ensure that best practice agenda is implemented and promoted for cancer services in Ireland.

The NCCP community oncology division also collaborates and leads on a number of the work-

streams of the current Ireland-Northern Ireland-National Cancer Institute Consortium, in cancer prevention, nursing and survivorship.

A comprehensive list of the research and audit activities undertaken by community oncology is provided in the supplementary information section (TD17).

## Challenges and Opportunities

The next ten years will see the Community Oncology Division strengthen and develop. In particular attention will be given to ensuring the infra-structure and integrated working relationships remain sustainable and focused on meeting patient needs.

The forthcoming challenges include:

- The need for great focus on primary prevention, particularly in collaboration with the Healthy Ireland Strategy, the HSE Health and Wellness Directorate and the Chronic Disease Programmes, and acknowledging the population cancer risk due to the national obesity epidemic.
- To make real progress in preventing the highly preventable cancers – e.g. through HPV and hepatitis B vaccination, and to prevent head and neck cancers by reducing smoking and alcohol incidence.
- Empowering the public to take a role in their own health and wellbeing, including the recognition of early symptoms of cancer.
- Ensuring equitable access for all, in particular to diagnostic services, while recognising the dependencies of NCCP on many other HSE services in this regard.
- Sustaining the existing good will and spirit of collaboration, when services feel overwhelmed due to the ageing population and increasing demand.
- Prioritising the development and implementation of survivorship initiatives, as the cancer survivor population expands.



# Hereditary Cancer Programme

The 2006 National Cancer Strategy recommended that “A National Cancer Genetics Policy should be developed by the National Cancer Forum”.

The 2006 National Cancer Strategy also recommended that “The HSE should develop specific programmes that promote early detection of cancer”.

## Background to Hereditary Cancer Services In Ireland

The rapid advances underway in cancer genetics were noted in the 2006 National Cancer Strategy, with an acknowledgement that “the increasing worldwide understanding of the role of genetics in the provision of cancer care is leading to an increased demand for the development of services in the area and presents major medical, organisational and financial challenges that need to be addressed”.

Identification of families with hereditary forms of common cancers allows better clinical management of the affected individuals, and pre-symptomatic testing of at-risk relatives. Relatives found to be at low risk can be reassured and do not require ongoing screening, while those found to be at high risk can be targeted for increased surveillance and prophylactic interventions.

The majority of hereditary cancer cases in Ireland are managed directly by the National Centre for

Medical Genetics (NCMG), which is based in Our Lady’s Children’s Hospital, Crumlin (OLCHC). The NCMG aims to provide a comprehensive service for all patients and families in the Republic of Ireland affected by or at risk of a genetic disorder. This is a comprehensive service including the provision of Clinical Genetics, Cytogenetics and Molecular Genetics services.

The focus of the clinical cancer work of the National Centre for Medical Genetics is the identification of families with hereditary cancer, with the aim of early cancer detection and better outcomes for family members at risk, and also the reassurance of those found not to be at excess genetic risk of cancer. Although the National Centre for Medical Genetics provides a national service for chromosome analysis of adult and child leukaemia, the Centre only carries out molecular testing for inherited disorders; it is not involved in the analysis of single gene changes in cancer cells that may have prognostic or therapeutic relevance for the treatment of the individual with cancer.

Since 1995, the NCMG has provided genetic counselling and molecular genetic testing to affected and unaffected patients with a family history of breast, ovarian or other potentially hereditary cancers. A cancer genetics clinic was also established in 1998 in St. James’s Hospital under the leadership of (the now retired) Prof. Peter Daly.

## Establishment of the Hereditary Cancer Programme

There is no comprehensive national policy on genetics and genetic testing in Ireland. In response to advances in diagnostics and the growing demand for services, the NCCP established a Hereditary Cancer Programme in collaboration with the National Centre for Medical Genetics in 2012. The aim of the programme is to improve access to assessment and genetic testing for those patients and their families whose cancer may have a hereditary component. The scientific leadership is provided by Prof. Andrew Green in the NCMG and the programme is designed to build on the capacity in NCMG. In line with the standards and with the oversight of the NCMG, new dedicated hereditary cancer clinics have been established by the NCCP in the Mater and St. James's Hospitals to improve access to assessment and genetic testing for patients and their families.

The Hereditary Cancer programme primarily focuses on hereditary breast, ovarian and bowel cancer, but also includes testing for rarer hereditary cancer syndromes. The programme formalises the relationship between NCCP and NCMG and allows for joint planning for a sustainable service and oversight of new technology and developments.

Work progressed to date includes collation of hereditary cancer activity data nationally, investment in the new hereditary cancer clinics in St. James's and the Mater Hospitals and the securing of funding for the laboratory testing generated by those clinics. Working groups are considering issues related to specific hereditary cancers, to agree best practice and management pathways and to ensure standardisation of practice nationally. Work ongoing includes the agreement of criteria for genetic testing among ovarian cancer patients and the management of those with identified cancer predisposition genes.

In addition to the above and given the conflicting scientific evidence available, the NCCP commissioned the Health Information and Quality Authority (HIQA) to carry out a health technology

assessment on breast surveillance among women under 50 who are at increased risk, e.g. due to family history<sup>18</sup>. As a result of this, a formalised breast surveillance programme is proposed for women with an identified genetic mutation, or equivalent risk, from the age of 30. A business case is currently being developed to progress this programme.

Additional funding has been allocated to provide for consultant sessions and nursing staff to support clinics in both St James's and the Mater hospitals since 2012. All cancer genetic testing ordered from these clinics is also funded by the NCCP. Funding to appoint a full-time consultant in cancer genetics was sought by the NCCP as part of the 2014 HSE service planning process but no funding was allocated. However, in June 2014 the Director General of the HSE agreed to approve a new post of national lead for hereditary cancer. Recruitment of this new Dublin-based consultant post, which will have a clinical and academic component, will commence this year.

## Hereditary Cancer Clinics Activity & Capacity

Clinical cancer genetics services are now provided in NCMG in Crumlin by two specialists, with a team of 2.6 WTE genetic counsellors and 1 WTE administrative staff. In St James's and the Mater hospitals in Dublin, two clinics per week are held by a medical oncologist/cancer geneticist. The NCMG also holds outreach clinics in Cork and Galway.

The NCMG has seen an increase in cancer genetic referrals, an increase in the numbers of cancer genetics patients seen and an increase in hereditary cancer gene testing (see below). From a referral rate of 600-700 per annum in the early 2000s the numbers of cancer genetic referrals reached 1,167 in 2011, and 1,283 in 2013, an increase of 60%. As a result, the waiting time to be seen in the genetics clinic has increased to 12 months, and the clinical services of the NCMG are working at capacity.

18 <http://www.hiqa.ie/healthcare/health-technology-assessment/assessments/surveillance-of-women-under-50-with-increased-risk-of-breast-cancer>

**Table 10.1: NCMG Clinical Activity 2007-2010**

Year	2007	2008	2009	2010
Number of appointments (DNA rate)	576 (5.5%)	757 (9.5%)	641 (11%)	724 (6.9%)
Number of patients seen	858	1098	832	985

Source: NCMG, 2014. Note: Referrals not accurately coded as cancer/non-cancer and genetic tests not electronically coded before 2011. Therefore these were manually coded by genetic counseling staff. Clinical activity affected in 2009/10 due to sick leave.

**Table 10.2: NCMG Clinical Activity 2011-2013**

Year	2011	2012	2013
Cancer genetic referrals	1167	904	1283
Total appointments (DNA rate)	601 (7.9%)	906 (4.8%)	973 (4.3%)
Total patients seen	811	1226	1,507
Cancer predictive genetic appointments	372	361	538
Diagnostic appointments attended*	187	501	393
Waiting List*	300	345	431

\*Source: NCMG, 2014. These figures relate only to the NCMG and do not reflect those who attended the clinics in SJH & the Mater which were established in 2012

All genetic testing is coordinated by the Molecular Genetics laboratory in the National Centre for Medical Genetics, whether carried out in house or outsourced to the UK. The hereditary cancer programme has oversight of clinic and testing activity levels. The numbers of tests carried out have increased rapidly over recent years (see table 10.3 below). The commonest reason for testing is for the BRCA1/2 genes, which are primarily associated with breast and ovarian cancer, followed by HNPCC/Lynch syndrome, which predisposes to bowel and other cancers. The growth has been seen in both the number

of cancer patients being tested (undergoing 'diagnostic' testing) and those relatives who are being tested for a specific mutation in their family (called 'predictive' or 'pre-symptomatic' testing). Data show an overall 73% increase in the number of hereditary cancer samples received by the NCMG since 2010 (Table 10.3). Essentially all of this growth has come from the additional clinical activity of the NCCP funded clinics, as clinical resources at NCMG do not permit any increase in activity.

**Table 10.3: All Cancers – Total Samples since 2010 by Referral Centre**

Referral Centre	2010	2011	2012	2013
National Centre for Medical Genetics	864	635	926	830
St James's Hospital	5	92	340	370
Mater Misericordiae University Hospital	3	3	192	339
Other Hospitals	65	90	109	86
<b>Totals</b>	<b>937</b>	<b>820</b>	<b>1567</b>	<b>1625</b>

Source NCMG 2014

**Table 10.4: NCMG Laboratory Activity 2010-2013 – Patients Undergoing BRCA Gene Testing**

	2010	2011	2012	2013
BRCA Predictive tests	184	173	284	346
BRCA full screen tests	149	115	367	361

Source NCMG 2014; Overall increase since 2010 is 88% for predictive tests and 142% for full screens

**Table 10.5: NCMG Laboratory Activity 2010-2013 – Total Samples\* by Disorder**

Disease Name	2010	2011	2012	2013
Breast Cancer	651	528	1121	1162
Lynch syndrome	161	144	175	193
Li-Fraumeni Syndrome/p53 gene	7	15	47	83
Phosphatase and Tensin Homolog	26	30	37	41
Tuberous Sclerosis	20	21	33	35
Von-Hippel Lindau	7	9	16	27
Familial Adenomatous Polyposis Coli	25	16	25	22
Multiple Endocrine Neoplasia Type 1	10	8	13	13
MYH polyposis	7	<5	11	12
RET Oncogene (MEN2, FMTC etc.)	14	16	26	8
E Cadherin	<5	<5	12	7
Peutz-Jeghers Syndrome	<5	5	<5	6
Phaeochromocytoma			24	5
BRAF V600E mutation	<5	22	18	<5
Birt-Hogg-Dube Syndrome	<5		<5	<5
SDHB Hereditary Paraganglioma (PHMG)			<5	<5
<b>Totals</b>	<b>937</b>	<b>820</b>	<b>1567</b>	<b>1625</b>

Source: NCMG, 2014 \* Note: The numbers of samples exceed the number of patients, as multiple tests can be carried out per patient

A far greater number of people undergo an assessment of their hereditary risk - in most cases requiring attendance at a clinic appointment but some may be reassured following remote assessment of their family history by questionnaire. Again, the number of patients requiring assessment at clinic continues to rise, with 1,283 patients referred directly to NCMG in 2013, compared to 600-700 in the mid 2000s (this excludes numbers sent directly to the St. James's & Mater Hospital clinics). While this is partly due to increased awareness, it also reflects the level of unmet need over recent years. This is confirmed by the high level of pick up of cancer predisposition genes among those patients with cancer who have diagnostic cancer genetic testing - 14.8% of women who have diagnostic breast cancer genetic testing are found to have a deleterious BRCA1 or BRCA2 mutation.

Hereditary cancer services in Ireland have struggled to keep abreast with demands and remain considerably under-resourced in terms of funding and staffing. Waiting times for an initial appointment remain unacceptably high, in NCMG in particular, with only about half being seen within 6 months. Much of this relates to the need for additional genetic counselors and support staffing, laboratory staff and resources for genetic tests. The additional hereditary cancer clinics in St. James' and the Mater Hospitals are helping to meet some of this need but are being run without any substantive clinical appointments, which is a serious risk in terms of sustainability. Laboratory staff numbers at NCMG have decreased over the period 2010-2013, while cancer sample numbers increased by 73%. This is also unsustainable and raises the likelihood of a clinical risk.

Currently the NCMG, in agreement with the NCCP, is offering diagnostic breast cancer genetic testing to women affected by breast or ovarian cancer, who meet high risk criteria. In the UK, revised NICE guidelines published in 2013 have recommended a significant change in practice, whereby BRCA1 and BRCA2 gene testing should be offered to women who are at high risk of having a BRCA1/BRCA2 mutation, regardless of whether they are affected by cancer or not. If such a recommendation were to be introduced in Ireland, it would require significant new investment in clinical and laboratory genetic services, to provide for the large number of additional women requiring testing.

A further unmet need is the fact that the referral of those with potentially hereditary colon cancer is under 20% of those for hereditary breast cancer. As in many other countries, the detection of hereditary colon cancer in Ireland is not being implemented sufficiently. If the expected number of hereditary colon cancer families were identified, there would be a significant increased need for genetic services for these families.

Currently the assessment of the likelihood of a cancer being hereditary in each cancer clinic is not structured or equitable. To ensure equity and quality care, each cancer clinic should have a family cancer clinic, where family history taking, cancer diagnosis validation, and risk assessment can be carried out using standardised protocols and clinical recommendations. Those at high risk can then be seen by cancer genetic services for diagnostic or predictive testing, and those at moderate risk can be managed at the local service, without involvement of cancer genetic services.

The current management of laboratory cancer genetic tests for the Mater Hospital and St James' Hospital involves the setting up of individual purchase orders and billing for each test for each patient seen in those clinics. This process is cumbersome and time consuming, and generates substantial administrative costs. Solutions are being sought to streamline the process, and minimise that administrative load.

From 2010 to 2013, there has been a 73% increase in samples received for cancer testing. Figures for Q1 in 2014 indicate that this level of testing continues to increase. Much of this is likely a result of unmet need over recent years and increased levels of awareness arising from some recent high profile cases.

All cancer genetic testing except BRCA predictive testing and MSI testing of tumours is sent abroad (predominantly to the UK) because of lack of resources in the laboratories in the NCMG. This results in an outflow of revenue from the NCCP and a loss of expertise at NCMG. Recent years have seen major advances in DNA sequencing technology, with massively parallel (or "Next Generation") DNA sequencing reducing costs and increasing the scope of genes that can be tested. This technology is now in use in all of the laboratories to which NCMG sends cancer samples for testing. There is an urgent need to invest in

this technology at NCMG to allow the resumption of testing for the common cancers in-house. The benefits of such investment include:

- A unique opportunity to introduce modern clinically effective and cost efficient DNA cancer screening technology to the NCMG to support NCCP's national cancer control remit
- Ability to substantially enhance the provision, access, sustainability and viability of quality cancer screening to the Irish population by Irish based scientists, with no further loss of revenue abroad
- Opportunity to realise annual cost savings with realistic prospects of more economies of scale, as the required capital infrastructure and scientific experience for this new technology will be in place. Any such growth will have to be additionally resourced for consumables and staff, and governed by service level agreements

The National Cancer Control Programme (NCCP) and NCMG will continue to collaborate via the hereditary cancer programme to ensure genetic testing is carried out in the most cost effective and clinically appropriate manner. Future plans to help meet the growing need will see the extension of hereditary cancer clinics to medical oncology services in the South and West. However this will necessitate a considerable investment in the overall service.

## Challenges

- Challenge in keeping pace with new technology and emerging clinical evidence
- The era of personalised medicine brings with it new indications for genetic testing, to inform individual risk and predicted response to treatment
- Lack of funding to support appointment of a dedicated permanent consultant geneticist post in cancer genetics
- Need for additional nursing, genetic counsellor and administrative support for existing cancer clinics
- Growth in laboratory testing requirements without commensurate increase in staffing

- Lack of/need for investment in laboratory equipment and automation
- Lack of national data base to capture referrals and link to clinical findings
- Lack of a national register of those with hereditary cancer - their outcomes, treatments, and long term health
- Long waiting times for appointments
- Increased awareness and understanding of genetic testing among the public – increased uptake of appropriate testing predicted, especially among those with cancer themselves, with resultant increase in demand on the service
- Improved understanding among all health care professionals but also a need for enhanced cancer genetics service, with the capacity to support other clinical colleagues
- The NCCP has a remit for developing cancer services and monitoring its volume and quality in the Irish public hospital system only. Private hospitals are outside this remit and not subject to NCCP scrutiny

## Opportunities

- Further develop the hereditary cancer programme in Ireland
- Recruitment of a dedicated leader for cancer genetics in Ireland
- Development of a national hereditary cancer policy
- Evaluation of repatriation of genetic testing to Ireland from the UK with new models of funding genetic tests
- Triage of patients in cancer clinics prior to referral to NCMG
- Identifying the specific genetic cause of hereditary cancer and offering pre-symptomatic testing to at risk relatives supports the HSE's objective of a specific programme of promoting the early detection, and indeed preventing, cancer in this known high risk population



# The National Screening Service

The 2006 National Cancer Strategy made 8 recommendations in relation to Cancer Screening:

No. 13 Population-based screening programmes should only be introduced where their population health benefit can be demonstrated using the National Cancer Forum criteria.

No. 14 Breast screening should be extended to include all women aged between 50 and 69.

No. 15 The national roll-out of the Irish Cervical Screening Programme should be completed as a matter of priority.

No. 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.

No. 17 The Department of Health and Children in conjunction with the HSE and BreastCheck should plan the alignment of population-based screening programmes.

No. 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.

No. 19 Opportunistic testing of asymptomatic individuals for cancer is not recommended.

No. 20 The HSE should develop specific programmes that promote early detection of cancer.

Since the publication of the 2006 National Cancer Strategy the National Screening Service has been established and delivers four population-based screening programmes in Ireland. When the four programmes are fully rolled out, over two million people in Ireland will be eligible to participate in one or more of the programmes.



## History and background: Population-based Screening in Ireland

In 1989, a pilot programme of screening for breast cancer, known as the 'Eccles Programme' was established by the Mater foundation. It was part of a European initiative and received support from the 'Europe Against Cancer' programme.

The Eccles programme had a breast cancer detection rate of 7.9 cancers per 1,000 screened indicating high prevalence of breast cancer and demonstrated a case for a breast screening programme in Ireland. This heralded the beginning of population-based screening in Ireland.

Following an independent evaluation of the Eccles Programme in October 1995, the Minister for Health announced the phased introduction of the national breast screening programme.

In 1996, the Department of Health published a document 'A Strategy for Cancer Services in Ireland'. Following this the Minister established a National Steering Committee to oversee the implementation of Phase 1 of the national breast screening programme. Phase 1 of the national programme commenced in early 2000.

The Steering Committee oversaw the development of the service including development of clinical protocols, establishing quality assurance mechanisms, and the recruitment of clinical and organisational staff.

The Steering Committee made a number of excellent and forward thinking decisions that served the new programme well and continue to have a positive impact on the quality and delivery of the BreastCheck programme today, including:

- Two year screening interval
- Double reading of mammograms
- Triple-assessment
- Two view mammography
- Inclusion of primary treatment (surgery) as part of the programme
- The BreastCheck Women's Charter

From inception, the remit of BreastCheck has been to provide Ireland's first quality assured, evidence based breast screening programme for women aged 50 to 64 years. The aim of BreastCheck is to screen women using mammography and to detect breast cancer at the earliest possible stage. It is a successful model of care consisting of mammographic screening, follow up and surgical management of women who are detected with breast cancer. The pioneering clinical-led model leveraged the learning from international programmes.

By the time of the publication of 'A Strategy for Cancer Control in Ireland' in 2006 by the National Cancer Forum and the Department of Health and Children, the BreastCheck programme had been in place for six years. Planning for Phase 2 - expansion of the breast screening service to the 13 counties in the West and the South of the country - was well underway with a planned commencement date of end 2007.

The 'A Strategy for Cancer Control in Ireland 2006' made other screening recommendations including:

- The extension of the upper age limit of breast screening to 69 years following national expansion
- Alignment of screening programmes
- National roll-out of the Irish cervical screening programme
- Establishment of a colorectal cancer screening programme

Since January 2014, the national screening programme is under the remit of the HSE Division of Health and Wellness. The NCCP and Health & Wellbeing now collaborate on planning, strategy and monitoring of performance of cancer screening, the NCCP is no longer engaged in the operational delivery of screening programmes.

## Extension of BreastCheck Age Range

This remains as an objective of the Programme for Government. It is acknowledged that it is an ambitious target in coming years. A business plan was submitted to the Department of Health in the summer of 2013 and awaits full approval and financial commitment. Extension of the age range will increase the eligible cohort by over 40%.

## Alignment of Screening Programmes

The National Breast Screening Board was dissolved on December 31, 2006 and in its place the National Cancer Screening Service Board was established as a statutory organisation chaired by Dr Sheelagh Ryan. Governance of BreastCheck was transferred to the board of the National Cancer Screening Service (NCSS) on its establishment in January 2007. In addition, the Board was given responsibility to roll out cervical screening nationally. Mr Tony O'Brien (current Director General of the HSE) was appointed as the first director of the NCSS.

## Cervical Screening

By 2006, the Irish Cervical Screening Programme (Phase 1) had been in operation in three counties, Limerick, Clare and North Tipperary. Governance of the former Irish Cervical Screening Programme (ICSP) Phase 1 was transferred to the National Cancer Screening Service Board on its establishment and it was given the remit to ensure the national roll-out of the cervical screening be completed as a national priority. CervicalCheck commenced on a national basis in September 2008.

## Colorectal Screening

Following the 'A Strategy for Cancer Control in Ireland 2006', the Minister for Health and Children asked the Board of the National Cancer Screening Service (NCSS) to explore the potential for the introduction of a national colorectal cancer screening programme. The programme was to encompass population screening, high risk screening and necessary developments in symptomatic colorectal cancer services. This was to follow resolution of a range of implementation issues.

In December 2009, the NCSS recommended the phased implementation of a population-based colorectal cancer screening programme for men and women, in line with international best practice and consistent with the EU Council Recommendation. The format of the programme had been agreed based on a Health Technology Assessment undertaken by the Health Information and Quality Authority (HIQA) on the cost-effectiveness, health outcomes and resource requirements of various options for a population-based colorectal cancer screening programme. This evaluation was completed in October 2009. Preparations for the programme commenced in late 2010 and continued until 2012.

## BowelScreen

The National Bowel Screening Programme started in October 2012 with the ultimate aim of reducing mortality from colorectal cancer in men and women aged 55-74 years in Ireland. The programme is being introduced on a phased basis to allow for the development of sustainable capacity for the full population. The programme is initially offering screening to men and women aged 60-69 years. The first round of screening is on track for completion by the end of 2015.

## Diabetic RetinaScreen

In 2011 the NCSS was tasked with developing and delivering a population-based screening programme for diabetic eye disease, which commenced in February 2013.

## National Cancer Screening Service - Role and Evolution

The role of NCSS included the following:

- To carry out or arrange to carry out a national breast screening service for the early diagnosis and primary treatment of breast cancer in women.
- To carry out or arrange to carry out a national cervical cancer screening service for the early diagnosis and primary treatment of cervical cancer in women.
- To advise on the benefits of carrying out other cancer screening programmes where a population health benefit can be demonstrated.
- To advise the Minister, from time to time, on health technologies, including vaccines, relating to the prevention of cervical cancer.
- To implement special measures to promote participation in its population-based screening programmes by disadvantaged people.

The Board of the NCSS was dissolved when the NCSS joined the Health Service Executive National Cancer Control Programme (NCCP) in 2010. In January 2014, the operational management of the National Cancer Screening Programme transferred to the new HSE division of Health and Wellbeing. The NCCP and Health & Wellbeing now collaborate on planning, strategy and monitoring of performance of the NCSS.

## Current Screening Focus

The National Cancer Screening Service, which will now be known as the National Screening Service (NSS) is now responsible for implementation and delivery of four population-based, call and re-call screening programmes in Ireland. These include:

- The ongoing provision of BreastCheck service and the national expansion of the programme targeting women aged 50 to 64 years.
- The roll-out of CervicalCheck – The National Cervical Screening Programme in September 2008 targeting over 1.1 million women aged 25 to 60 years.
- The establishment of BowelScreen – The National Bowel Screening Programme in October 2012 and phased introduction initially to men and women aged 60 to 69 years.
- Implementation of Diabetic RetinaScreen – The National Diabetic Retinal Screening Programme to provide regular screening and treatment of diabetic retinopathy, a common complication of diabetes, to people with diabetes aged 12 years and over. Although not a cancer screening programme, this has been aligned with the other population-based screening programmes.

## Quality Assurance

Quality Assurance (QA) is an integral component of each screening programme. The elements below are important for the development and the ongoing implementation of each screening programme. These ensure that preventative action and/or corrective action is taken on an ongoing basis and that the overall risk management of each programme is central.

**Quality Assurance structures include:**

- Quality Assurance committees for each programme; these are responsible at the outset for development of a set of Quality Assurance guidelines and Key Performance Indicators (KPIs). Each QA committee is involved in the ongoing review of its programme and oversees programme adherence to guidelines.
- Executive Management Team for each programme to review issues and evolve implementation policies.
- Clinical Advisory Groups for each programme where external expertise is of value.
- Expert Groups set up to examine a particular issue and provide guidance.

**Quality Assurance processes include:**

- Ongoing monitoring and review for continuous improvement
- Clinical audits
- Standard Operating Procedures (SOPs) - comprehensive SOPs are developed for each programme and delivery
- Peer review
- Stakeholder feedback including client feedback
- MOUs (memorandum of understanding)
- Contracts

**Figure 11.1: Policy, Management and Quality Assurance Structure**



## Quality Standards and Guidelines

A set of comprehensive standards, measurements and KPIs for all aspects of each programme has been developed. Standards are updated from time to time dependent on programme needs.

- **BreastCheck** - Guidelines for Quality Assurance in Mammography Screening (3<sup>rd</sup> Ed. 2008)
- **CervicalCheck** - Guidelines for Quality Assurance in Cervical Screening (2<sup>nd</sup> Ed. 2014)
- **BowelScreen** - Guidelines for Quality Assurance in Colorectal Screening (1<sup>st</sup> Ed. 2012)
- **Diabetic RetinaScreen** - Standards for Quality Assurance in Diabetic Retinopathy Screening (1<sup>st</sup> Ed. 2013)

The guidelines provide standards, KPIs and measurements for the programmes which form the basis for data reporting and statistical review and are included in the published annual reports for each programme.

## Quality Assurance Committees

Each programme has a dedicated Quality Assurance Committee.

### • Directly Delivered Programmes

#### **BreastCheck**

As BreastCheck is a directly delivered programme, the Quality Assurance Committee, chaired by Quality Assurance Director, comprising of staff from all disciplines, meets quarterly to review and discuss quality issues.

## External Accreditation

As part of quality assurance, an external quality assurance certification process is planned for Q3/Q4 2014. It is intended that the European Reference Centre for Breast Screening (EUREF) will carry out the process. It is a voluntary certification process, which when all criteria are fulfilled demonstrates adherence to a recognised quality system. In 2002 EUREF carried out this process for BreastCheck which at the time was delivering Phase 1 of the programme in the eastern part of the country and successfully achieved voluntary accreditation. It was envisaged that once the programme had completed at least one round of the national programme the process would be repeated and planning has begun for this. Work has begun on the fourth edition of the guidelines. Following the external accreditation process, the edition will be finalised.

### • QA Multidisciplinary Consultants' Group

All consultants either directly employed, or involved in delivery of aspects of the programme, meet on an annual basis, usually in October or November.

### • Purchaser-Provider Programmes with MFTP elements

As CervicalCheck, BowelScreen and Diabetic RetinaScreen follow a purchaser-provider model, Quality Assurance Committees, led by an independent chairperson, have been established and are in place prior to the commencement of the programmes. The membership includes representatives nominated by professional bodies and associations, or by direct invitation from the NCSS.

As part of the development of Guidelines for Quality Assurance in Cervical Screening, and Colorectal Screening, external peer review evaluations, including international experts, took place.

## NCSS Programme Delivery

The National Cancer Screening Service is dedicated to the continued delivery of screening programmes, sharing expertise and learning across population-based screening programmes and driving effectiveness through strengthening the single governance model in place for screening.

Each population-based screening programme is evidence based and leverages best international practice. Each programme is quality assured, clinically unique and each is designed using a model appropriate to that programme. All programmes are fully audited against a range of quality and client-centred criteria as set out in a programme Charter. Programme performance is continually measured against the respective Charter to ensure that the programme is performing at optimal level. All programmes are managed and supported through a central structure and some shared resources.

Communications, promotional activities and screening promotion are co-ordinated centrally to increase awareness and participation in the national programmes.

There is a varied range of stakeholders including clients, media, charities, lobby groups, patient advocacy groups, health professionals, professional bodies, clinical and non-clinical service providers, clinical community, HSE and voluntary hospitals with which the NCSS engages on a regular basis. Education and awareness programmes and activities are planned to facilitate a mutually supportive stakeholder environment and enable informed consent and increased participation across the programmes.

Population based, call-recall screening, particularly in the cancer field, is well established in a number of countries internationally. The NCSS has strong linkages with bodies and organisations abroad which provides an invaluable source of assistance and expertise and assist in collaboration.

## Challenges across the National Cancer Screening Service

Recruitment and moratorium - over recent years the remit of the NCSS has increased from delivery of two screening programmes to four programmes while at the same time the management and support team has reduced. This is against a backdrop of a growing and an aging population in Ireland and an increasing burden of cancer. The ongoing development and delivery of the programmes, in particular the focus required for the two newer programmes is extremely challenging and creates a risk to the timely and highly quality assured implementation of the programmes.

It is imperative that the continued safe and quality-assured introduction of the new programmes BowelScreen and Diabetic RetinaScreen, together with the ongoing management and delivery of the current BreastCheck and CervicalCheck programmes, retain the appropriate level of support required to ensure all programmes continue to deliver their objectives.

When all four population-based screening programmes are fully rolled out, over two million people in Ireland will be eligible to participate in one or more of the programmes.

The NCSS became part of the Health and Wellbeing Division of the Health Service Executive in January 2014. There continues to be ongoing linkages to the NCCP for cancer screening strategy and performance management.

## BreastCheck

BreastCheck is the National Breast Screening Programme, a population-based call re-call programme, that offers women aged 50 to 64 a free mammogram every two years. BreastCheck is a successful and high quality screening service for women who have no symptoms of breast cancer. The aim of BreastCheck is to reduce the number of breast cancer mortalities in these women, by detecting breast cancer at the earliest possible stage.

The BreastCheck service is different from the symptomatic breast services provided at specialist breast clinics throughout the country because the woman is not referred to BreastCheck by a GP and does not have symptoms of a breast cancer.

Service standards and Quality Assurance systems are in place throughout the programme. These high level standards are in line with international guidelines to ensure that the best service is provided to women. While it is internationally accepted that no screening system is 100 per cent accurate, BreastCheck aims to ensure that the screening service is safe and effective.

A specialist BreastCheck multidisciplinary team provides the screening service to women. The integrated team involves administration, consultant medical and other staff including anaesthetists, histopathologists, radiologists, surgeons, radiographers and breast care nurses. The team is involved in the screening, detection, diagnosis and treatment of breast cancer. The success of the programme is due to the close working links and operations between the administration of BreastCheck and the clinical team.

## Programme History

BreastCheck commenced screening in February 2000 in the eastern part of the country. Two screening units were built, one on the campus of St Vincent's University Hospital and the second on the campus of Mater Hospital, each with four associated mobile screening units. BreastCheck patients requiring surgery are admitted to the host hospitals.

The 'A Strategy for Cancer Control in Ireland' published in 2006 by the Cancer Control Forum and the Department of Health and Children recommended that the BreastCheck programme be rolled out nationally as quickly as possible.

Following tendering and planning, the programme expanded in the West and South of the country in December 2007. Two new units, with state of the art digital equipment were built, and a number of mobile units were commissioned to facilitate the breast screening service to women living in the South and West. The BreastCheck Southern Unit is located in Cork city. Initially South Infirmity Victoria University Hospital was the host hospital. Following service configuration in the South, Cork University Hospital became the host hospital. The Western Unit is based in Galway on the campus of Galway University Hospital. To facilitate the expansion, over 100 staff were recruited and employed in the West and the South.

In 2007, at the time of the national expansion to the south and west, the programme upgraded from using analogue mammography screening equipment to digital screening equipment. The BreastCheck programme was one of the first internationally to provide digital mammography.

BreastCheck now has four static centres: two in Dublin, one in Cork and one in Galway. Each centre has four associated mobile units which provide screening as close to women's homes as possible. The majority of screening takes place on mobile units. Some screening, all assessment and follow up takes place at the static centres. The initial round of screening of women in 13 counties in the West and the South was achieved in 2010.



Improving the quality of screening and breast disease services in Ireland is a key priority and BreastCheck continues to link with the NCCP and symptomatic breast disease services and the eight designated cancer centres.

In some locations the programme is now in its eighth round of screening.

The following figures relate to the BreastCheck programme, since the start of the programme in January 2000 to mid June 2014:

- 444,585 women have been screened,
- 1,171,935 mammograms have been provided, and
- 7,184 cancers have been detected.

The following figures relate to the BreastCheck programme in the years 2011, 2012 and provisional figures for 2013 and indicate numbers of women invited, screened and cancers detected each year. (Table 11.1)

Copies of all annual reports and publications are available on the NCSS Website: <http://www.cancerscreening.ie/publications/index.html>

The most recent BreastCheck programme report for 2012/13 is attached in TD 16

**Table 11.1: Year that the Women’s First Invitation in the Screening Round was Issued**

	2011	2012	2013*
Number invited	172,076	183,632	210,241
Number eligible invited	168,129	179,222	203,312
Number screened	125,329	128,002	144,192
Uptake rate (based on known target population i.e. number invited)	72.8%	69.7%	68.6%
Uptake rate (based on eligible invited)	74.5%	71.4%	70.9%
Number of cancers detected	832	858	850
*provisional figures - not yet validated			

Source: NCSS 2014

## Challenges and opportunities

- Concern regarding uptake – A key challenge is maintaining high levels of screening over time, particularly with women new to the programme. This is experienced by population screening programmes internationally. A targeted campaign to encourage women aged 50-64 to participate and to provide additional online resources is planned for 2014. An uptake rate of 70% is key to achieving the aim of the programme in reducing deaths from breast cancer in the screening population. A higher than 70% uptake rate has always been achieved by BreastCheck since start of programme. The trend since 2012 shows that the uptake rate is reducing especially among new women to the programme (initial women).
- The recruitment moratorium within the HSE continues to pose a key challenge for the programme.
- An ongoing shortage of radiographers both nationally and internationally poses a significant challenge.
- As set out in the BreastCheck KPIs, hospital admission for women with breast cancer diagnosis within three weeks can be difficult to achieve.
- Age range extension - the NCSS welcomes the Government's commitment to extend the age range to include women aged 65-69 years as outlined in The 'Strategy for Cancer Control in Ireland' 2006, and in the Programme for Government and Future Health – A strategic framework for reform of the health service'. Approval and funding to extend the age range to women aged 69 years has not been agreed. A business plan has been submitted to the Department of Health and awaits full approval and financial commitment. BreastCheck is currently available to women aged 50-64 years; a cohort of over 380,000. Recruitment and training of the required clinical and administrative staffing complement will be critical. Most notable will be the requirement of radiographers, a professional grade which remains in short supply in Ireland and elsewhere.
- It is important to note that while the extension has been deferred, continued government commitment signals recognition of the value of population-based screening programmes as worthwhile health initiatives. It has long been the intention to extend the programme and there is clear evidence to support this.
- Ageing population and growth in numbers - the impact of the ageing population in Ireland is that the current cohort together with the extended age range will bring the total eligible population to over 544,000; an increase of over 41 per cent. This presents a particular challenge as part of the planning, costing and investment for the extended age range.
- Equipment and capital investment - the majority of mammography and medical equipment in the current programme is either overdue for replacement, or will become due within the next few years. The impact is that equipment, which is out of warranty, is less effective. An approval for capital funding in line with the 2014 capital plan was received and a plan for replacement of equipment for the BreastCheck programme has begun.
- Service reconfiguration: South - the reconfiguration of health services in the South a number of years ago changed the host hospital from the South Infirmary Victoria Hospital to Cork University Hospital. As the BreastCheck unit is geographically distant from CUH, the additional travel time for clinical and nursing staff on a daily basis between both sites has created a burden on the unit.

- Ongoing debate about breast screening - there is continued debate about the merits of breast screening. An independent breast screening review undertaken in the United Kingdom was published in late 2012. The independent panel assessed both the benefits and harms associated with population breast screening. The report found that breast screening programmes in the UK save lives; however the available evidence showed that for each breast cancer death prevented, about three cases are detected by screening that would not have become clinically apparent in the woman's lifetime in the absence of screening. Some of the abnormalities detected, due to advances in diagnostic processes, may not progress to affect a woman's survival. However, it cannot be determined which abnormalities fall into this category.

The review recommended that it is vital to give women information that is clear and accessible, so that they can understand both the potential risks and benefits of screening and make an informed decision around participation. BreastCheck provides a number of information leaflets and an additional factsheet is available for women who would like further detailed information about DCIS (ductal carcinoma in situ). BreastCheck provides opportunities, in the small number of cases where a cancer is diagnosed by the programme, for the woman to explore and fully discuss treatment options.

## **CervicalCheck**

### **Programme History**

In Ireland, during the last thirty years, cervical cancer rates have been rising despite the widespread availability of opportunistic screening with deaths from cervical cancer increasing by an average of 1.5% per year since 1978.

On 1 January 2007, governance of the cervical screening programme was moved from the Health Service Executive to the National Cancer Screening Service (NCSS) Board, established under Statutory Instrument 632 of 2006.

On 1 September 2008, CervicalCheck - The National Cervical Screening Programme was launched, extending the programme nationwide. CervicalCheck provides free smear tests through primary care settings to the approximately 1.1 million women in Ireland aged 25-60 years that are eligible for screening. A successful national programme in Ireland has the potential to cut current mortality rates from cervical cancer by up to 80%.

### **Quality Standards**

Quality standards, to address each step of the cervical screening process, were developed for CervicalCheck by a dedicated quality assurance committee with subsequent peer review. The Guidelines for Quality Assurance in Cervical Screening were originally published in January 2010 and have recently been updated based on learning from the programme over the first five years of operation and developments in technology. The second edition was published in 2014.

CervicalCheck has established, documented, implemented and maintains a quality management system (QMS) for the Programme Administration Office and works to continually improve its effectiveness in accordance with the requirements of the International QMS Standard IS EN ISO 9001:2008.

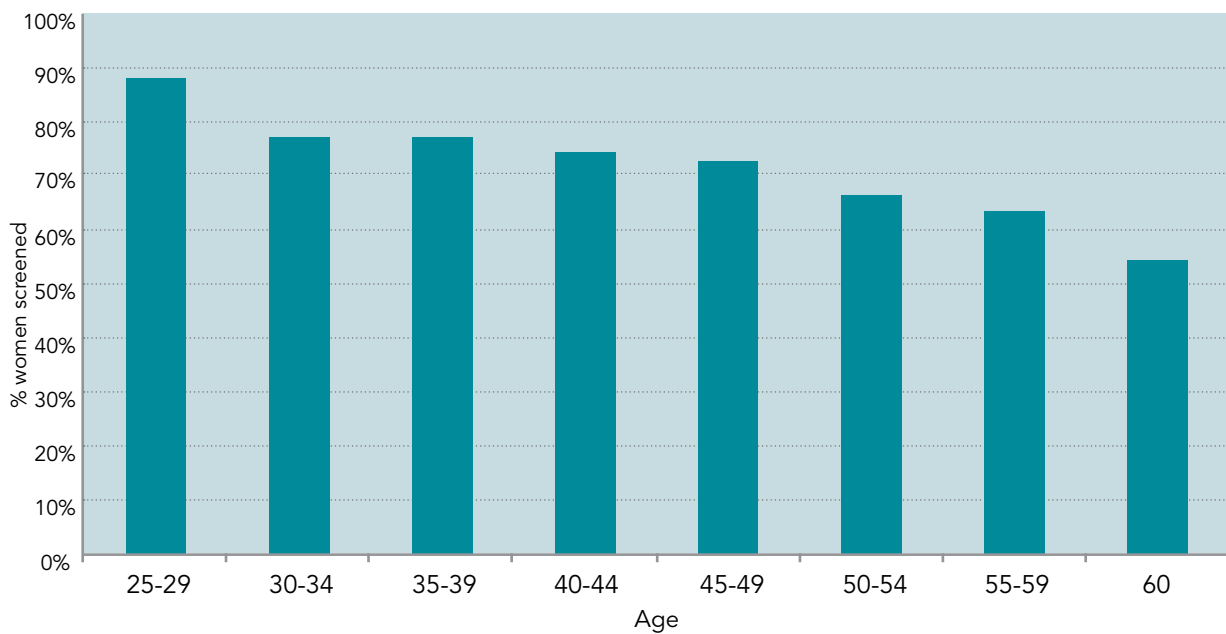
## Programme Activity

During the first five years of the programme, in excess of 1.66 million smear tests were performed in over 916,000 women. This constituted 73.7% of the target population. In general, younger women were more likely to participate in screening with 82.7% of women aged 25-29 years screened compared to 62% of women in the 55-59 year old group. Averages of 1,250 smear tests were performed daily as part of the programme.

## Primary Care and Smeartaking

CervicalCheck through the NCSS contracted for the provision of smearing services with general practitioners and clinics in the primary care setting nationwide. The agreement is a legally binding contract between the NCSS and the service provider (GPs and clinics) and is structured on the basis of a fee per service for an eligible client in line with CervicalCheck's quality assurance guidelines.

**Figure 11.2: Coverage from 1 September 2008 to 31 August 2013. Percentage of Women Screened as Part of CervicalCheck**



Source NCSS 2014

### Smertaker Training

The Smertaker Training Unit co-ordinates and delivers all smertaker educational initiatives. The introduction of cervical screening on a national basis led to a demand for training potentially over 4,600 smertakers on an ongoing basis. Between 2003 and 2013, 1,644 smertakers (GPs, trainee GPs, practice nurses) and administrative staff took part in smertaker training programmes organised by the Smertaker Training Unit.

### Cytology

Cytology services are procured through a public tendering process. This has resulted in a significant reduction in time required for a woman to receive her result. In 2013, following a second public procurement process, two laboratories (one in Ireland and one overseas) provide cytology services to the programme. In addition, in 2013 a separate training facility was established at a second laboratory in Dublin.

### Colposcopy

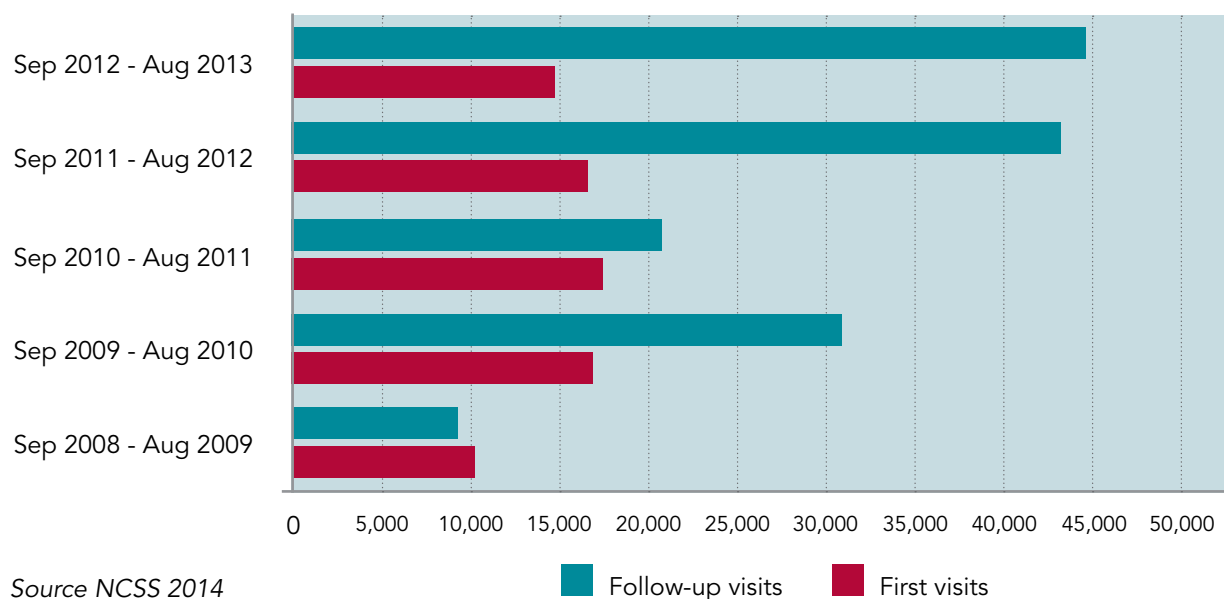
Quality assured colposcopy services are important, ensuring women with a screen-detected abnormality are provided with the optimum care. Since 2008, fifteen colposcopy services staffed by

dedicated multidisciplinary teams, work with the programme.

Significant investments were made in providing adequate facilities and information technology links. It was calculated that 16,500 new patient slots would be required per year and service level agreements documented the resources provided for an agreed quantum of new patients attending to ensure adequate capacity. All colposcopists were either accredited by the BSCCP or in training under supervision and all services agreed to take part in regular MDT meetings. The development, establishment, and on-going management of the service level agreement including the fee per treatment feature, a forerunner of Money Follows The Patient, contributes to improving service delivery for those individuals who had been referred for treatment to a colposcopy clinic.

The number of women attending colposcopy increased significantly in the first five years of the CervicalCheck programme with a peak of 17,500 new patients attending for the first time in the third year of the programme. A marked increase in the number of follow up appointments can be explained by increasing numbers of women with low-grade cytology undergoing surveillance. This figure peaked in the fifth year of the programme with 43,983 attended follow up appointments.

**Figure 11.3: Numbers of Women Attending Colposcopy during the First Five Years of the CervicalCheck Programme**



Source NCSS 2014

Long waiting times were a feature of colposcopy services before the introduction of CervicalCheck. In the fifth year of the programme, the waiting times met national standards for all categories of smear test abnormalities.

The objective of any cervical screening programme is to detect and treat high grade abnormalities, which if left untreated, could progress to invasive cancer. The numbers of biopsies increased markedly during the first five years of the programme. Overall for this time period, 25,912\* women were diagnosed as having CIN2, CIN3 or adenocarcinoma in situ. Invasive cancer was diagnosed in 572\* women.

\*Figures correct as of the most recent draft of the annual report for the fifth year of the programme

Copies of recent annual reports and publications are available on the NCSS Website: <http://www.cancerscreening.ie/publications/index.html>

A copy of the most recent CervicalCheck programme report is included in TD 15.

### **Introduction of HPV testing in Colposcopy**

The treatment of CIN can reduce the risk of invasive cancer by over 90 per cent but the risk of recurrence means that treated women still have five times the risk of invasive cancer compared to women who have always had normal smear tests.

Careful follow-up measures are required to identify treatment failures at the earliest opportunity and prevent subsequent cancer. Traditional protocols involve more intensive screening with annual cytology tests for up to 10 years.

In recent years attention has focused on ways to define the risk of recurrence more accurately and to stratify follow up protocols according to the risk.

On the recommendations of the HPV Scientific Advisory Group and subsequent peer review, HPV testing was introduced in colposcopy as part of the CervicalCheck programme in 2012 as an adjunct to cytology in the follow up of women who received treatment at colposcopy. Two combined cytology and HPV tests are available for women post-treatment at colposcopy, one at six months

post-treatment and the second at 18 months post treatment. Women with results categorised as low risk at this time are discharged to routine screening.

### **HPV testing to manage uncertainty at Colposcopy**

Women with low-grade cytological abnormalities constitute the majority of referrals to colposcopy. While some of these women require treatment, most do not and probably represent a transient infection with the human papillomavirus which will resolve spontaneously.

Management strategies try and balance early diagnosis of high grade CIN with the avoidance of default and unnecessary treatment and anxiety for women. While any management should be tailored to the needs of the woman including age, patient choice and risk of non compliance, the majority of women who do not have high grade disease should undergo surveillance.

Traditionally these women were managed with six-monthly colposcopy and cytology without conclusive evidence of the value of colposcopy or the recommended six-month screening interval. A fresh approach has been implemented in 2014 which uses the negative predictive value of HPV testing to return the woman to normal screening in a more efficient and effective manner.

### **HPV Immunised Cohort**

The HPV immunisation programme which commenced in 2010 for first years in secondary school with a catch up programme for girls in the sixth year of secondary school means that these women will be protected from being infected with the high risk HPV types that cause over 70% of invasive cancers. The HPV vaccinated cohort will start entering the CervicalCheck programme in 2019 and the approach to screening for these women will have to change significantly. CervicalCheck is currently planning to implement these changes, part of which includes a HTA process later in 2014 in conjunction with The Health Information and Quality Authority (HIQA).

## Challenges and Opportunities

Much has been achieved in the first five years of the CervicalCheck programme. The challenge is to build on these achievements and sustain the momentum to enable the fulfillment of the ultimate goal – a reduction of cancer incidence and mortality from cervical cancer. The most recent data from the NCRI shows incidence continuing to rise as the prevalent disease is identified. The target of reducing mortality by 50% and incidence by 30% by 2018 seems ambitious.

## Colorectal Cancer

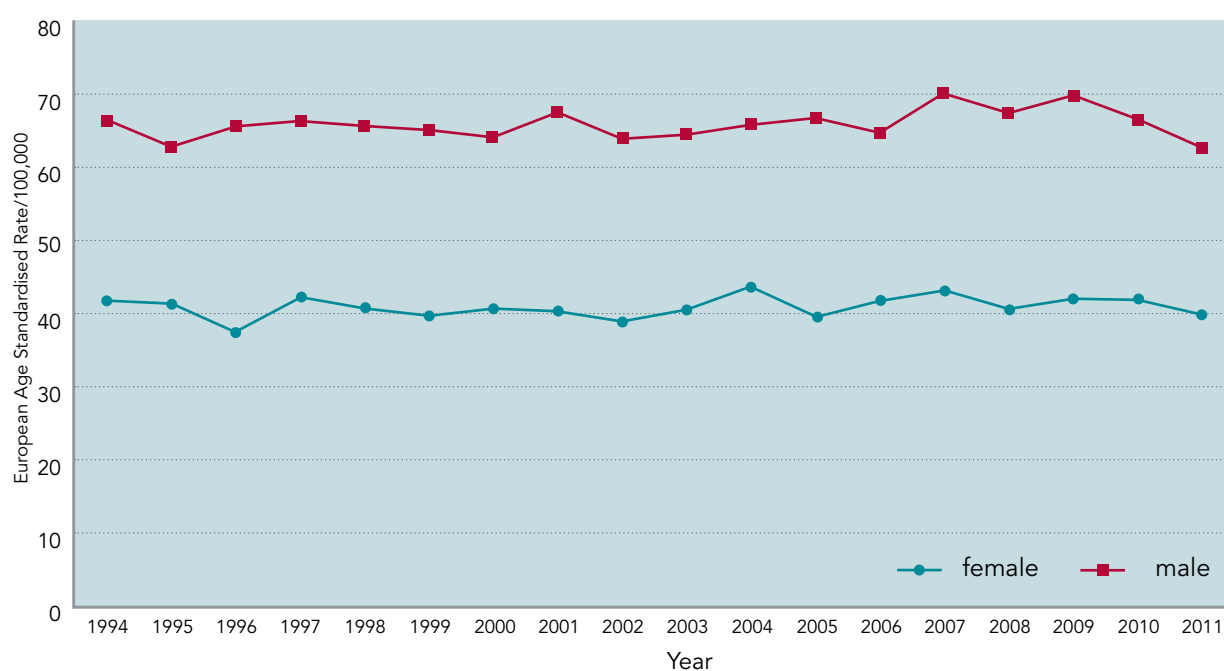
In Ireland, colorectal cancer is the second most commonly diagnosed cancer and the second most common fatal cancer among both men and women. Over the last 15 years, the number of cases of colorectal cancer diagnosed in Ireland has risen by approximately 20% in both sexes. There are over 2,400 newly diagnosed cases each year. Approximately 1,040 people die from colorectal cancer each year, 610 men and 430 women. Although the number of cases diagnosed continue to rise, the last twenty years has also seen a significant 20% increase in five year survival from 50.1% to 60.6%.

**Table 11.2: Colorectal Cancer Key Facts\***

	Male	Female	Total
Number of new cases per year (2009-2011 averages)	1,405	1,031	2,436
Number of deaths per year (2011)	610	430	1,040
Number alive with this cancer (2011)	8,212	6,604	14,816

\*National Cancer Registry Ireland

**Figure 11.4: Trends in Incidence Colorectal Cancer 1994-2011**





**Table 11.3: Trends in Five Year Relative Survival Colorectal Cancer**

Period	Relative Survival	95% Confidence Interval
1994-1999	50.1 %	(48.8-51.3%)
2000-2004	53.9 %	(52.6-55.1%)
2005-2009	59.2 %	(57.6-60.7%)
2008-2010*	60.6 %	(59.0-62.1%)

\* Hybrid estimate

### Background to the Establishment of a National Colorectal Cancer Screening Programme

Following the ‘A Strategy for Cancer Control in Ireland 2006’, the Minister for Health and Children asked the Board of the National Cancer Screening Service (NCSS) to explore the potential for the introduction of a national colorectal cancer screening programme. The Board of the NCSS established an Expert Advisory Group on Colorectal Cancer to explore the potential benefits of introducing a colorectal cancer screening programme in Ireland. The Expert Group, chaired by Professor Niall O’Higgins, evaluated the clinical and organisational requirements for the establishment of an effective, efficient and quality assured screening service. The Group presented its first (interim) report to the Board of the NCSS in December 2007.

An independent peer review of the report was completed in August 2008 by an international panel of experts on colorectal cancer screening (Prof Wendy Atkin & Prof Robert Steele [UK], Professor Jean Faivre [France] and Prof Michael O’Brien [USA]). On completion of this evaluation in December 2008, the Board of the NCSS recommended to the Minister a national, population-based, colorectal cancer screening programme for men and women aged 55-74 years.

In June 2009, the Minister requested the Health Information and Quality Authority (HIQA) to explore a means of delivering a high quality colorectal screening programme within existing resources. In December 2009, the NCSS recommended the phased implementation of a population-based colorectal cancer screening programme for men and women, in line with international best practice and consistent with the EU Council Recommendation.

### NCSS Recommendations

The Board of the NCSS recommended:

- The eligible population for screening should be men and women aged 55-74 years.
- The programme to operate on a two yearly screening round.
- The faecal immunochemical test (FIT) to be the primary screening tool.
- Persons with a positive result from the primary screening test to be offered a colonoscopy.
- The screening pathway would include primary treatment, after which the patient would be discharged from the screening programme for follow up in the symptomatic service in accordance with best clinical practice.

## Screening Programme Preparation

During 2010 to 2012 the following steps were undertaken:

- **Colonoscopy Capacity**

The NCSS focused on immediately identifying and building sufficient capacity in colonoscopy services nationwide to sustain the implementation of the programme, but also maintaining and enhancing the symptomatic service capability. The NCSS requested expressions of interest from all publicly funded hospitals that wished to be considered as a screening colonoscopy unit as part of a national programme. The NCSS undertook a baseline analysis of endoscopy facilities that expressed interest. It was conducted in partnership with the representative professional bodies, the Royal Colleges and the UK Joint Advisory Group on Gastroenterology (JAG).

- **Recruitment of Clinical Nurse Specialists in Gastroenterology – Colorectal Disease Screening and Management**

The NCSS received approval for the recruitment of 20 Clinical Nurse Specialists to support the introduction of a population screening programme.

- **Quality Assurance Framework Development**

The NCSS sought and developed a multidisciplinary process to agree Quality Assurance (QA) processes and standards for a national programme. An independent QA Chairperson, Chairs (Clinical Consultants) of three designated specialist sub-groups (endoscopy, laboratory/pathology, surgery) and members of each sub-group representing clinical expertise in each field were appointed by the NCSS. These sub-groups, in addition to a Programme sub-group developed a full suite of standards.

- **Faecal Immunochemical Test (FIT) Service**

The NCSS completed a tendering process for the provision of the FIT service. This is one of the first population cancer screening programmes in the world using the FIT as the primary screening test in a national setting.

- **Population Communications**

Initial market and consumer research and brand development were undertaken to inform the best population communications approach that would support the programme in its aim to achieve an uptake of 50-60%.

- **Client Support**

FIT test kits would only be sent to those who indicate that they are willing to use it. It was necessary to develop easily understandable materials and accessible channels of communication to potential users. In addition, a procurement process took place that led to the selection of a call centre with the intention of managing calls from those wishing to participate in the programme, request a FIT kit and other general inquiries.

- **Population Register and Clinical Data Repository**

The population register is a secure electronic database managed by the National Cancer Screening Service that contains the demographic details of men and women who are eligible to participate in the screening programme. The Health (Provision of Information) Act 1997 allows the National Screening Service to obtain and store demographic details and clinical results.

## Designing a commissioning model for a colorectal screening programme

During the planning phase it was known that approximately 95% of the programme would take place outside of a hospital setting (in the patient's home) and in the FIT testing laboratory.

For the approximately 5% of clients who would require referral to hospital for a colonoscopy and possible surgery, it was decided to design a commissioning model of reimbursement for all hospital based elements of the programme in which money would follow the patient. The commissioning is managed via signed memoranda of understanding (MOU) with the relevant hospitals.

- Screening colonoscopy units would be reimbursed for each screening colonoscopy performed.
- Histopathology laboratories in designated cancer centres would be reimbursed for histopathology arising from a screening colonoscopy.
- Hospitals providing CT colonography as part of the programme would be reimbursed for each scan.
- Designated cancer centres would be reimbursed for each screen detected cancer referred and treated.

A fundamental principle was that any hospital providing screening colonoscopies as part of a screening programme would have to demonstrate that they could control their symptomatic waits. An MOU would allow for performance monitoring of each screening colonoscopy unit and ensure that any patient presenting symptomatically would not be disadvantaged.

## Surgery

The management of screen-detected colon and rectal cancer is not materially different from that of the management of symptomatic disease. All screen detected cancers, colon and rectal would be referred to one of eight designated cancer centres.

## BowelScreen

### Launch of BowelScreen – The National Bowel Screening Programme

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 years in Ireland.

In order to allow the development of sustainable capacity for the full population, the programme is being implemented on a phased basis, starting with men and women aged 60-69 years. The first round of screening is on track for completion at the end of 2015.

Approximately ninety five per cent (95%) of participants will have a normal result and will be re-invited for screening in two years time. Approximately 5% of participants will have a result that requires a colonoscopy to be performed as a follow up test.

The procedure is carried out in one of the programme's screening 15 colonoscopy units. Those with a normal result from colonoscopy are re-invited for screening in two years time. Those with polyps requiring surveillance are followed up with a BowelScreen colonoscopy in one or three years depending on the classification of risk. Those diagnosed with a cancer are referred to a designated cancer centre for treatment and are discharged from the screening programme.

The following figures relate to the BowelScreen programme, since the start of the programme 22 October 2012 to May 2014:

- 144,000 Invitations issued
- 43,000 Normal FIT results
- 2,330 Colonoscopies
- 83 Cancers

This data is not yet validated and is provisional at this time.

## Challenges and opportunities

BowelScreen – The National Bowel Screening Programme has the opportunity to play a part in significantly reducing mortality from colorectal cancer in Ireland. When the programme is operational at full capacity and extended to the entire eligible population (aged 55-74), the full impact of screening on clinical health outcomes and cost-effectiveness will be realised and evaluated.

However significant challenges remain regarding the resource impact on the programme and on hospital services.

While 95% of BowelScreen takes place outside of a hospital, a main resource constraint is at the level of hospital services. Availability of hospital capacity is vital to ensure the success of BowelScreen.

The resource impact on endoscopy services is perhaps the most challenging. For example, in 2006 there were 50,470 colonoscopy discharges in Ireland in HIPE reporting hospitals. In 2011, this rose to 67,678 colonoscopy discharges representing a 34.1% increase in that five year period. The demand for colonoscopy procedures continues to rise, replicating the picture seen in the NHS.

Round one of the BowelScreen programme is on track to be delivered by the end of 2015. Over time the programme will be extended to the full eligible population.

## Diabetic RetinaScreen

There is currently a global epidemic of diabetes (especially Type 2), which means that diabetic retinopathy will continue to be a public health problem. Untreated sight-threatening diabetic retinopathy (DR) is the most common cause of blindness in people of working age in Ireland. It is estimated that the diabetes prevalence in Ireland equates to 190,000 with many cases as yet undiagnosed.

Diabetic retinopathy is caused when diabetes (raised blood glucose levels) damage the small blood vessels/capillaries in the back of the retina leading to haemorrhages, which can affect vision. Diabetic retinopathy may not cause symptoms until it is quite advanced and close to affecting a person's sight, therefore screening is essential to identify and treat issues early. Diabetic retinopathy can be diagnosed at an early stage in people with both Type 1 and Type 2 diabetes and evidence demonstrates that if detected early enough, appropriate treatment can be provided which may reduce the risk of sight deterioration.

All people with diabetes are at some risk of getting diabetic retinopathy. People in the categories below are at greater risk:

- Those with diabetes for a long time
- Those with diabetes that is poorly controlled
- Those with high blood pressure
- Those on insulin treatment

After 20 years with diabetes, nearly all patients with type 1 and over 60% of patients with type 2 diabetes will have some degree of retinopathy.

## Establishment of the Diabetic Retinopathy Screening Programme

Due to the experience of the Screening Service in delivering high-quality population-based screening programmes, it was formally requested by the Health Service Executive that the NCSS commence the development of a national diabetic retinopathy screening programme in 2011 under the auspices of the NCCP.

Following this request, the NCSS committed to the development of a national diabetic retinopathy screening programme and commenced actively preparing for the introduction of the programme working closely with the National Directorate of Clinical Strategy and Programmes. Following a planning stage, Diabetic RetinaScreen - The National Retinal Screening Programme was launched in February 2013.

## **Aim of Diabetic RetinaScreen**

The aim of the programme is to reduce the risk of sight loss amongst people with diabetes, by the early identification and effective treatment if necessary of sight threatening diabetic retinopathy, at the appropriate stage during the disease process.

The national programme is a population-based, call-recall programme of screening for sight-threatening diabetic retinopathy, which will be delivered on an annual basis once the first round of screening has been completed. Screening will be offered to people with diagnosed diabetes, aged 12 years and over, registered with the programme.

The programme is delivered locally and provided to the highest, internationally comparable, quality assurance standards. Systematic screening involves digital photography of the retina followed by a three-stage image grading process to identify the changes of sight-threatening diabetic retinopathy in the retina.

The programme will aim to reach a growing eligible population of an estimated 190,000 people. This is based upon 5.6% of the population having diabetes, with a programme uptake rate of 80%. It is estimated that 25% of those screened will require referral for further investigation and possible treatment. Of this, 18% will be treated for diabetic retinopathy and 7% will be treated for non-diabetic retinopathy related conditions.

## **Development of a Screening Register for Diabetic Retinopathy**

A national register of all people with diabetes does not currently exist in Ireland. In order to facilitate the commencement of a national diabetic retinopathy screening programme, an extensive register of people diagnosed with diabetes was created during the last quarter of 2011 and early 2012. This information was compiled from national health schemes, such as the General Medical Scheme (GMS), Drugs Payment Scheme and Long Term illness Scheme in Dec 2012. This register is used to invite people to participate in the programme. A facility for GPs to verify their diabetic patients will be added over time.

## **Development of a Quality Assurance Framework**

A quality assurance framework has been developed to ensure that every aspect of the screening programme would operate in line with international best practice standards. A Quality Assurance Committee was established and completed the development of standards for quality assurance in diabetic retinopathy screening for the national programme.

## **Procurement of Photography and Grading Service Providers**

A rigorous public procurement process for the selection of the photography and grading service provider to undertake the screening test and associated grading system was completed. Two companies were selected and are providing services for the programme.

## Procurement of Treatment Capacity

The Screening Service together with the National Diabetes Programme completed a process to determine treatment model and identify the necessary treatment capacity requirements in order to determine the resources required to manage screen-detected abnormalities, without negatively impacting symptomatic service capability. Governance has been agreed in order to minimise delays for those transitioning from screening to treatment.

The treatment aspect of the programme was initially under the remit of the HSE Diabetes Programme but was included in the remit of the Screening Service at the end of 2012. A model to determine resources required to address capacity was developed. In co-operation with the Irish College of Ophthalmologists and HSE Clinical Programmes, the initial treatment locations were identified and to date Memoranda of Understanding (MOUs) are in place with eight hospitals in locations through out the country for the supply of these services.

## Invitation Targets

The national programme achieved the target for 2013 and invited 30% of the eligible population on the register to participate in the programme. To date, the programme is on track to achieve the target and invite the remaining 70% of the register by the end of 2014.

## Challenges and opportunities

- Recruitment and retention of critical staff.
- Achievement of the programme standard of an 80% uptake participation rate.
- Growing diabetic population.
- Availability of an increased number of screening locations to clients for the initial screening appointment.
- Move to annual screening in 2015, once the initial round is complete.

Round one of the Diabetic RetinaScreen programme is on track to be delivered by the end of 2014. Once this initial round of screening is complete, the programme will introduce and deliver annual screening.

# Development of National clinical Guidelines

No. 41: The 2006 National Cancer Strategy recommended that “HIQA should establish site specific multidisciplinary groups at a national level to develop guidelines for quality in major cancers”.

## Development of National Clinical Guidelines

‘A Strategy for Cancer Control in Ireland 2006’ recommended that “national site-specific multidisciplinary groups should be convened to develop evidence based guidelines for cancer care. These groups should provide guidance for all common cancers”.

In 2011, the NCCP commenced the development of national evidence-based clinical guidelines for the diagnosis, staging and treatment of common cancers. These evidence-based guidelines aim to:

- Improve the quality of clinical care,
- Prevent variation in practice,
- Address areas of clinical care with new and emerging evidence,
- Encompass best research evidence in conjunction with clinical expertise, and

- Incorporate the use of evidence based methodology and command the respect of stakeholders, including the HSE, the department of Health’s National Clinical Effectiveness Committee (NCEC) and regulatory authorities such as the Health Information and Quality Authority (HIQA)

The National Cancer Control Programme (NCCP) has commenced the development of national evidence-based clinical guidelines for the diagnosis, staging and treatment of five common cancers, commencing with: Breast, Prostate, Lung, Gastrointestinal (oesophageal, pancreatic & colorectal) and Gynaecological (Gestational trophoblastic disease (GTD)) Cancers.

## Guideline Development

Guideline development groups (GDGs) were established with nominations received from the relevant professional medical colleges (Royal College of Physicians, Royal College of Surgeons). Chairpersons were agreed by the group members. Membership of each Guideline Development Group includes representatives from all relevant clinical disciplines including Radiology, Pathology, Surgery, Medical Oncology and Radiation Oncology, a Project Manager, a Methodologist and a Clinical Librarian.



The work of each GDG was completed in discipline specific subgroups (i.e. pathology, surgery, radiation oncology etc) to expedite the process and to ensure the best utilisation of clinician time. It is a labour intensive process and would not be possible without the significant contribution of time and expertise of all the clinicians and librarians involved.

## Governance

Governance of the guideline development process is provided by a multidisciplinary Guideline Steering Group, which is chaired by the Director of the NCCP. The Steering Group meets quarterly to assess progress of each of the individual GDGs and to provide oversight and leadership, to address any queries as they arise and to ensure all guidelines are being developed using an evidence-based approach. Members of each GDG have completed a conflict of interest form. The current membership is listed in TD 10.

## Methodology for Developing Evidence-Based Guidelines

Guideline development is a complex multi-year project and internationally, it requires on average two years to complete an evidence-based clinical guideline.

The principal benefit of developing evidence based guidelines is to improve the quality of care received by patients. Other benefits include the following:

- Improvements in the quality of clinical decisions,
- Improvement in patient outcomes,
- Potential for reduction in morbidity and mortality and improvement in quality of life,
- Promotion of intervention of proven benefit and discouragement of ineffective ones, and
- Improvements in the consistency and standard of care (NCCP 2012)

A methodologist qualified in evidence-based practice was appointed from within NCCP staff to design and oversee the methodology for the

development of the guidelines. The methodology was based on the principles of Evidence Based Practice (Sackett et al. 2000) The appointment of a dedicated NCCP project manager for each of the GDGs to manage, support and co-ordinate each aspect of the guideline development has been a critical success factor in the development of this project. Training in evidence-based guideline development was provided by the NCCP for all clinicians and librarian participating in the GDGs.

## NCCP Guideline Development Methodology

- Step 1 Develop clinical questions
- Step 2 Search for the evidence
- Step 3 Appraise the literature for validity and applicability (AGREE II instrument for existing guidelines and SIGN checklists for primary literature)
- Step 4 Formulate and grade the recommendations (evidence is applied in conjunction with clinical expertise and applicability to the Irish setting)
- Step 5 Draft Guideline (including national stakeholders and international expert review)

Weekly methodology meetings, chaired by the methodologist, are held in the NCCP and attended by all project managers and research staff. These meetings have provided training in aspects of guideline development, peer to peer support for the project managers and a forum to resolve issues and difficulties. Quarterly meetings are also held with this team and the librarians to address issues arising.

## Implementation and Audit

The implementation plan is based on the Com-B theory of Behaviour Change (Michie et al 2011). A multidisciplinary clinical team is responsible for the implementation of the guideline recommendations.. Audit criteria will be established for each guideline (based on KPIs) and an audit plan will be developed by the NCCP.

## National Endorsement

The National Clinical Effectiveness Committee (NCEC) was established by the Department of Health in September 2010. The NCEC is responsible for endorsing all national clinical guidelines. Upon completion, the NCCP guidelines will be submitted to the National Clinical Effectiveness Committee (NCEC) in the Department of Health for national endorsement. The NCCP has liaised closely with the NCEC to ensure that the methodology used will meet the standards set out by the NCEC.

## Progress to Date

The NCCP has prioritised the development of these national clinical guidelines and has developed an evidence-based approach to their development to ensure delivery of robust national clinical guidelines.

Guidelines for the Diagnosis Staging and Treatment of Breast Cancer has been published on the NCCP website., The draft guideline for Lung Cancer will be available for review in 2015. Guidelines for Oesophageal, Pancreatic and Colorectal Cancers are underway. Guidelines for Prostate Cancer and Gestational Trophoblastic Disease are to be published in 2015.

An additional five cancers have been identified for future development of guidelines which will be progressed pending availability of resources.

## Summary

The NCCP has implemented the recommendation of the 2006 National Cancer Strategy in establishing site specific multidisciplinary groups at a national level to develop guidelines for quality in major cancers. These evidence based clinical guidelines aim to ensure standardised multidisciplinary care for patients, putting evidence into practice to improve patient outcomes.

**Table 12.1: Guidelines Development Group Progress – June 2014**

Guidelines Development Group (Tumour Group)	Ask			Search		Appraise		Apply		Guideline
	Questions	Revise	Sign Off	Library	Sign off	Guidelines	Primary Literature	Extract Data	Agree Recommendations	Sign off by Tumour Group
<b>Breast</b>										
Surgery	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Radiology	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Medical Oncology	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Palliative Care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Radiation Oncology	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Prostate</b>										
Active Surveillance	✓	✓	✓	✓		✓	✓	✓	✓	✓
Diagnosis+Radiology	✓	✓	✓	✓		✓	✓	✓	✓	✓
Pathology	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Medical Oncology	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Radiation Oncology	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Surgery	✓	✓	✓	N/A		✓	N/A	✓	✓	✓

Guidelines Development Group (Tumour Group)	Ask			Search		Appraise		Apply		Guideline
	Questions	Revise	Sign Off	Library	Sign off	Guidelines	Primary Literature	Extract Data	Agree Recommendations	Sign off by Tumour Group
Palliative Care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Gynaecological										
Gestational Trophoblastic Disease	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Lung</b>										
Respiratory physicians	✓	✓	✓	N/A		✓	N/A	✓	✓	✓
Radiologists	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Pathologists	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Surgical	✓	✓	✓	✓	✓	✓	N/A	✓	✓	✓
Medical Oncology	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Radiation Oncology	✓	✓	✓			✓	✓	✓	✓	
Palliative care	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
<b>Oesophageal &amp; OGJ Tumours</b>										
Radiology	✓	✓	✓	✓		✓	✓	✓		
Surgery Gastro	✓	✓	✓	✓		✓	✓	✓	✓	
Pathology	✓	✓	✓	✓		✓	✓	✓		
Radiation Med Onc	✓	✓	✓	✓		✓	✓	✓		
<b>Pancreas</b>										
Radiology	✓	✓	✓	✓		✓	✓	✓		
Surgery	✓		✓			✓		✓		
Pathology	✓		✓	✓		✓	✓	✓		
Radiation Oncology	✓		✓			✓		✓		
Medical Oncology	✓		✓	✓		✓		✓		
<b>Colorectal</b>										
Radiology	✓	✓	✓	✓	✓	✓	✓	✓		
Surgery	✓	✓	✓	✓	✓	✓	✓	✓		
Gastroenterology	✓	✓	✓	✓		✓		✓		
Pathology	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Radiation Oncology	✓	✓	✓	✓	✓	✓	✓	✓		
Medical Oncology	✓	✓	✓	✓		✓		✓		

Shaded boxes indicates commenced but not completed

# Cancer Intelligence

The 2006 National Cancer Strategy recommended that:

- No. 43. HIQA should develop cancer surveillance systems that will build on the existing system of cancer registration.
- No. 45. HIQA should ensure that a minimum national dataset should be collected for all cases of cancer.
- No. 48. Information systems and information technology should be developed by the HSE to support the management and delivery of cancer services.

Many of the oversight/monitoring roles originally identified for HIQA have now been adopted by the NCCP or the NCRI (inc. recommendations 43, 45,).

Health care is essentially an information science. Data is required at every level in a healthcare organisation - to enable clinicians to diagnose disease, identify possible intervention opportunities and achieve health outcomes; to enable patients to make informed choices regarding their treatment and to facilitate managers and clinical leaders to plan, manage and improve the health service. Data and information lie at the core of any quality improvement system.

The original strategy document 'A Strategy for Cancer Control in Ireland 2006' envisaged the establishment of a cancer surveillance system, built on the existing system of cancer registration which had the following main aims:

- monitoring trends in cancer incidence, prevalence and survival
- evaluating the effectiveness of cancer prevention and screening
- evaluating the quality and outcomes of cancer care
- evaluating the impact of environmental and social factors on cancer risk
- supporting investigations into the causes of cancer
- providing information in support of genetic counselling services

Since the publication of the original strategy document, the OECD developed a conceptual framework to measure system performance in cancer. ([http://www.oecd.org/els/health-systems/Focus-on-Health\\_Cancer-Care-2013.pdf](http://www.oecd.org/els/health-systems/Focus-on-Health_Cancer-Care-2013.pdf))

Five main domains of system performance are described

- **Access** to cancer care – includes such measures as time to access specialist review and key procedures, access to cancer drugs, equity of access to services
- **Effectiveness** of cancer care – refers to the assessment of clinical effectiveness all along the steps of the cancer care path. It includes both outcome measures such as survival rates, mortality, stage at diagnosis and process measures such as adherence to agreed guidelines and appropriate use of cost effective procedures
- **Governance** of cancer care – relate to the organisation of care delivery and the relationships that are established between different care providers within the care structure
- **Costs** of cancer care – hospital and community services expenditure on cancer, drug costs
- **Human resources and structures** – diagnosis and treatment equipment capacity, staff capacity and hospital capacity (volume and distribution of acute beds, day care beds and theatre slots)

In Ireland, as is the case with most jurisdictions, data on these domains come from multiple sources.

The major national source of comprehensive cancer data is the National Cancer Registry (NCR) [www.ncri.ie](http://www.ncri.ie). The National Cancer Registry Board was first established in 1991 when the then Southern Tumour Registry became the National Cancer Registry. The NCR has remained an independent entity with its own Board since its inception and has been led by Dr Harry Comber as Director since 1992. The NCCP has been represented on the NCR Board since 2009 and the Board has been chaired by the Director of the NCCP, Dr Susan O'Reilly, since early 2013.

The NCR has captured data on all cancer cases in Ireland since 1994. The NCR database has information on demographics, tumour

characteristics, treatment and some follow-up information on all cancer cases in Ireland, irrespective of where patient is diagnosed. As a registry, it does not contain comprehensive clinical data and is collected retrospectively, often more than a year after initial treatment. It is the definitive source of information on cancer incidence, mortality, prevalence and survival.

The Hospital Inpatient Enquiry (HIPE) is designed to capture hospital activity in the public hospital system. It covers all admissions with cancer for a particular time period, irrespective of when the patient was diagnosed. HIPE captures information on diagnosis and detailed surgical treatment data, but is limited in radiotherapy coding and has little medical oncology data. At a national level it is anonymised and unlinked to individual patient records, so patients cannot be tracked across hospitals.

The breast and cervical screening programmes carry data on all women screened and record clinical data on the cancers diagnosed. The breast data has been linked to the NCR data and there are provisions for doing the same with the cervical data.

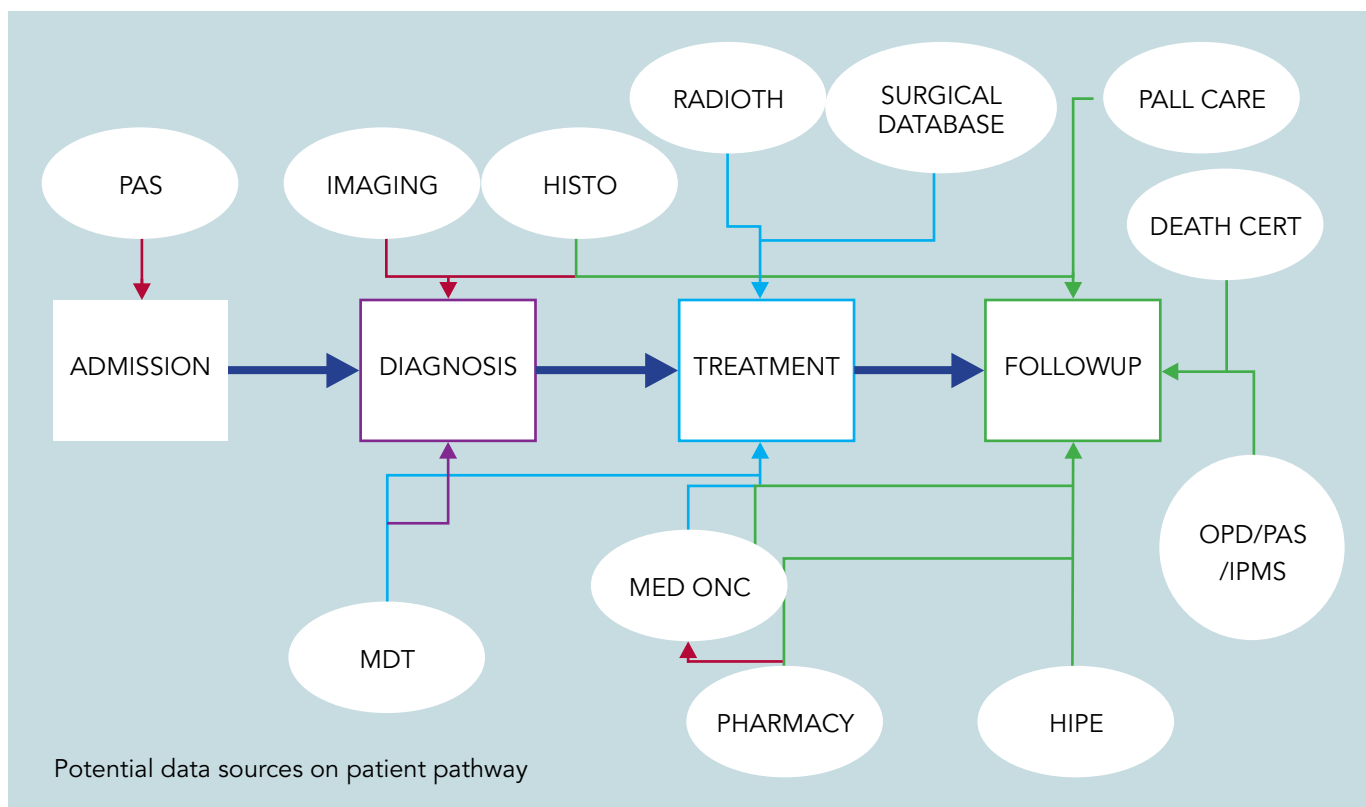
There is some limited data on outpatient attendances at medical oncology and radiotherapy clinics. These are collected at local level and reported to the HSE's Business Intelligence Unit.

The utilisation and cost of some intravenous high cost cancer drugs is captured by the NCCP Cancer Drug Management Programme and some other cancer drugs are captured on the Primary Care Reimbursement System.

There are eight symptomatic breast disease databases, one in each of the cancer centres.

There are a variety of other local databases, including radiation oncology treatment data, hospital- and consultant-specific databases, and others. In addition to the cancer specific databases, there are a variety of hospital databases that are current or potential providers of some of the key data items (Figure 13.1).

**Figure 13.1: Potential Data Sources on Patient Pathway**



Costs and human resources are compiled by the relevant hospital financial and HR systems and data on access and effectiveness of services are extracted from administrative, laboratory, radiology systems and clinical systems or notes. Governance is monitored with documentation of organisational structures, policies, protocols and procedures.

### Achievements

- To date, standards and their associated quality measures or key performance indicators (KPIs) have been defined for symptomatic breast disease, lung, prostate, rectal, upper gastrointestinal and pancreatic cancers as well as for radiation (access only) and medical oncology.
- An initiative, led by the NCRI, to define the national core cancer dataset has been completed and the core dataset disseminated to all cancer centres.
- A project to transfer histopathology data electronically to the NCRI and Cervical Check is being rolled out to public hospitals with histopathology laboratories.
- A cancer information system to enable quality assurance and clinical audit was provided in Cork, Limerick and Waterford hospitals as these cancer centres lacked any such facility for data capture.
- National collation of the KPIs for symptomatic breast disease commenced in 2010 and monthly, quarterly and annual reports are produced.
- National collation of upper gastrointestinal and pancreatic KPIs as well as access to radiation oncology commenced in 2012 and monthly, biannual and annual reports produced.

- Monitoring of the rapid access clinics for lung and prostate cancer commenced in 2012 and monthly reports are produced.
- Lung, prostate and rectal KPI suites were piloted in 2012 and 2013. Full national roll out of these KPIs commenced in 2014.
- Access to medical oncology has been monitored since 2013 and monthly reports produced. The full suite of KPIs is being piloted in 2014.
- Volume and centralisation of cancer surgery for all major cancers is monitored using HIPE data on a bi-annual basis. The NCRI database also provides insight into the centralisation of cancer surgery across all service providers both public and private.
- NCRI data on cancer incidence and cancer projections is invaluable for service planning.
- A deficit of staff with data management and/or data analytical skills continues to impede quality measurement.
- Further manipulation of existing administrative sources (e.g. outpatient data, Special Delivery Unit data) to answer specific cancer queries has proven to be challenging.
- The two year lag in reporting of cancer treatments by the NCRI has limited its utility in service planning and evaluation.
- Lack of resources in the NCRI to provide follow up data beyond one year after diagnosis has proven problematic when trying to estimate disease prevalence for the purpose of estimating service requirements and planning drug budgets.
- Most frameworks that address requirements for quality improvement recommend linking budgets to performance – currently there is inconsistent and patchy data available on the cost of cancer care at individual or hospitals level. While the HSE is introducing measures to improve patient level costing, no robust data on the comprehensive cost of cancer care are available.

## Challenges

- Lack of a unique identifier has made duplication of records and reporting inevitable and has made tracking of patients outside the hospitals where initial treatment occurs extremely difficult. However, this challenge will hopefully be addressed by the legislation that is currently progressing through the Houses of the Oireachtas regarding a national unique identifier.
- Current information governance legislation inhibits sharing of data on an individual level, which has resulted in multiple organisations extracting similar data on patients for their own individual purposes and multiple databases.
- Current information governance legislation inhibits pooling of data on a national level. In addition to the legislative barriers, the wide variety of databases collecting data in the cancer centres would make such a pooling exercise extremely expensive.



# Cancer Diagnostics and Quality Assurance

No. 31: The 2006 National Cancer Strategy recommended that “Patients should have their diagnosis established and their treatment planned by site specific multidisciplinary teams”.

## Introduction

Accurate, complete and timely diagnostic reports from pathologists and radiologists are a basic requirement for a cancer control programme.

Multidisciplinary care has been highlighted as an essential component in the management of patients with cancer. A multidisciplinary team meeting is a deliberate, regular, meeting involving a range of health professionals with expertise in the diagnosis and management of cancer. The purpose of the meeting is to facilitate best practice management of all patients with cancer. The key principle of multidisciplinary care is that all cancer patients will have the opportunity to have prospective treatment and care planning by an appropriate multidisciplinary team. Interactions between pathology, radiology and clinical specialists at meetings add quality to the diagnosis, disease staging and patient management decisions. Radiologists and pathologists are core members of and important contributors to the cancer multidisciplinary team. The role of these two specialists is different from other multidisciplinary

team participants in that they often belong to several groups and actively contribute in many multidisciplinary team meetings.

In support of the centralisation of cancer services, the growth in demand and the need to develop quality assured services the NCCP funded over thirteen (13.5) additional consultant radiologist posts, ten consultant histopathologist and nine senior scientist posts in designated cancer centres between 2007 and 2009.

## Pathology

Pathology is the medical specialty concerned with the study of the nature and causes of diseases. It underpins every aspect of medicine, from diagnostic testing and monitoring of chronic diseases to cutting-edge genetic research and blood transfusion technologies. Pathology is integral to the diagnosis of every cancer. Accurate, timely diagnosis and information on the extent of disease is essential to plan treatment and future management of a patient with cancer.

In recognition of the importance of pathology in cancer control, funding was allocated for an additional ten consultant pathology posts in 2008-2009, in the main to support breast, lung and prostate cancer services.

## Radiology

Radiology is defined as the specialty encompassing all aspects of medical imaging that yields information regarding anatomical, physiological and pathological status of disease. It includes those interventional techniques necessary for diagnosis, as well as minimally invasive therapy, which fall under the remit of departments of clinical radiology.

Routine clinical, laboratory, and radiologic examinations for malignancies are performed for the purpose of tumour detection, diagnosis, and accurate staging, so as to enable optimal treatment planning. Specific radiologic examinations for each malignancy depend on the site, histology, grade, and pattern and extent of spread based on clinical evaluation.

In recognition of the important role of radiology in cancer control, 13.5 radiologists were funded by the NCCP in 2008-2009.

## National Quality Assurance Programmes in Histopathology, Radiology and Endoscopy

Quality Assurance (QA) plays an important role in the delivery of health care services and is a useful tool in helping to avoid adverse health outcomes by improving practice or quality of care. All health practitioners aim to provide excellent service to patients and achieve optimal health outcomes. Most health practitioners ensure this happens by constantly reviewing, assessing and monitoring their work through a variety of processes including the review of Key Performance Indicators, investigation of critical incidents, peer review and audit of their service. Regardless of the approach taken, the underlying aim of any quality assurance activity is to identify ways in which health practitioners' practices and competence can be improved and the quality of current services can be maintained and improved.

The Report of the Commission on Patient Safety and Quality Assurance ([www.dohc.ie/publications/pdf/en\\_patientsafety.pdf?direct=1](http://www.dohc.ie/publications/pdf/en_patientsafety.pdf?direct=1)) concluded that

clinical audit should be viewed as an essential and integral component of professional practice which will contribute to improved patient outcomes. It acknowledges that there are challenges to clinical audit including fear of litigation through disclosure of data and states that "to encourage participation in clinical audit, clinicians need to feel safe with the process and to be assured that it will not be used against them in a punitive manner". The Commission recommended the introduction of an exemption from Freedom of Information legislation and the granting of legal protection from disclosure to data related to patient safety and quality improvement that are collected and analysed by healthcare organisations solely for purposes of improving safety and quality. Such legal protection is provided in a number of countries and it is hoped will be included in the forthcoming Health Information Bill.

Following a number of high profile cancer misdiagnoses between 2006 and 2008, the Faculty of Pathology, Royal College of Physicians of Ireland (RCPI), recognised there was an urgent need to ensure that diagnostic standards are high, not only for cancer but in general and are improving continuously with advances in knowledge.

Following discussion with the NCCP, it was agreed that Faculty of Pathology, RCPI would lead on the development and implementation of a National Quality Assurance Programme in Histopathology. The programme management is by RCPI. The National QA programmes in Radiology and GI Endoscopy followed in 2010 and 2011 respectively. The fundamental aim of these QA Programmes is to ensure patient safety and enhance patient care with timely, accurate and complete pathology, imaging and endoscopy diagnoses and reports. The NCCP has provided sponsorship of these programmes since their inception. As programmes are now beginning to mature and their remit is much broader than cancer, sponsorship of the programmes transferred to HSE Quality and Patient Safety Division in 2014 which will fund the programmes from 2015 onwards.

## National Histopathology Quality Assurance Programme

Pathology, like other diagnostic services, involves decision-making with a degree of uncertainty and a level of error is unavoidable. The National Histopathology Quality Assurance Programme evolved in response to misdiagnoses in breast cancer in Ireland and subsequent investigations by the Health Information and Quality Authority. The primary aim of the Programme is to improve quality and enhance patient care.

The National Histopathology QA Programme is funded by the NCCP and is the result of a collaborative process between representatives of the Faculty of Pathology, RCPI, NCCP, HSE ICT, Acute Hospitals, Directorate of Quality and Patient Safety, relevant HSE departments, Department of Health, Independent Hospitals Association of Ireland, and the Health Information and Quality Authority (as an observer). The scope of the Programme includes histopathology, cytopathology, neuropathology and autopsy. All national private, public and voluntary hospitals with histopathology laboratories participate.

The quality assurance guidelines have been updated regularly since they were first issued in 2009. ([http://www.rcpi.ie/content/docs/000001/312\\_5\\_media.pdf](http://www.rcpi.ie/content/docs/000001/312_5_media.pdf)). They are intended for use primarily by consultant pathologists and focus mainly on the clinical interpretation and reporting of histopathology and also autopsy practice. QA data is extracted and encrypted from Hospital Laboratory Information Systems and submitted regularly to a central database, the National Quality Assurance Intelligence System (NQAIS). To date 33 public and private laboratories are participating and generating local QA reports.

Data is uploaded and analysed for accuracy on a monthly basis. These data are formally reviewed, within each hospital, by the clinical lead and Quality Committee on at least a quarterly basis to examine trends, identify where targets are being met and also areas of underperformance with a view to developing and implementing quality improvement initiatives.

The current quality monitors are:

- Inter Institutional consultation
- Intradepartmental consultation
- Correlation of frozen section diagnosis with final diagnosis
- Cytology quality assurance
- Retrospective review
- Multidisciplinary Team Meetings
- Laboratory based non-conformances
- Laboratory based External Quality Assessment
- Turnaround Time
- Addendum reports
- Reports communicated directly to clinician by pathologist

Targets have been set for intradepartmental consultation, turnaround time and frozen section correlation. The first national report was published in February 2014. ([http://www.rcpi.ie/content/docs/000001/1623\\_5\\_media.pdf?1392311091](http://www.rcpi.ie/content/docs/000001/1623_5_media.pdf?1392311091))

The report shows an improvement over time, with targets now being reached. It is planned to set targets for the remaining quality activities.

## National Radiology Quality Assurance Programme

Radiology, like many diagnostic services, involves decision making under conditions of uncertainty and a certain degree of error is inevitable.

The National Quality Assurance Programme in Radiology was launched in 2010. It followed on reported cases of cancer misdiagnoses which reaffirmed the critical role of QA in the delivery of patient care. Few formal measures were in place to reassure the public that error is kept to an absolute minimum and few national benchmarks for key aspects of diagnostic services were in place to measure performance.

The Programme is recognised as a key initiative in enhancing patient safety and has received wide support from organisations within the healthcare sector that are driving the agenda of improved patient care.

The National QA Programme has been funded by the NCCP since 2012 and is managed by RCPI and is led by the Faculty of Radiologists of the Royal College of Surgeons in Ireland (RCSI), in collaboration with:

- Royal College of Surgeons in Ireland
- Directorate of Quality & Patient Safety HSE
- Independent Hospitals Association of Ireland (IHAI)
- HSE Information and Communication Technology
- HSE Acute Services
- Department of Health
- Health Information and Quality Authority - observer

The objective of this QA programme (combined for diagnostic and interventional radiology) is to provide guidelines for practical and implementable QA measures, which, in conjunction with existing local quality systems, will enable each hospital to monitor and evaluate their own performance in an effort to improve patient safety. These guidelines have been developed following consultation with Radiologists within the Faculty and in a number of pilot hospitals. International QA standards and guidelines have been reviewed and adapted for this QA programme. The Faculty has made a number of recommendations within the guidelines and will assist in their phased implementation. These recommendations include the quality activities that should be carried out and how to conduct activities. Key quality indicators have been identified to collect QA data. As the data matures, each hospital will be able to monitor its own performance and compare it to the aggregate national performance and intelligent targets to be set by the Faculty.

The basic objective of the rollout of this QA Programme is to promote patient safety and enhancement of patient care with accurate, timely and complete Radiology diagnoses and reports.

Access to diagnostic radiology and interventional radiology services is for all patients and therefore the benefit to improvements in patient safety through this QA programme will be for the whole population.

Guidelines and an Information Governance Policy have been published and participating departments have begun quality assurance activities.

Quality indicators have been developed in relation to:

- Retrospective peer review
- Prospective double reporting
- Multidisciplinary Team meetings
- Discrepancy meetings
- Communication of unexpected clinically significant, urgent and critical radiological findings
- Focused audit
- Report turnaround time
- Report completeness
- Inter institutional review

In addition to the guidelines for diagnostic radiology which will apply equally to interventional radiology, there are some specific areas of quality assurance to interventional radiology which are outlined in these guidelines:

- Outcomes meetings
- Multidisciplinary team meetings
- Communication of unexpected clinically significant, urgent and critical radiological findings
- Focused audit
- Report completeness
- External review – registries

A sophisticated ICT system has been procured to support QA activities in the Radiology Departments. Rollout of the system began in March 2014 and is envisaged to take two years to complete.

## National Endoscopy Quality Assurance Programme

In advance of the introduction of BowelScreen, the Conjoint Board of RCPI and the RCSI, in association with the HSE, launched the National Quality Assurance Programme in Gastrointestinal (GI) Endoscopy in 2011. The programme aims to establish a quality assurance framework in each endoscopy unit that ensures a high-quality, consistent and accurate service, translating into a quality patient experience.

The programme is managed by the Conjoint Board of RCPI and RCSI, in collaboration with:

- National Cancer Screening Service
- Quality & Patient Safety Directorate
- Independent Hospitals Association of Ireland
- HSE Information and Communication Technology
- HSE Acute Hospitals
- Department of Health
- Health Information and Quality Authority - observer

The National QA Programme has a defined governance structure which comprises of a Steering Committee with representation from the Conjoint Board of the RCPI and RCSI and other stakeholders.

GI Endoscopy Quality Assurance guidelines were developed by a multidisciplinary Working Group of endoscopy physicians, surgeons and nurse endoscopists who were appointed by the Conjoint Board and these guidelines have now been distributed to all participating units. They define key areas of QA in the delivery of endoscopic procedures and how to embed them in routine clinical practice. The guidelines ensure that there is a consistent and standard method of recording Key Quality Data (KQD) across all participating hospitals.

For each QA activity, a number of targets, or Quality Indicators (QI), have been identified. Where there are no quality indicators due to a lack of

sufficient evidence upon which to base a standard, a key recommendation has been made.

Key Quality Data required for the programme are collected locally by each unit on their Endoscopy Reporting System (ERS). Targets/QIs have been set using best international practice.

The National Quality Assurance Intelligence System (NQAIS), already used by the National QA Programme in Histopathology, was adapted from the HSE Health Information Unit system. NQAIS is the central data repository for the GI Endoscopy programme and has been enhanced to store, analyse, access and report on key quality data.

The Quality Assurance Programme is entering into the implementation phase, with the testing of NQAIS-Endoscopy system taking place in a number of pilot sites. Once the GI Endoscopy Quality Assurance Programme is fully implemented, each endoscopy unit will be able to create quality assurance reports, from NQAIS, based on the quality activity of the unit as set out in the guidelines.

The reports will enable units to monitor, review and improve the quality of their work in the context of national norms and evidence based quality indicators.

The guidelines have been circulated to all public, private and voluntary hospitals in Ireland providing endoscopy services. The introduction of this programme has many benefits including:

- Improved patient care and increased public confidence in diagnosis
- Standardised QA systems
- Data available to individual units to review their own performance against national targets.
- Identification of good practice and areas of improvement
- Improved communication within and between institutions



The 2006 National Cancer Strategy recommended that:

- No. 51. The third National Cancer Forum, in partnership with the HRB, should advise on the development of a specific plan for cancer research
- No. 52. There should be improved clinical trial entry for patients, both in terms of the number of trials conducted and the enrolment to them
- No 53. Ireland should establish a national tissue biobank to support research and service delivery
- No. 54. The HRB should establish a national cancer research database

Promotion of access to clinical translational and health services research in the country makes an important contribution to improving the care of those with cancer.

The NCCP strongly supports the integration of research into clinical practice but is not responsible for funding or delivery. There are several key players in the promotion of cancer research in Ireland. Key amongst these are ICORG (All Ireland Co operative Oncology Research Group),

the Health Research Board (HRB), the Irish Cancer Society, the National Cancer Registry of Ireland (NCRI) and a number of smaller charities who support and promote research and patient participation in clinical trials. All of the designated cancer centres are linked with Irish universities and play an active role in both clinical and translational research.

The majority of cancer clinical trials conducted in Ireland are overseen by the All Ireland Co operative Oncology Research Group (ICORG). This is a North South organisation that brings clinical cancer research to Ireland. In the past fifteen years ICORG has succeeded in offering research options to over 10,300 patients. ICORG ([www.icorg.ie](http://www.icorg.ie)) is responsible for scaling up the number of clinical trials available and the accrual of patients across the academic centres in the country.

In 2013, ICORG had over seventy cancer clinical trials open to recruitment, with more than 100 active and collaborated with over fifty pharmaceutical companies and universities worldwide. During the year 1,600 patients nationally enrolled in ICORG clinical trials. In addition, access was made available to over twenty five new cancer drugs and treatments and there were seven publications in high impact medical journals.

While the NCCP does not directly fund research it has provided some financial support to ICORG to assist with data management and in moving forward a number of clinical trials in order to reduce the time from planning stage to start-up. The Director of the NCCP, Dr. Susan O'Reilly is a member of the Board of ICORG. A detailed report on progress achieved in 2013 is available in TD 14.

Irish Oncologists have typically been well represented in international collaborations and have been important members of international research collaborations designing and leading effective clinical research. This undertaking has significant benefits not only for patients with cancer in Ireland, who have access to innovative therapeutics. In addition, the hospital benefits where, in some circumstances, the availability of free research-based treatment has reduced the financial cost of providing drug therapy for patients in selected circumstances such as phase 3 randomised trials. ICORG has estimated that participation in cancer clinical trials has saved the State over €5m in funding annually.

Ireland is also a participating state in the International Agency for Research on Cancer (IARC), which provides valuable research into many aspects of cancer control.

In translational research, clinical trials are an opportunity for tissue acquisition and for the study of molecular oncology changes that may either be predictive or prognostic in determining the underlying nature and behaviour of cancers. The establishment of specialised molecular cancer laboratories with high volumes of referrals will improve quality and facilitate large clinical trials. Many hospital laboratories in conjunction with academic research centres are now planning to acquire next generation sequencers which will significantly improve the capacity to process tests and to undertake research.

Cancer research is included within the statutory remit of the National Cancer Registry. The primary aim of the research programme of the Registry is to provide information which will help reduce the cancer burden, through understanding of:

- aetiology and risk factor prevalence
- stage distribution of cancer and factors affecting this, including screening
- patterns of care, their determining factors and results
- outcomes of cancer care, including patient-reported outcomes, survival and long-term sequelae of cancer

The Director of the NCCP, Dr. Susan O'Reilly, is also the current Chair of the Board of the National Cancer Registry of Ireland. A detailed report of the recent research work of the National Cancer Registry is included in TD 13.

For the future of research in Ireland the NCCP envisages that the considerable advances in personalised medicine in determining treatment decisions for cancer with specific molecular abnormalities and genetic mutations will continue to drive the direction of research, both in clinical trials and in translational science. Developments in these areas will inevitably drive the directions of therapeutics for patients and, over time, we anticipate that a combination of innovation and evidence based best practice along with highly organised cancer systems, prompt access to screening, diagnosis and care will continually improve outcomes for patients in Ireland.



# Appendix 1



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

## **National Cancer Control Strategy**

### **Establishment of Managed Cancer Control Networks And Designation of Eight Cancer Centres**

**Tony O'Brien**

**26<sup>th</sup> September 2007**

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## **A Strategy for Cancer Control in Ireland - Vision**

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

## 1. Introduction

In 2006 the government published **A Strategy for Cancer Control in Ireland**. The Strategy emphasised the association between volumes of certain procedures and patient outcomes, stating that it was not in the best interests of patients that hospitals perform small volumes of cancer surgery.

Launching the Strategy the Minister for Health Mary Harney, TD said *'To ensure that every patient gets the best quality care, we need to develop better ways of hospitals and health professionals working together based on connection and partnership rather than on isolation and self-sufficiency.'*

The Strategy identified an evidence based requirement to establish specialist Cancer Centres, each serving a minimum population of 500,000. Ireland will therefore require eight such centres. The strategy recommended that Cancer Centres should be networked together in Managed Cancer Control Networks and that there should be a broad aim of equipping each of the HSE's four regions with broad self sufficiency of services in relation to the more common forms of cancer.

Cancer Centres within the national Managed Network should be seen as equal partners, but in order to ensure adequate case-volume and expertise, some of the Cancer Centres will be required to provide a higher level of care for those less common cancers that need larger volumes than would present if that form of cancer were to be treated at all Cancer Centres.

In June 2006 the HSE announced its intention to establish a National Cancer Control Programme to implement the Strategy. The HSE had concluded that there was a need for a national programme to provide the necessary governance, integration and leadership to create the essential framework for a successful transformation of cancer control activities in Ireland.

This Programme will manage, organise and deliver cancer control on a whole population basis, through the application of evidence-based policy to clinical practice and all other components of cancer control. The delivery of cancer services on a programmatic basis will serve to ensure equity of access to services and equality of patient outcome irrespective of geography.

Delivering on this objective and improving cancer outcomes is about far more than just re-organising hospital services, but there are significant and immediate gains to be made from changes in the provision of acute cancer services.

A vital step in this process is the identification of eight cancer centres and the re-alignment of a number of existing hospital services from their present locations. In many instances there are simply too many hospitals treating too few patients.

## Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

Given the importance of cancer surgery, in particular, in determining outcomes for patients with cancer, this is likely to be a significant reason for Ireland's relatively poor cancer survival and the relatively poor survival for certain cancers outside of Dublin. This is contrary to patient interests and diffuses both resources and expertise in an entirely counter productive way. This can no longer be permitted.

The HSE established an Advisory Group to assist it in designing the Cancer Control Programme (See Appendix B) and commissioned a Working Group (See Appendix A) to review the available evidence and make informed and expert judgements on the most appropriate configuration of the Managed Cancer Control Networks and centres.

At one level the issues which underpin this approach may appear extremely complex. At another level they are in fact quite straightforward. Ireland has many excellent, highly skilled and expert cancer specialists. We do not at present make best or consistent use of these talents and we have not yet created the optimum environment for consistent success.

Ireland already achieves good outcomes by international standards in the field of paediatric cancer. Paediatric Cancer services are already concentrated appropriately to achieve critical mass and optimum care. Ireland has developed a successful and effective model of population based breast cancer screening. BreastCheck's clinical performance is based on a case volume related centralised model and it is achieving world class levels of performance.

However, Ireland has not thus far adopted this approach for acute adult cancer services in general. Ireland does not, in general, have good outcomes by international standards, for the population as a whole. The full implementation of the Cancer Strategy will enable us to do much better. The designation of cancer centres and the resulting reorganisation of services is a critical step.

I wish to acknowledge the hard work and commitment of all those involved in this process and, in particular, the members and other participants of the Advisory and Working Groups.

It is essential that the changes outlined in this Report are implemented if we are to achieve our true potential in cancer control. This Report was approved by the Advisory Group on September 24<sup>th</sup> 2007 and has been accepted by the Health Service Executive.

**Tony O'Brien**  
Chairman  
**HSE Managed Cancer Control Networks and Centres Working Group**

## **2. Essential Characteristics of a National Cancer Control Programme in order to implement a Managed Cancer Network model**

The full implementation of the Cancer Control Strategy and the achievement of optimal cancer outcomes will require the adoption of a new approach to the management of hospital based cancer services across geographical locations and traditional institutional boundaries.

For this reason it will be necessary for the National Cancer Control Programme to become the budget holder for all identifiable cancer related HSE expenditure. In this way it will have the capacity to redirect resources between services and the capacity to enter into an appropriate blend of governance arrangements ranging from direct management to commissioning and performance management models. The Programme will have the characteristics of an Agency within the HSE.

The Director of Cancer Control will require significant authority over cancer control assets to ensure that they are used to best effect. Equally the Director will require the authority to direct the discontinuation of any services that do not meet the standards and criteria set.

It is important to stress that the development of the National Cancer Control Programme signals a profound change in the approach of the health services to the management of key cancer control assets. Key cancer assets will be managed in the interests of the population as a whole in a tightly co-ordinated networked system. Key services and facilities are therefore no longer to be regarded as the prized assets of individual institutions. It is an essential characteristic of the Cancer Control Programme that such assets are understood to be under the ultimate control of the Cancer Control Programme itself.

Clarity about the character of the Programme is central to understanding the inter-relationship between the different cancer centres and the rationale for the distribution of specific services between those centres. This can be illustrated in the context of radiation oncology.

When completed, the National Plan for Radiation Oncology will ensure the public provision of radiotherapy at six (6) public sites in the country. However access to these services will be equal as between all eight (8) managed cancer control centres. It should not be regarded as necessary for each cancer centre to have radiotherapy on its own site in order for its patients to have equality of access to the radiation oncology service.

The radiation oncology facilities being developed under the national plan will be controlled by the National Cancer Control Programme, will operate to a single set of operational standards and protocols, and will provide absolute equality of access based on clinical need. A similar approach will be applied to all other sub-specialties.

## Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

The National Cancer Control Programme will also<sup>1</sup>:

- Be committed to regional implementation of interventional cancer control services according to nationally derived policies and plans.
- Define national operational standards and 'best practices' according to evidence of benefit on a tumour by tumour basis.
- Monitor compliance with practices of cancer control according to commonly agreed 'best practices' based upon evidence for most cost-effective use of public funds.
- Ensure accountability for the delivery of interventional services according to annual operating plans (incorporating volumes, access, quality and safety) within agreed budgets and with public reporting of performance, quality and safety measures.
- Establish a strategy for cancer research across institutions (university, institution and foundation-based), including the integration of science and medicine towards achieving enhanced cancer control outcomes.
- Act according to ethical and moral standards/principles consistent with 'best practices' of cancer control and optimal use of public funds for public health benefits.
- Develop common infrastructure capabilities to facilitate population-based, outcomes focused cancer control, i.e. ICT, web-site, health records (EHR) etc.
- Ensure that staff work within accepted/established norms of competence (as defined through programmes relating to professional disciplines of care, and including reporting relationships, manpower and workload standards and expectations of competence). Centres ensure the presence and application of procedures to ensure compliance.
- Be committed to 'outreach' or provision of expertise across communities as a means of minimizing impacts of geography/distance.

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<sup>1</sup> The significant input of Dr Simon B. Sutcliffe, President, BC Cancer Agency, in assisting with the definition of Characteristics of a National Cancer Control Programme is acknowledged.



### **3. Operation of Managed Cancer Control Networks**

Managed Cancer Control Networks will facilitate the provision of care which is fully integrated between primary care, hospitals, palliative care, psycho-oncology and supportive care. This will enable full advantage to be taken of the resources available to ensure the delivery of services that are of the highest quality and are equitable and accessible. The emphasis in such a network will be on connection and partnership rather than isolation and self-sufficiency, on distribution of resources rather than centralisation, and on maximising the benefits for all patients.

A Managed Cancer Control Network must feature the sharing of patients, expertise and resources. It will allow, for example, hospitals to cooperate to provide services when the population base of each is too small for them to do this in isolation. A good example will be radiotherapy which should exist in each network and provide access to patients from all centres within that region in a manner which is determined by clinical need as distinct from other considerations.

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

Managed Cancer Control Networks will require capacity for Human Resources development, including education, training and post-graduate development across a range of professions related to cancer control (service delivery, academia, and support services);

Managed Cancer Control Networks will require system capacity expansion potential – future opportunities to expand both national and regional capacity through:

- Facilities expansion (new and/or modifications to existing)
- Capital equipment expansion
- Services expansion – both standard and sub-specialty services
- Research capacity expansion (new facilities and/or modifications to existing clinical and/or university facilities)
- HR training facilities expansion – technical/trade schools, academic facilities, professional ‘placement’ and training.

#### **4. Criteria for the designation of Cancer Centres**

Successful cancer centre models elsewhere have been examined in conjunction with the Strategy. On the basis of this examination the following criteria have been established for the designation and ongoing development of cancer centres:

- Each Cancer Centre must serve a population of at least 500,000
- In the Irish context each of the four HSE Regions will be required to have broad self sufficiency in respect of the most common cancers
- Each HSE Region will have two Cancer Centres in a Managed Cancer Control Network.
- Rare and complex cancers will be treated by a subset of the eight cancer centres, consistent with evidence based practice and likely population incidence
- Centres will be designated for the treatment of rare and complex cancers based on an analysis of existing patterns of care and pre-existing resources within the limitations of the criteria outlined above.
- Cancer Centres must be well supported by general medical and surgical infrastructure (including all general consultation services, including pathology, lab-medicine and radiology/imaging as well as support services, e.g. respiratory, physiotherapy, occupational therapy, rehabilitation, nutrition, palliative care)
- Cancer Centres will require availability of critical surgical subspecialty services to support cancer control activity
- Cancer Centres will require availability of medical oncology/systemic therapy support – consultation, therapy, curative and palliative therapies, clinical trials, etc.
- Host hospitals must be receptive to and have the capacity to sustain a multi-disciplinary team environment engaging health professionals across common clinical services and academic endeavours
- Cancer Centres will require host hospitals with an academic environment – availability of university and/or technical education facilities for education and specialty training for health professions
- Cancer centres will require a research environment within the national network – availability of university facilities, research institutions and research infrastructure

## 5. Anatomical Site Specific Cancers and Cancer Centres

Evidence related to cancer volumes and cancer outcomes has been reviewed in order to determine the number of centres that should be involved in the diagnosis and treatment of each form of cancer.

### **Cancers have been categorised as follows:**

- Those requiring more than one Cancer Centre per Network;
- Those requiring one Cancer Centre per Network;
- Those requiring less than one site per network;
- Those requiring one National Centre only.

### **This process has been additionally informed by:**

- A “principles document” commissioned from the British Columbia Cancer Agency
- Existing international recommendations for the organisation of individual anatomical site specific cancers (listed below), where they are available;
- information on cancer incidence and mortality, cancer projections and hospital utilisation data;
- Demography and hospital utilisation data
- Expert opinion from the Advisory and Working Groups.

The *National Quality Assurance Standards for Symptomatic Breast Disease Services* has also been reviewed. An approach to the implementation of these standards has been developed and this has also served as a general template for the change management approach for other symptomatic services following the designation of the cancer centres. See section 6.

Following designation, all acute sector cancer investment will be re-directed to the selected centres and away from existing fragmented services.

It will be necessary to strengthen services at the eight centres to enable them to cope effectively with the workload which will be redirected from elsewhere. It will also be necessary to develop mechanisms to enable appropriate expertise located outside the eight centres to be migrated into re-configured services.

## Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

The following are identified as core operating requirements for each Cancer Centre in respect of each tumour group:

- All patients must be seen, reviewed, treatment decisions made, and treated by an MDT team prior to surgical or other intervention
- Provision of national protocols for treatment options and follow-up care plans on a tumour by tumour basis
- Specialist nursing
- Dual / Tri modality care – access to pre and post op Radiation Oncology
- Adequate access to appropriate radiology and pathology services as well as other laboratory services
- Appropriate access to prosthetic and reconstructive services
- Full participation in research including clinical trials
- Undergraduate and postgraduate teaching in oncology
- Rapid access clinics
- Dietetic services
- OT, physiotherapy and other support services on site
- Counselling services
- Access to genetic services
- Availability of clinical and compounding pharmaceutical services
- Psycho oncology services
- Social work services
- Community care services on discharge
- Access to day bed/ambulatory care facilities during therapies
- Access to specialist palliative care

The National Programme will need sufficient resources to implement appropriate systems of clinical and other QA audit together with population based cancer surveillance.

## 6. Designation of Cancer Centres

Designated Cancer Centres will deliver diagnostic, surgical, medical (systemic) and radiation oncology services.

The delivery of systemic therapy services (medical oncology/chemotherapy), once centrally planned, will be delivered within the Network under national protocols. Patient support and palliative care services will also be provided at local level to ensure ease of access.

Cancer Centres will be located and networked within each of the four HSE administration regions.

The HSE Regions are:

- HSE Dublin North East
- HSE Dublin Mid Leinster
- HSE South
- HSE West

The Managed Cancer Control Networks and designated Cancer Centres within each Region will be as follows:

<b>Dublin North East</b>
1. Beaumont Hospital, HSE Dublin North East
2. Mater Misericordiae Hospital, HSE Dublin North East
<b>Dublin Mid Leinster</b>
3. St James's Hospital, HSE Dublin Mid Leinster
4. St Vincent's University Hospital, HSE Dublin Mid Leinster
<b>HSE South</b>
5. Cork University Hospital, HSE South
6. Waterford Regional Hospital, HSE South
<b>HSE West</b>
7. University College Hospital Galway, HSE West (with some linkage to Letterkenny see page 12)
8. Limerick Regional Hospital, HSE West

## Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

### Linkage to Letterkenny

There are particular and unique geographical circumstances applying to Donegal. This is reflected in north-south co-operation in the provision of radiotherapy from Belfast.

On a sole exception basis, the Managed Cancer Control Network in the West will therefore be permitted to enter into outreach service delivery in Letterkenny as an **additional** activity. This exception is subject to:

- The core case volumes at Galway meeting the minimum criteria (not taking into account any remote care caseload arising from this provision)
- All other QA criteria being satisfied on the same basis as for care delivered in Galway
- Services to be provided by staff attached to the Galway Cancer Centre
- Integrated clinical governance provided by the Galway Centre
- Outreach activity if undertaken, should be incorporated in rigorous process and outcome audit as though the activity took place at Galway to ensure that the provision of such an outreach service does not serve to place patients availing of it at any disadvantage compared with patients treated in Galway
- The potential to meet the needs of cancer patients in Donegal through North-South initiatives, such as the Belfast Radiation Oncology service must be optimised and fully facilitated

## **7. The Configuration of services per Anatomical Site Specific Cancers is as follows.**

**The section of the Report details the process of change in relation to each major anatomical site specific cancers. It specifies the number of centres which will be designated for the purpose of providing primary curative surgery in the context of full multi-disciplinary care.** For each of the anatomical site specific cancers to be treated at less than eight of the designated cancer centres, the National Cancer Control Programme will review data and other available evidence and designate centres accordingly.

### **Breast**

There are currently about 2,000 breast cancers managed surgically in the public hospital system in Ireland. It can be expected that BreastCheck, the National Breast Screening Programme will reduce this number of symptomatic presentations over time by between 33% and 50%. Taking into account existing levels of activity in some larger Centres, and the minimum throughput (150 new cases per year) in the report of the Expert Group chaired by Professor O'Higgins, this indicates that Ireland will require no more than eight such Centres.

**It has been concluded that the treatment of symptomatic breast disease will be delivered at all Eight (8) Cancer Centres.**

The implementation of the transition to eight centres outlined below illustrates the approach of the National Cancer Control Programme to the reorganisation of cancer services for each tumour group.

Services will be withdrawn sequentially from hospitals which do not meet the defined criteria for delivery of symptomatic breast care, commencing with the lowest volume hospitals and ultimately including all hospitals which do not meet the Guideline standards. Arising from the designation of cancer centres, the HSE will direct the following hospitals with low case volumes to no longer provide multi-disciplinary symptomatic breast services and surgical treatment with **immediate** effect:

1. Naas General Hospital
2. Tullamore General Hospital
3. St Columcille's Hospital, Loughlinstown
4. Mallow General Hospital
5. Louth County Hospital
6. Cavan General Hospital
7. Our Lady's Hospital, Navan
8. Mid Western Regional Hospital, Nenagh
9. Ennis General Hospital
10. St Michael's Hospital, Dun Laoghaire
11. Roscommon County Hospital
12. Portlinculla Hospital
13. Mercy University Hospital, Cork (Cytology and Histopathology services in association with SIVUH exempted)



## Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

A number of these hospitals have in practice already discontinued symptomatic breast services. The National Hospitals Office has already planned the redirection of this symptomatic caseload.

Additional groups of hospitals will be similarly directed, in line with the further development of quality assured capacity in the eight designated centres.

It has also been concluded that it is necessary to ensure that HSE provided or funded facilities are no longer available to provide services, such as cytology and histopathology, to public or private sector hospitals and clinics which do not meet the O'Higgins guidelines, or in the absence of appropriate multi-disciplinary processes. Independent verification of such compliance by private sector providers will be required.

### **Colon**

It has been concluded that curative surgical treatment of primary colon and rectal cancers should be distinguished due to the high level of care and surgical skill required for the treatment of rectal disease.

It has been concluded that the curative surgical treatment of primary colon cancers will be delivered at all **Eight (8) Cancer Centres**

### **Colorectal**

The treatment of colorectal cancers was identified as a subset of colon cancers.

It has been concluded that curative surgical treatment of primary colorectal cancer should be delivered in **Four (4) Centres, one (1) within each Network**.

### **Thoracic**

It has been concluded that there is a need for **Four (4) Centres nationally, one (1) within each Network**, for the curative surgical treatment of primary thoracic cancers.

### **Testicular**

It has been concluded that there is a need for **Four (4) Centres nationally, one (1) within each Network**, for the curative surgical treatment of primary testicular cancers

### **Upper GI**

The Working Group concluded that there is a need for **Two (2) Centres nationally** for the curative surgical treatment of primary Upper GI cancers.

### **Hepatobiliary including Pancreas**

It has been concluded that curative surgical treatment of primary Hepatobiliary cancers will be provided in **One (1) National Centre**.

### **Gynaecological**

It has been concluded that there is a need for **Four (4) Centres nationally, one (1) within each Network**, for the curative surgical treatment of primary gynaecological cancers.

Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

### **Brain and Other CNS**

It has been concluded that curative surgical treatment of primary Brain and Other CNS diseases will be provided in **One (1) National Centre**.

### **Haematological**

It has been concluded that there is a need for **Four (4) Centres nationally, one (1) within each Network**, for the treatment of haematological cancers.

### **Head and Neck**

It has been concluded that curative surgical treatment of complex primary Head and Neck diseases will be treated in **One (1) National Centre**.

### **Paediatric Oncology**

It has been concluded that Paediatric Oncology will continue to be provided in **One (1) National Centre**.

This model is already operating with considerable success. Every child who develops cancer has their diagnosis established and treatment planned at the OLHSC in Crumlin. This model of care has resulted in Ireland having a better performance for cancer care for children than adults, when compared to European benchmarks.

OLHSC oncology services should continue until the new National Children's Hospital is established and it should therefore be the appropriate centre for the delivery of paediatric oncology thereafter.

### **Primary Bone and Soft Tissue Sarcomas**

It has been concluded that there is a need for **One (1) National Centre** for the treatment of Primary Bone and Soft Tissue Sarcomas.

### **Skin**

It has been concluded that there is a need for **Four (4) Centres nationally, one (1) within each Network**, for the treatment of complex skin cancers, requiring multi disciplinary care.

### **Urological**

It has been concluded that there is a need for **Four (4) Centres nationally, one (1) within each Network**, for the curative surgical treatment of primary urological cancer.

## Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

This Report and its recommendation has been accepted by the HSE and implemented as follows:

### **8. How will these changes be implemented?**

The implementation of the Managed Cancer Control Networks will necessitate tapering in of additional capacity at the designated centres in tandem with the sequential withdrawal of services from other locations. It will be necessary for the distribution of other acute services in the hospital sector to be rebalanced by the National Hospital's Office.

It is likely that those hospitals withdrawing from the provision of surgical oncology will be in a position to receive non-oncology services displaced from the designated cancer centres as a result of their increased oncology workloads and resulting demands on core services and facilities.

In order to ensure the rapid transformation of cancer care in line with the Strategy for Cancer Control it will be necessary for the HSE to put in place arrangements which allow for:

- i. Providing the Director of cancer control with full control over the use of funding for all cancer control activity within hospitals
- ii. Non cancer related clinical activity to be moved, through the application of incentives by the HSE, from designated cancer centres to other locations thereby allowing capacity to be increased in the cancer centres
- iii. The Director of cancer control to provide incentives for care to be provided through cancer centres, while applying financial disincentives to smaller facilities which are not designated as cancer centres to ensure that care does transfer to designated centres
- iv. Development of standardised care pathways for individual cancer types to be applied to each managed cancer control network which reflect the designation of cancer centres
- v. Publication and marketing of information for GPs and the public in general on care pathways, accessibility and referral criteria and on waiting times for such services to ensure that fully informed referral decisions are made by patients and general practitioners
- vi. A structured programme of quality assurance, support and information services to underpin the re-organisation of services so as to ensure that cancer patients will receive quality services as close to home as possible.
- vii. It will be a priority for the National Cancer Control Programme to establish detailed transition plans for the migration of services in accordance with quality assurance guidelines to be established for each tumour group.

## Establishment of Managed Cancer Control Networks and Designation of Eight Cancer Centres

It will take time for these arrangements to be fully developed and implemented. The HSE has made initial decisions in respect of some cancers in smaller centres which will be implemented as follows:

- 13 centres (see page 16) to stop doing breast cancer surgery immediately, to be followed by further staged reductions in the number of centres.
- In addition to this, all non Cancer Centres will be directed not to conduct low volume, complex, elective cancer surgery for a number of primary cancers such as lung, pancreas, oesophagus, rectum etc. The specific hospitals will be identified through analysis of surgical activity on a hospital specific basis with a view to enacting these changes by January 2008.
- St Luke's Hospital, Rathgar will be integrated in the Cancer Control Programme and continue in operation pending full implementation of the National Plan for Radiation Oncology.

The HSE will actively inform the public of these decisions as they are made and will actively use financial incentives and other control measures to ensure that hospitals comply.

# Appendix 2

## Cancer Surgery Activity within and without cancer centres 2007 – 2013

Distribution of discharges from public hospitals following primary surgical treatment of the following cancers: rectal, upper gastrointestinal, prostate, renal, testicular, bladder, breast, lung, ovarian, uterine and radical cervical resection for a cancer diagnosis.

YEAR	ALL OESOPHAGEAL RESECTIONS for Upper GI cancers			ALL GASTRECTOMIES for Upper GI cancers		
	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)
2007	84 (62.7)	50 (37.3)	134 (100.0)	86 (55.5)	69 (44.5)	155 (100.0)
2008	100 (71.9)	39 (28.1)	139 (100.0)	106 (62.4)	64 (37.6)	170 (100.0)
2009	104 (73.8)	37 (26.2)	141 (100.0)	98 (59.4)	67 (40.6)	165 (100.0)
2010	104 (73.2)	38 (26.8)	142 (100.0)	124 (68.5)	57 (31.5)	181 (100.0)
2011	114 (73.5)	41 (26.5)	155 (100.0)	90 (62.9)	53 (37.1)	143 (100.0)
2012	96 (75.6)	31 (24.4)	127 (100.0)	90 (60.4)	59 (39.6)	149 (100.0)
2013	96 (77.4)	28 (22.6)	124 (100.0)	87 (66.4)	44 (33.6)	131 (100.0)

Source: HIPE, ESRI. Data generated by HIPE Portal.

YEAR	ALL RECTAL CANCER SURGERY			ALL LUNG CANCER SURGERY		
	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)
2007	190 (43.4)	248 (56.6)	438 (100.0)	241 (100.0)	0 (0.0)	241 (100.0)
2008	199 (49.1)	206 (50.9)	405 (100.0)	272 (100.0)	0 (0.0)	272 (100.0)
2009	237 (51.7)	221 (48.3)	458 (100.0)	282 (100.0)	0 (0.0)	282 (100.0)
2010	249 (54.2)	210 (45.8)	459 (100.0)	297 (100.0)	0 (0.0)	297 (100.0)
2011	279 (66.4)	141 (33.6)	420 (100.0)	321 (100.0)	0 (0.0)	321 (100.0)
2012	311 (72.0)	121 (28.0)	432 (100.0)	401 (100.0)	0 (0.0)	401 (100.0)
2013	317 (76.6)	97 (23.4)	414 (100.0)	385 (100.0)	0 (0.0)	385 (100.0)

Source: HIPE, ESRI. Data generated by HIPE Portal.

YEAR	ALL PROSTATE CANCER SURGERY			ALL RENAL CANCER SURGERY		
	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)
2007	156 (60.9)	100 (39.1)	256 (100.0)	182 (68.9)	82 (31.1)	264 (100.0)
2008	139 (54.7)	115 (45.3)	254 (100.0)	192 (69.3)	85 (30.7)	277 (100.0)
2009	150 (57.7)	110 (42.3)	260 (100.0)	211 (75.6)	68 (24.4)	279 (100.0)
2010	186 (61.4)	117 (38.6)	303 (100.0)	228 (76.5)	70 (23.5)	298 (100.0)
2011	241 (68.9)	109 (31.1)	350 (100.0)	222 (75.3)	73 (24.7)	295 (100.0)
2012	247 (72.4)	94 (27.6)	341 (100.0)	258 (75.7)	83 (24.3)	341 (100.0)
2013	201 (69.3)	89 (30.7)	290 (100.0)	240 (77.9)	68 (22.1)	308 (100.0)

Source: HIPE, ESRI. Data generated by HIPE Portal.

YEAR	ALL BLADDER CANCER SURGERY			ALL TESTICULAR CANCER SURGERY		
	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)
2007	239 (54.6)	199 (45.4)	438 (100.0)	65 (46.8)	74 (53.2)	139 (100.0)
2008	289 (57.1)	217 (42.9)	506 (100.0)	73 (54.1)	62 (45.9)	135 (100.0)
2009	376 (64.5)	207 (35.5)	583 (100.0)	61 (53.5)	53 (46.5)	114 (100.0)
2010	370 (58.0)	268 (42.0)	638 (100.0)	77 (55.8)	61 (44.2)	138 (100.0)
2011	382 (61.9)	235 (38.1)	617 (100.0)	70 (53.8)	60 (46.2)	130 (100.0)
2012	369 (60.7)	239 (39.3)	608 (100.0)	80 (59.3)	55 (40.7)	135 (100.0)
2013	377 (59.7)	255 (40.3)	632 (100.0)	60 (53.6)	52 (46.4)	112 (100.0)

Source: HIPE, ESRI. Data generated by HIPE Portal.

YEAR	ALL BREAST CANCER SURGERY			ALL PANCREATIC TUMOUR SURGERY		
	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)
2007	1237 (54.7)	1026 (45.3)	2263 (100.0)	45 (59.2)	31 (40.8)	76 (100.0)
2008	1490 (58.4)	1060 (41.6)	2550 (100.0)	58 (65.9)	30 (34.1)	88 (100.0)
2009	1917 (78.1)	539 (21.9)	2456 (100.0)	44 (57.1)	33 (42.9)	77 (100.0)
2010	2465 (99.4)	15 (0.6)	2480 (100.0)	65 (72.2)	25 (27.8)	90 (100.0)
2011	2421 (99.6)	10 (0.4)	2431 (100.0)	45 (58.4)	32 (41.6)	77 (100.0)
2012	2423 (99.1)	23 (0.9)	2446 (100.0)	76 (79.2)	20 (20.8)	96 (100.0)
2013	2209 (99.8)	4 (0.2)	2213 (100.0)	80 (93.0)	6 (7.0)	86 (100.0)

Source: HIPE, ESRI. Data generated by HIPE Portal.

YEAR	ALL UTERINE CANCER SURGERY			ALL OVARIAN CANCER SURGERY		
	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)
2007	105 (44.3)	132 (55.7)	237 (100.0)	117 (57.9)	85 (42.1)	202 (100.0)
2008	169 (60.6)	110 (39.4)	279 (100.0)	158 (68.7)	72 (31.3)	230 (100.0)
2009	225 (69.2)	100 (30.8)	325 (100.0)	163 (71.2)	66 (28.8)	229 (100.0)
2010	197 (67.9)	93 (32.1)	290 (100.0)	142 (76.8)	43 (23.2)	185 (100.0)
2011	179 (67.8)	85 (32.2)	264 (100.0)	129 (74.1)	45 (25.9)	174 (100.0)
2012	198 (72.8)	74 (27.2)	272 (100.0)	179 (81.7)	40 (18.3)	219 (100.0)
2013	222 (80.4)	54 (19.6)	276 (100.0)	132 (88.6)	17 (11.4)	149 (100.0)

Source: HIPE, ESRI. Data generated by HIPE Portal.

YEAR	ALL RADICAL CERVICAL CANCER SURGERY			ALL OTHER CERVICAL CANCER SURGERY		
	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)	Number (%) within a Cancer Centre	Number (%) outside a Cancer Centre	Total (%)
2007	66 (55.9)	52 (44.1)	118 (100.0)	118 (10.6)	998 (89.4)	1116 (100.0)
2008	78 (61.9)	48 (38.1)	126 (100.0)	272 (23.9)	867 (76.1)	1139 (100.0)
2009	117 (68.4)	54 (31.6)	171 (100.0)	474 (30.8)	1067 (69.2)	1541 (100.0)
2010	110 (72.8)	41 (27.2)	151 (100.0)	438 (25.3)	1295 (74.7)	1733 (100.0)
2011	100 (65.8)	52 (34.2)	152 (100.0)	771 (28.2)	1961 (71.8)	2732 (100.0)
2012	79 (65.3)	42 (34.7)	121 (100.0)	718 (27.8)	1865 (72.2)	2583 (100.0)
2013	65 (72.2)	25 (27.8)	90 (100.0)	630 (27.6)	1651 (72.4)	2281 (100.0)

Source: HIPE, ESRI. Data generated by HIPE Portal.



## Data Definitions

**Rectal cancer surgery** is defined as any hospital discharge with a primary diagnosis of C19 (malignant neoplasm of rectosigmoid junction), C20 (malignant neoplasm of rectum), D011 (carcinoma in situ of rectosigmoid junction) or D012 (carcinoma in situ of rectum) AND any procedures in blocks 934 (rectosigmoidectomy or proctectomy), 935 (anterior resection of rectum) or 936 (total proctocolectomy).

**Oesophageal resections for upper GI cancer** is defined as any hospital discharge with a primary discharge of C15 (malignant neoplasm of oesophagus), C16 (malignant neoplasm of stomach), D001 (carcinoma in situ of oesophagus) or D002 (carcinoma in situ of stomach) AND any procedures in blocks 858 (oesophagectomy by abdominal & thoracic mobilisation), 859 (oesophagectomy by abdominal & cervical mobilisation), 860 (oesophagectomy by abdominal & transthoracic mobilisation) or 3029400 (cervical oesophagectomy).

**Gastrectomy following upper GI cancer** is defined as any hospital discharge with a primary discharge of C15 (malignant neoplasm of oesophagus), C16 (malignant neoplasm of stomach), D001 (carcinoma in situ of oesophagus) or D002 (carcinoma in situ of stomach) AND any procedures in blocks 875 (partial gastrectomy), 879 (other gastrectomy) or 3052000 (local excision of lesion of stomach).

**Lung cancer surgery** is defined as any hospital discharge with a primary diagnosis of C33 (malignant neoplasm of trachea), C34 (malignant neoplasm of bronchus & lung), D021 (carcinoma in situ of trachea) or D022 (carcinoma in situ of bronchus & lung) AND any procedures in blocks 551 (partial resection of lung), 552 (lobectomy of lung) or 553 (pneumonectomy).

**Prostate cancer surgery** is defined as any hospital discharge with a primary diagnosis of C61 (malignant neoplasm of prostate) or D075 (carcinoma in situ of prostate) AND any of the following procedures: 3720900 (radical prostatectomy), 3721000 (radical prostatectomy with bladder neck reconstruction) or 3721100 (radical prostatectomy with bladder neck reconstruction and pelvic lymphadenectomy)

**Bladder cancer surgery** is defined as any hospital discharge with a principal diagnosis of C67 (malignant neoplasm of bladder) or D090 (carcinoma in situ of bladder) AND any of the following procedures in blocks 1100 (Endoscopic resection of bladder lesion or tissue), 1101 (Endoscopic resection of bladder neck), 1102 (Cystectomy) or 1103 (Other excision procedures on bladder).

**Testicular cancer surgery** is any hospital discharge with a principal diagnosis of C62 (malignant neoplasm of testis) AND with any of the following procedure block codes: 1184 (Orchidectomy) or 3760700 (Radical excision of retroperitoneal lymph nodes) or 3761000 (Radical excision of retroperitoneal lymph nodes, subsequent).

**Renal cancer surgery** is any hospital discharge with a principal diagnosis of C64 (malignant neoplasm of kidney, apart from renal pelvis) or C65 (malignant neoplasm of renal pelvis) AND with any of the following procedure block codes: 1048 (partial nephrectomy), 1049 (complete nephrectomy) or 1053 (radical nephrectomy) or 1054 (nephroureterectomy).

**Breast cancer surgery** is defined as any hospital discharge with a primary diagnosis of C50 (malignant neoplasm of breast) or D05 (carcinoma in situ of breast) AND any procedures in blocks 1744 (excision of lesion of breast), 1747 (subcutaneous mastectomy) or 1748 (simple mastectomy).

**Pancreatic tumour surgery** is defined as any hospital discharge with a primary diagnosis of C24 – C25 (malignant neoplasm of other and unspecified parts of the biliary tract, malignant neoplasm of pancreas), D136 – D137 (Benign neoplasm of pancreas), C221 (Intrahepatic bile duct carcinoma), K862 – K863 (cyst and pseudocyst of pancreas) AND any procedures in block 978 (pancreatectomy), 979 (other excisions procedures of pancreas), 3057800 (excision of lesion of pancreas or pancreatic duct) or 3045802 (local excision of lesion of bile ducts or sphincter of Oddi).

**Uterine cancer surgery** is defined as any hospital discharge with a principal diagnosis of C54 (malignant neoplasm of the corpus uteri) or C55 (malignant neoplasm of uterus, part unspecified) AND any procedures in blocks 1268 (Abdominal hysterectomy), 1269 (Vaginal hysterectomy) or Pelvic Exenteration procedures - anterior (9045000) posterior (9045001) and total (9045002).

**Ovarian cancer surgery** is defined as any hospital discharge with a principal diagnosis of C56 (malignant neoplasm of ovary) or C57 (malignant neoplasm of other and unspecified female genital organs) AND with any procedures in blocks 1243 (Oophorectomy), 1252 (Salpingo-oophorectomy), 1268 (Abdominal hysterectomy), 1269 (Vaginal hysterectomy) or Pelvic Exenteration procedures - anterior (9045000), posterior (9045001) and total (9045002).

**Radical cervical cancer surgery** is defined as any hospital discharge any hospital discharge with a principal diagnosis of C53 (malignant neoplasm of the cervix uteri) or D06 (carcinoma in situ of the cervix uteri) AND with any procedures in blocks 1268 (Abdominal hysterectomy), 1269 (Vaginal hysterectomy) or Pelvic Exenteration procedures - anterior (9045000) posterior (9045001) and total (9045002).

**All other cervical cancer surgery** is defined as any hospital discharge with a principal diagnosis of C53 (malignant neoplasm of the cervix uteri) or D06 (carcinoma in situ of the cervix uteri) AND with any procedures in blocks 1275 (destruction procedures of the cervix) or 1276 (excision procedures of the cervix).

# Appendix 3

## Update on the implementation of the 55 Recommendations of the 2006 Cancer Control Programme. June 2014

In the intervening years since the publication of the 2006 Cancer Strategy the roles and remits of many of the bodies referred to have changed so not all actions are now appropriate for the body identified. Many of the oversight/monitoring roles originally identified for HIQA have now been adopted by the NCCP or the NCRI (i.e. recommendations 40, 41, 43, 45, 46, 49).

	Recommendation	Update June 2014
1	A third National Cancer Forum should be appointed by the Minister with terms of reference and composition reflecting the changed health system.	Following the 2006 Strategy for Cancer Control, the National Cancer Control Programme was established in 2007 in the HSE. The NCCP is working to implement the Strategy which aims to achieve better cancer prevention, early detection (including screening programmes) and well organised programmes of treatment that maximise survival through a co-ordinated national service, based on international evidence and best practice. Regular ongoing meetings are held between the Department of Health and the NCCP on the monitoring of progress and the development of cancer policy

	Recommendation	Update June 2014
2	<p>The recommendations of the Review of the National Health Promotion Strategy, 2004 should be implemented across all sectors.</p>	<p>The Department of Health is leading a new, whole-of-Government, whole-of-society, approach to health improvement, <i>Healthy Ireland</i>. The publication of <i>Healthy Ireland – A Framework for Improved Health and Wellbeing 2013 - 2025</i> is a major milestone for the future provision of health and social care in Ireland. It provides the structure to enable service providers to influence major change in the development, implementation and delivery of health and social care for future generations. It emphasises the need for a collaborative approach between the health sector and other areas of Government and public services to work together, to affect improvements in social protection, food safety, education, housing, transport and the environment. These are the key factors which influence health and social outcomes for the entire population. Tackling health inequalities, introducing preventative health measures and health promotion activities, to be delivered in the community, were the key messages in the consultative process which informed the publication of <i>Healthy Ireland</i>. It is widely recognised that these factors are economically more prudent than costly acute care and treating increasingly costly long-term chronic diseases.</p> <p>The HSE National Service Plan 2014 identifies the reconfiguration and realignment of work practices, programmes and teams to deliver against the actions in <i>Healthy Ireland</i> as a key priority</p> <ul style="list-style-type: none"> <li>• Develop a cross-divisional ‘health services’ 3 year implementation plan and work programme for <i>Healthy Ireland</i>.</li> <li>• Review workforce capacity commencing with community dietetics and community nursing services.</li> <li>• Review programmes, funding strategies and activities on a phased basis across the Division to ensure they are a) evidence-based, sustainable and cost effective; b) orientated to promote health and reduce disease among communities and populations most at risk; and c) appropriately aligned to the work plans of the other Divisions.</li> <li>• Develop Health Intelligence with the support of internal and external partners.</li> </ul> <p>Other national disease specific policies and strategies have been produced and resourced including:</p> <ul style="list-style-type: none"> <li>• HSE Framework for Action on Obesity (2008-2012)</li> <li>• The Establishment of a Ministerial Special Action Group on Obesity</li> <li>• The National Tobacco Control Framework (2010)</li> <li>• The National Drugs Strategy 2009-2016</li> <li>• Promoting Physical Activity in Ireland (2009)</li> <li>• Building Healthier Hearts (1999) and National Cardiovascular Health Policy 2010-2019</li> <li>• The National Obesity Task Force (2005).</li> <li>• The HSE established a Clinical Programme for the Prevention of Chronic Diseases</li> <li>• Roll out of Health Promoting Schools in the HSE-South</li> <li>• 2 cities in the South and 1 in the West established as WHO designated healthy cities – Cork, Waterford and Galway and the establishment of a National Network for Healthy Cities in Ireland</li> </ul> <p>The National Cancer Control Programme has a community oncology section which has a significant focus on health promotion and works with the HSE Health and Wellbeing Division to promote healthy lifestyle and reduce cancer incidence.</p>

	Recommendation	Update June 2014
3	Compliance with all provisions of the Public Health (Tobacco) Acts, 2002 and 2004 should be monitored.	<p>Tougher regulation of the tobacco industry and a proactive approach to law enforcement have been key pillars of government tobacco control policy since 2000.</p> <p>The HSE Environmental Health Service is responsible for enforcing tobacco control legislation e.g. on smoking in the workplace, under-age sales of tobacco, point of sale restrictions and illegal promotions by the tobacco industry.</p> <p>The HSE Environmental Health Service implements a national tobacco control inspection programme to assess and secure legislative compliance. In general, compliance with the Public Health (Tobacco) Act provisions has been high. However, significant problems remain in relation to smoking in the work place, (section 47 of the Act) particularly in relation to licensed premises and non-compliant smoking shelters and also in relation to sales of tobacco products to minors under the age of 18 (section 45 of the Act).</p> <p>Since the commencement of Section 47 in 2004 until the end of 2013 a total of 251 prosecutions were taken by the HSE resulting in 263 convictions. These prosecutions and convictions were mainly in respect of licensed premises including; pubs, night-clubs and hotels. In recent years more than 50% of prosecutions have related to smoking areas in licensed premises. A number of owners and proprietors have been prosecuted and convicted on multiple occasions.</p> <p>In relation to the sale of tobacco to minors, the HSE undertakes compliance checks, also known as test purchases, in retail outlets to determine if retailers will sell tobacco products to minors. The EHS test purchase programme together with associated retail audits highlight a significant ongoing non-compliance issue. As a result there have been 43 prosecutions with 33 convictions between 2009 and 2013.</p> <p>The HSE operates a lo-call Compliance Line (1890 333 100) that offers an effective route through which the public can register complaints and concerns in respect of tobacco control. As a support mechanism for the National Tobacco Control Inspection Programme, the line plays an important role in building and maintaining compliance.</p> <p>The HSE National Tobacco Control Office manages the register of tobacco retailers.</p> <p>Compliance and enforcement of tobacco legislation is the responsibility of Environmental Health Officers of the HSE.</p> <p>The National Tobacco Control Inspection Programme outlines the priorities each year, based on available resources. Compliance rates with tobacco legislation are generally very high. Based on inspections undertaken in 2012, compliance with smoke-free workplace legislation is 98%.</p> <p>The HSE's National Tobacco Control Office (formerly Office of Tobacco Control) undertakes periodic independent audit of retail premises to measure compliance with point-of-sale (POS) and sales to minor's legislation. The most recent Audit was undertaken in 2011. In 2011, 98% of premises surveyed were compliant with POS provisions. 73% of premises refused to sell cigarettes to minors.</p> <p>The National Tobacco Control Office (NTCO) was established in January 2011 following the dissolution of the Office of Tobacco Control under the Public Health (Tobacco) (Amendment) Act 2010. The remit of the NTCO is to co-ordinate the tobacco control programme in the HSE. It has responsibility for discharging the statutory functions prescribed under the Public Health (Tobacco) Acts 2002-2012 and supporting and driving the delivery of the 61 actions in the Tobacco Control Framework 2010.</p> <ul style="list-style-type: none"> <li>• Additional undertaking by the HSE/DOH in relation to Tobacco Control include:</li> <li>• HSE Tobacco Control Framework(2010): <i>WHO MPOWER model</i></li> <li>• Tobacco Free Campuses Policy: <i>'smoking by employees, patients, visitors and any other parties will be prohibited within all HSE campuses on or before 31st December 2015'</i></li> <li>• Public Health (Tobacco) Acts 2002, 2004 &amp; 2009: <i>Smoke free workplace / public places: cinemas, restaurants etc</i></li> <li>• HSE Service Plan 2013: <i>Training of staff in Brief Intervention</i></li> </ul>

	Recommendation	Update June 2014
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.	Excise increases on cigarettes were achieved in Budgets as follows: 2006 – 50c 2007 – 30c 2008 – 50c 2009 – 25c 2010 – 0 2011 – 25c 2012 – 10c 2013 – 10c
5	Nicotine replacement therapy should be made available free of charge to all medical card holders.	Completed
6	The Report of the Strategic Task Force on Alcohol, 2002 should be implemented in full.	<p>The Government recently approved an extensive package of measures to deal with alcohol misuse to be incorporated in a Public Health (Alcohol) Bill. These measures are based on the recommendations contained in the Steering Group Report on a National Substance Misuse Strategy, 2012. The package of measures to be implemented will include provision for:</p> <ul style="list-style-type: none"> <li>• minimum unit pricing for alcohol products;</li> <li>• the regulation of advertising and marketing of alcohol;</li> <li>• structural separation of alcohol from other products in mixed trading outlets;</li> <li>• health labelling of alcohol products; and</li> <li>• regulation of sports sponsorship.</li> </ul> <p>The Government also approved that:</p> <p>Public health messaging relating to alcohol will be based on grams of alcohol. Weekly low-risk drinking guidelines should be 168 grams (17 standard drinks) for men and 112 grams (11 standard drinks) for women.</p> <p>The other measures will be progressed by the relevant departments and organisations.</p> <p>An Implementation Group for Alcohol has been established within the HSE to address the actions in the Report of the Steering Group on a National Substance Misuse Strategy for which the health service has responsibility.</p> <p>This Implementation Group is led by Social Inclusion (Primary Care Division) with a specific Health and Wellbeing sub group to progress all relevant actions. Work has commenced in regard to a communications strategy; actions in regard to prevention and enforcement. Environmental Health Services are actively working with the DOH in regard to regulations and legislation.</p>

	Recommendation	Update June 2014
7	<p>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.</p>	<p>A review carried out in July 2011 found that of the 24 recommendations relevant to the Health Sector, 12 have been implemented in full, there is significant progress in 3, 8 are progressing and will remain ongoing and there was partial implementation of 1. No recommendation was outstanding. In 2013-14 significant progress has been made re the “partially implemented recommendation above i.e. re highlighting obesity on the undergrad and post grad curriculum of those in relevant Health Sciences (see details below).</p> <p>In recent years there has been an increasing focus on obesity with the publication of the following documents:</p> <ul style="list-style-type: none"> <li>* HSE Framework for Action on Obesity 2008 – 2012</li> <li>* DOHC –HSE Physical Activity Guidelines for Ireland</li> <li>* DOHC Changing Cardiovascular Health : National Cardiovascular Health Policy 2010 – 2012</li> <li>* DOHC National Nutrition Guidelines &amp; Re-modelled Food Pyramid</li> <li>* HSE Childhood Obesity Surveillance Initiative (COSI) in the Republic of Ireland: Findings from 2008, 2010 and 2012</li> </ul> <p>The publication of <i>Healthy Ireland</i> underlines the importance of a healthy population as a major asset for Irish society however it also highlights adverse trends in relation to obesity, diabetes and physical activity. The HSE National Service Plan 2014 contains specific reference to further deliver on priority areas including diet and nutrition with a supporting package of obesity reduction programmes (€0.1m) targeted at key at risk groups. Examples of this is the expansion of the Smart Start Programme in Child Care facilities from 9 counties to 18 and the provision of funding to support W82GO programme for clinically obese children in the Children’s University Hospital, Temple Street, The introduction in Q4 2014 of school growth monitoring of 5-7 year olds in 4 pilot sites with communication of results to all parents, referral of parents of overweight children to self help resources &amp; community prevention programmes with clinically obese (&gt;98th centile) referred to the W82GO Lifestyle Intervention Programme provided by newly trained Multidisciplinary Teams in the community to support the 4 pilot sites. Clinical backup &amp; training via Temple Street Hospital - Hub &amp; Spoke approach. Approx 1,800 children in each of the 4 pilot areas will be measured with approx 450 (25%) expected to be overweight or obese (moving from surveillance to screening), with a view to eventual national roll out if deemed appropriate following evaluation.</p> <p>The NCCP also participates on the Royal College of Physicians Policy Group on Obesity.</p> <p>There has been significant ongoing work undertaken in regard to Obesity by the HSE in conjunction with key stakeholders;</p> <p>ICGP has developed a whole segment on obesity management <a href="http://www.icgp.ie/weightmanagement">www.icgp.ie/weightmanagement</a>.</p> <p>The HSE – ICGP Weight Management Treatment Algorithm stresses the link of obesity to cancer - the benefits of 10% weight loss (for those with a BMI &gt; 25) to a reduction in cancer deaths is stated. It is also recommended that cancer is addressed as part of the relevant medical history assessment.</p> <p>Childhood obesity has been a major focus in 2013. The HSE-ICGP Weight Management Treatment Algorithm for Children was published. In autumn 2013, Safefood launched a three year all island Childhood Obesity Social Marketing Campaign in partnership with the HSE and the Healthy Ireland Framework in the Republic of Ireland and the ‘Fitter Futures for All’ Implementation Plan in NI.</p> <p><a href="https://www.healthpromotion.ie/index.php/newsView/campaign_to_take_on_childhood_obesity">https://www.healthpromotion.ie/index.php/newsView/campaign_to_take_on_childhood_obesity</a></p>



	Recommendation	Update June 2014
7		<p>Publications have been produced for both parents &amp; health professionals and have been distributed nationwide to crèches, health centres, GP surgeries, public health nurses and local libraries. These are available to order under the obesity section of the health promotion website:</p> <p><i>Your Child's Weight a Guide to Preventing Childhood Obesity</i> available to download from <a href="https://www.healthpromotion.ie/hp-files/docs/HPM00851.pdf">https://www.healthpromotion.ie/hp-files/docs/HPM00851.pdf</a> Hard copies of this 20page A5 booklet can be ordered from <a href="http://www.healthpronotion.ie">www.healthpronotion.ie</a> Order Code: HPM00851</p> <p>A Guide for Health Professionals: Assisting Parents and Guardians in communicating with their children about body weight. <a href="http://www.hse.ie/weightmanagement">www.hse.ie/weightmanagement</a></p> <p>Other resources include Healthy Eating Schools Pack', &amp; Eat Smart Move More booklet and reward charts.</p> <p>The HSE-ICGP Healthy Weight Management Guidelines Before, During and After Pregnancy were produced. It is hoped to launch these with an accompanying support resource for health professionals – <i>Brief Intervention for Healthy Weight Management Before, During &amp; After Pregnancy</i> by year end.</p> <p>The HSE has dedicated a section of its website to informing health professionals of the resources available to support healthy weight management: <a href="http://www.hse.ie/weightmanagement/">http://www.hse.ie/weightmanagement/</a></p> <p>In 2013, updated growth charts were launched and training provided to relevant HSE staff for use with growth monitoring of children – these include guidance on assessment of BMI charts for detection of childhood obesity. <a href="http://www.hse.ie/growthmonitoring/">http://www.hse.ie/growthmonitoring/</a> By the end of 2014 an elearning module on <a href="http://www.hseland.ie">www.hseland.ie</a> will be available. The ICGP (funded by Safefood &amp; supported by the HSE) have developed a blended learning pack for primary care staff which includes growth monitoring.</p> <p>The introduction of a tax on sugar-sweetened drinks and improved nutritional labelling are among the priorities being considered. A Health Impact Assessment, on the potential impact on obesity following introducing of a tax on sugar sweetened beverages was presented to SAGO. It was undertaken by the IPH under the chairmanship of Prof. Donal O Shea.</p> <p>The NCCP itself has seconded a staff member from Health Promotion to support it in its work in educating health care professionals and the public on ways to reduce cancer.</p> <p>A review of the implementation of the Report of the Taskforce on Obesity concluded that significant progress had been made however there were challenges in fostering non-health sectoral leadership and in the development of workable, meaningful and sustainable mechanisms for intersectoral cooperation at national, regional and local levels.</p> <p>The Special Advisory Group on Obesity has recently established a sub group to develop a new Obesity Strategy.</p> <p>The NCCP itself has seconded a staff member from Health Promotion to support it in its work in educating health care professionals and the public on ways to reduce cancer.</p>

	Recommendation	Update June 2014
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.	<ul style="list-style-type: none"> <li>• The HSE works with other sectors to address the marketing of food to children. See Irish Heart Foundation "Marketing of Food and Beverages To Children: Stakeholder views on policy options in Ireland. Findings from the PolMark Report Dec. 2009". <a href="http://www.irishheart.ie/iopen24/pub/full_polmark_reportjan5th_final.pdf">www.irishheart.ie/iopen24/pub/full_polmark_reportjan5th_final.pdf</a></li> <li>• The Healthy Catering Guidelines for Staff and Visitors in Healthcare Facilities (DOHC) is being implemented via the Health Promoting Hospitals Network.</li> <li>• The HSE Corporate Catering Event Policy is being implemented within the HSE and is shared with other organisations e.g. HSE Community Games.</li> <li>• The HSE Salt Procurement Policy has had implications for the production (reformulation) of bread in companies seeking to supply HSE facilities.</li> <li>• The HSE submitted a number of submissions to the Broadcasting Authority of Ireland.</li> <li>• (BAI) in reviewing its code of standards for the advertising of food and drink to children. The revised code of standards, while not going far enough, will have an impact on the food and drink industry and hopefully will lead to product reformulations or new foods &amp; drinks that are low in Fat, Salt &amp; Sugar and higher in Fibre.</li> <li>• In conjunction with the Irish Heart Foundation the HSE promotes Happy Heart Catering Awards in all catering facilities. The standards are currently being revised to include calorie posting.</li> <li>• The HSE Healthy Vending Policy has been signed off by the Senior Management Team. The policy mandates a 60% "Better Choice" and 40% "Other" products in all vended offerings. This 60% Better Choice products can be revised upwards with authority given to local management to mandate 100% Better Choice products in key areas for vulnerable groups e.g. Paediatric wards &amp; clinic areas &amp; Diabetic Clinic waiting areas. Procurement plan to have a National Vending Contract in place by end September 2014.</li> <li>• The HSE Expert Group on Healthy Vending and Calorie Posting are working on a HSE Calorie Posting Policy to govern food provision in Staff Canteens, Visitor Restaurants &amp; Coffee Shops. Calorie posting is already included in the HSE Healthy Vending Policy. Letterkenny General and Cherry Orchard Hospitals will form a pilot to inform the policy and provide learning for its implementation. The Policy should be signed off by end 2014. The IHF will include calorie posting as part of the standard requirements for the Happy Heart Catering Award.</li> <li>• Currently the HSE, DOH (Hi), DCYA and Safefood are cooperating on a three year all island childhood obesity social marketing campaign with the aim of working with parents of 0-12 yrs from low income groups to eat more healthy food, reduce consumption of food of little or no nutritional value and to become more physically active.</li> </ul>

	Recommendation	Update June 2014
9	<p>The recommendations of the Report of the National Task Force on Obesity, 2005 in relation to physical activity should be implemented in full.</p>	<p><i>Healthy Ireland</i> emphasises the importance of increased physical activity to reduce chronic diseases and disabilities and underlines both the human and economic cost of overweight and obesity. A specific implementation plan for physical activity is currently being developed by the DOH in conjunction with key stakeholders (target date for final draft of the national physical activity plan March 2014).</p> <p>The HSE National Service Plan 2014 reinforces the objectives of <i>Healthy Ireland</i> in the need for increased physical activity. In addition to maintaining current provision (examples below) it also provides for supporting the DOH in the development and implementation of the national physical activity plan and will increase <i>Brief Intervention</i> training to GPs and expand the <i>Be Active After School Programme</i> from 18 counties to 23.</p> <ul style="list-style-type: none"> <li>• <a href="http://www.getirelandactive.ie">www.getirelandactive.ie</a> has been developed to be a one-stop shop for the promotion of physical activity in all its forms from participation to competition. In addition the HSE has (in partnership with relevant codes) established <a href="http://www.getirelandwalking.ie">www.getirelandwalking.ie</a>, <a href="http://www.getirelandcycling.ie">www.getirelandcycling.ie</a> and have signed a partnership deal with 8 other bodies to enhance participation in physical activity.</li> <li>• The GP Exercise Referral Programme and Green Prescription are being rolled out throughout the country in a phased basis</li> <li>• The HSE and DOH have established a Healthy Club Programme with the GAA</li> <li>• The HSE has developed the award winning Be Active After Schools Programme</li> <li>• In Partnership with ISC and Local Sports Partnership embarked on encouraging marginalised group to increase physical activity e.g. older people, people with disability, low income groups etc</li> <li>• The HSE is the Title Sponsor of Community Games</li> <li>• The HSE and Special Olympics developed a Healthy Athlete Programme</li> <li>• The HSE and Border Counties Child Care Committees Network have developed a national programme for all preschool facilities called Smart Start</li> </ul> <p>The HSE formed a National Steering Group on Obesity. This group translated the Taskforce recommendations for which the health service has a lead role into the HSE Framework for Action on Obesity 2008–2012. The HSE Steering Group Annual Review for 2012 states that the HSE achieved all recommendations of the National Taskforce on Obesity as pertaining to physical activity and the HSE.</p> <p>The HSE is currently working with the DoH and other stakeholders in regard to the development of a National Physical Activity Plan under the auspices of <i>Healthy Ireland</i>. A draft will be available for consultation in late August/early September. The plan takes a cross-sectoral approach as advocate in <i>Healthy Ireland</i> and will focus on a life course approach with getting people more active through walking, running, and through improved interagency working. Communicating the message of increasing physical activity will form a key element of the plan.</p>
10	<p>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.</p>	<p>In December of 2013 the Government published the Public Health (Sunbeds) Bill. Under the Public Health (Sunbeds) Act 2014 from the 21st of July 2014, it will be illegal for a sunbed operator to allow a person under 18 years of age to use a sunbed. All sunbed operators will be required to provide training for staff and display health warnings on their premises.</p>

	Recommendation	Update June 2014
11	<p>The public should be made aware that radon measurements can be undertaken by the Radiological Protection Institute of Ireland. Consideration should be given to providing financial support for testing in high-radon areas and for any necessary remedial work, on a means-tested basis.</p>	<p>The RPII have identified certain parts of the country, predominantly in the south east and the west as being at risk from radon. A map showing these "High Radon Areas" is published on their website. <a href="http://www.rpii.ie/radon-map.aspx">http://www.rpii.ie/radon-map.aspx</a></p> <p>In February this year The National Radon Control Strategy for Ireland was launched by the Minister for the Environment, Community and Local Government. The Strategy proposals which have a 4 year timeframe is set out under six general themes:</p> <ol style="list-style-type: none"> <li>1. Radon prevention in new buildings;</li> <li>2. Use of property transactions (sales and rental) to drive action on radon;</li> <li>3. Raising radon awareness and encouraging individual action on radon;</li> <li>4. Advice and guidance for individual householders and employers with high radon results;</li> <li>5. Promoting confidence in radon services; and</li> <li>6. Addressing radon in workplaces and public buildings.</li> </ol> <p>The Strategy document is available at <a href="http://www.environ.ie/en/Publications/Environment/EnvironmentalRadiation/FileDownload,35484,en.pdf">http://www.environ.ie/en/Publications/Environment/EnvironmentalRadiation/FileDownload,35484,en.pdf</a></p> <p>The RPII carry out public awareness campaigns of the dangers of exposure to radon in the home in these areas. The objective of a campaign is to raise awareness of radon as a public health issue and to advise people to test their home and if high levels are found to reduce those levels. Since March 2010 campaigns have been carried out in Sligo, Carlow, Waterford, South Tipperary, Galway, Kerry, Wexford, Louth and Kilkenny. Details of campaigns are available at <a href="http://www.rpii.ie/Your-Home/Radon-Awareness-Campaigns.aspx">http://www.rpii.ie/Your-Home/Radon-Awareness-Campaigns.aspx</a>. A further campaign will be carried out later this year.</p> <p>Each year the RPII organises a National Radon Forum. The Forum provides an opportunity for those with a role to play in reducing the risk from radon in Ireland to meet and discuss radon activities and concerns. This includes measurement companies, remediation companies, scientists, government representatives, local authorities, representatives of national agencies with responsibility for building standards, health and safety experts and the public. The most recent forum was held in Kilkenny during February 2014. Details of previous fora are on the RPII website <a href="http://www.rpii.ie/Your-Environment/Radon-and-your-environment/National-Radon-Forum.aspx">http://www.rpii.ie/Your-Environment/Radon-and-your-environment/National-Radon-Forum.aspx</a></p> <p>Since 2008 nearly 20,000 local authority homes have been measured for radon. This compares with 56,000 private homes measured since the 1990s. The continued work on radon by local is to be commended as it addresses the risk to tenants associated with high radon levels.</p> <p>The Home Renovation Incentive scheme, which was launched by the Government in March, includes work needed to reduce radon levels in a home. The scheme allows homeowners to qualify for tax credits at 13.5% of the cost of renovation, repair or improvement works. Full details of the scheme are available from Revenue <a href="#">here</a>.</p> <p>The Scheme of Housing Aid for Older People available to assist older people, generally over 60 years, to have necessary repairs or improvements carried out to their homes. Where a suite of works is being grant aided under this scheme, Local Authorities may also, as part of the package of works, assist with the provision of radon remediation works, where applicable.</p> <p><a href="http://www.environ.ie/en/DevelopmentHousing/Housing/SpecialNeeds/OlderPeople/">http://www.environ.ie/en/DevelopmentHousing/Housing/SpecialNeeds/OlderPeople/</a></p>

	Recommendation	Update June 2014
12	The HSE should put in place arrangements to monitor inequalities in cancer risks, cancer occurrence, cancer services and cancer outcomes.	<p>The National Cancer Registry of Ireland (NCRI) was established to record information on all cancer cases occurring in Ireland and has been collecting such data since 1994. Included within this remit is survival analysis.</p> <p>In 2011 The NCRI &amp; the Northern Ireland Cancer Registry, published a report identifying major unexplained variations across the island in the risk of most common cancers. <a href="http://www.ncri.ie/publications/cancer-atlases-and-geographic-studies/all-ireland-cancer-atlas-1995-2007">http://www.ncri.ie/publications/cancer-atlases-and-geographic-studies/all-ireland-cancer-atlas-1995-2007</a></p> <p>Health Equity Audit incorporated into the Health Needs Assessment pilot for PCT's</p> <p>Inequalities module added to the to the National Cancer Education Programme for Nurses Working in Primary Care</p> <p>Resources and literature on cancer will be included in Health Inequalities Hub being developed in partnership with the Institute of Public Health in Ireland.</p> <p>A Tobacco-Free Future - An all-island report on tobacco, inequalities and childhood 2013 reveals declines in smoking rates among both children and pregnant women over the past decade, both North and South of the border. This report published by the Institute of Public Health in Ireland (IPH) and the TobaccoFree Research Institute Ireland (TFRI), shows that while tobacco control measures are being successful, disadvantaged children are at particular risk of tobacco-related harms.</p>
13	Population-based screening programmes should only be introduced where their population health benefit can be demonstrated using the National Cancer Forum criteria.	<p>Health Technology Assessments (HTA) are undertaken in advance of the proposed introduction of any screening programme approval.</p> <p>In 2009 HIQA completed a HTA for the colorectal screening programme.</p>
14	Breast screening should be extended to include all women aged between 50 and 69.	<p>The BreastCheck Programme provides free mammograms to all women aged 50-64. A priority of the BreastCheck Programme at present is to maximise national uptake in the 50-64 year age cohort. It also aims to extend the upper age range to include the 65-69 age cohort as soon as possible in line with available resources.</p>
15	The national roll-out of the Irish Cervical Screening Programme should be completed as a matter of priority.	<p>This programme was introduced nationally in September 2008. First three-year round was completed in 2011 and the report published in 2012. <a href="http://www.cervicalcheck.ie/fileupload/Publications/CervicalCheckprogrammereport1Sept2010-31August2011-Final.pdf">http://www.cervicalcheck.ie/fileupload/Publications/CervicalCheckprogrammereport1Sept2010-31August2011-Final.pdf</a></p>

	Recommendation	Update June 2014
16	<p>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.</p>	<p><b>BowelScreen</b>, The national Bowel Screening programme commenced in 2012 commencing with men and women aged 60-69.</p>
17	<p>The Department of Health and Children in conjunction with the HSE and BreastCheck should plan the alignment of population-based screening programmes.</p>	<p>The National Cancer Screening Service was established in January 2007. It currently delivers four national screening programmes.</p> <p>The National Cancer Screening Service encompasses</p> <p><b>BreastCheck</b> - The National Breast Screening Programme,  <b>CervicalCheck</b> - The National Cervical Screening Programme,  <b>BowelScreen</b> - The National Bowel Screening Programme and  <b>Diabetic RetinaScreen</b> – The National Diabetic Retinal Screening Programme.</p>
18	<p>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.</p>	<p>International evidence does not suggest population based screening for prostate cancer.</p>

	Recommendation	Update June 2014
19	Opportunistic testing of asymptomatic individuals for cancer is not recommended.	The NCCP has called for a ban on home PSA testing for prostate cancer. The NCCP has contacted the Irish Medicines Board in relation to its concerns and this is currently being addressed at European Commission level.
20	The HSE should develop specific programmes that promote early detection of cancer.	<p>Screening promotion incorporated into the National Cancer Screening programme plans.</p> <p>Significant work is underway to liaise with primary care to promote early detection.</p> <p>Nationally there are three cancer screening programmes in operation; BreastCheck, CervicalCheck and BowelCheck.</p> <p>Rapid access breast, lung and prostate clinics have been established to facilitate early referrals from primary care to designated cancer centres for those with suspected cancer.</p> <p>GP referral guidelines and forms have been developed for pigmented lesions</p> <p>Work is ongoing with the ICGP to develop guidelines for improved detection of ovarian and head &amp; neck cancers.</p> <p>A national hereditary cancer programme, in collaboration with the National Centre for Medical Genetics, Crumlin has been established to improve access to assessment and genetic testing for those patients whose cancer may have a hereditary component and their families. The programme focuses on hereditary breast, ovarian and bowel cancer, as well as rarer hereditary cancer syndromes.</p>
21	All cancer care should be delivered through a national system of four Managed Cancer Control Networks, each serving a population of approximately one million people.	Cancer services are now centralised around 8 Designated Cancer Centres established in 4 networks. Letterkenny Hospital is a satellite of University College Hospital Galway for breast cancer surgery.
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.	There are two network manager posts within the NCCP. These posts cover all four cancer networks.



	Recommendation	Update June 2014
23	A lead clinician for each Cancer Centre should be appointed. In addition, a clinician should be appointed to lead the development of cancer care pathways for each major site specific cancer in partnership with all stakeholders within the network. The Cancer Control Network Director should head this team of lead clinicians.	National Lead Clinical Groups have been established for breast, urology, lung and gastrointestinal cancers in the eight cancer centres. There are also lead clinicians for upper gastrointestinal cancers in the four national centres. There are also national leads for pancreatic cancer, neuro-oncology, gynae cancers, colorectal cancers and neuro-endocrine cancers. The nominated clinicians are responsible for facilitating compliance with national standards and key performance indicators for the specific service and have a key role in contributing to the continuous development and improvement of the service in their own cancer centre and nationally through participation in NCCP processes, including national audit, quality and risk meetings.
24	The HSE should develop care pathways for cancer care to link primary care services, hospital services and other relevant services.	The NCCP has developed GP referral guidelines and pathways have been implemented for breast, lung, pigmented lesions and prostate cancers.  Additional pathways have been developed for referral of patients from regional to tertiary centres for pancreatic cancers. Other care pathways are in development.
25	Improved cancer information services should be available to primary care.	Within the NCCP there is a Community Oncology Team whose role includes collaboration with and supporting of GPs and primary/community care nursing staff.  The NCCP has developed GP and patient booklets have been produced on referral to the symptomatic breast clinic, prostate and lung rapid access clinics.  NCSS provides information sessions to Primary Care for its screening programmes and provides free training programmes for smear-takers as part of its Cervical-check programme.  General Practice E-Learning programmes have been developed for a range of cancer related topics including smoking cessation and the ABC of early cancer detection.

	Recommendation	Update June 2014
26	The HSE should develop programmes that support primary care professionals in the provision of cancer services.	<p>Education and development programmes have been established for:</p> <ul style="list-style-type: none"> <li>• Nurses who work in primary care</li> <li>• An intensive skills based course has been developed for public health nurses to enable them to provide some care to medical oncology patients in their own home. This service is integrated with the hospital specialist medical oncology service. A resource book has been published to support this service.</li> <li>• A Cancer Nursing Strategy has been developed to provide a framework for the professional development for all nurses who care for patients with cancer, from generalist to specialist settings.</li> </ul> <p>Multiple meetings have taken place with GPs via their CME structures, in many locations around the country, to provide an update on NCCP developments and how to use the standardised referral procedures.</p> <p>The NCCP has employed a GP and has worked closely with the Irish College of General Practitioners. E-learning programmes have been developed for a range of cancer related issues including brief interventions for smoking cessation, assessment of urological symptoms, management of breast problems in primary care and appropriate referral</p>
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.	Designated cancer centres have their own internal systems in place to manage patient pathways and deal with individual queries.
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.	There are eight designated Cancer Centres (Letterkenny Hospital is a satellite of University College Hospital Galway for breast cancer surgery).

	Recommendation	Update June 2014
29	The HSE should conduct a needs assessment for cancer services with a particular emphasis on hospital-based cancer treatment that addresses the need for continued expansion in capacity and maximises the use of ambulatory care.	<p>Since the establishment of the NCCP there has been continued assessment of requirements for cancer services within hospitals. The NCCP has worked closely with the designated cancer centres to plan for the appropriate expansion in radiation oncology, medical oncology and surgical oncology facilities.</p> <p>The future capital requirements for radiotherapy have been identified under the National Plan for Radiation Oncology and expansion is underway in Cork &amp; UCHG. In addition, the NCCP has worked with acute hospitals and HSE Estates to assess and prioritise expansion of oncology day facilities.</p> <p>Designation of in-patient beds for cancer patients is linked to the reconfiguration of acute hospital services. The NCCP has conducted a number of utilisation reviews of cancer facilities to ensure appropriate mix of ambulatory and inpatient services.</p>
30	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 a sustained investment in the development of a National Network of Radiation Oncology services on six hospital sites. The St. Luke's Radiation Oncology Network has been established with radiotherapy delivered on three sites in Dublin. The units in Cork and Galway are managed directly by the host hospital. All radiotherapy centres are participating on the National Radiation Oncology Planning & Implementation Committee.
31	Patients should have their diagnosis established and their treatment planned by site-specific multidisciplinary teams.	Multidisciplinary team planning (MDT) meetings has become the standard for care for the majority of new patients.
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.	<p>In 2007 eight designated Cancer Centres were selected by the HSE to improve patient care. The eight designated centres were to provide treatment and services for all cancer surgery including breast cancer, with a governance structure in place for systemic therapy which will continue to be delivered locally involving:</p> <p>HIQA carried out a national quality review of the eight centres (plus the satellite centre in Letterkenny Symptomatic Breast Disease Services in 2009. <a href="http://www.hiqa.ie/system/files/Symptomatic_Breast_Disease_Services_National_report_2010%20.pdf">http://www.hiqa.ie/system/files/Symptomatic_Breast_Disease_Services_National_report_2010%20.pdf</a></p>
33	The HSE should conduct a national needs assessment for rare cancers.	In line with the European Union recommendations, a national policy for all rare diseases was published in July of 2014. The report makes specific recommendations and references to cancer. <a href="http://health.gov.ie/wp-content/uploads/2014/07/EditedFile.pdf">http://health.gov.ie/wp-content/uploads/2014/07/EditedFile.pdf</a>

	Recommendation	Update June 2014
34	A National Cancer Genetics Policy should be developed by the National Cancer Forum.	<p>The NCCP is developing a national strategy for familial cancer risk assessment and evaluation for genetic mutations that predispose to hereditary cancer. A national hereditary cancer programme, in collaboration with the National Centre for Medical Genetics, Crumlin has been established to improve access to assessment and genetic testing for patients and their families. The programme focuses on hereditary breast, ovarian and bowel cancer, as well as rarer hereditary cancer syndromes.</p> <p>Approval was given in June 2014 for the appointment of a national lead for hereditary cancer.</p>
35	The HSE should ensure that each Managed Cancer Centre Control Network has a comprehensive specialist palliative care service.	<p>Palliative Care services within the HSE are under the remit of the Acute Hospitals Division in consultation and collaboration with the National Clinical Programme for Palliative Care. A National Clinical Lead has been appointed.</p> <p>It is HSE policy to ensure that palliative care services are provided to all patients regardless of diagnosis. While deficits exist in some areas of the country, the HSE has a Framework in place to address these and is working to roll out services nationally. There are currently 38 acute hospital specialist palliative care teams (including in each of the Major Cancer Centres); 156 specialist in-patient beds across nine locations; Home care is provided in every county; and day care is available in 7 locations. In addition there are approximately 170 palliative care support beds across the country.</p>
36	A formal linkage should be established between the National Cancer Forum and the National Council for Specialist Palliative Care.	<p>The National Council for Specialist Palliative Care is no longer in existence. Strategic planning and clinical responsibility for Palliative Care is under the remit of the National Clinical Programme. This is undertaken in collaboration with Palliative Care Services within the Acute Hospitals Division.</p> <p>A Palliative Care Consultant participates on the NCCP the Steering Committee for Tumour Groups and on the NCCP Survivorship Group.</p>
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.	<p>Psycho-oncology is included within cancer nursing education programmes.</p> <p>Increasing emphasis is now placed on Survivorship and during 2014 the NCCP will develop a comprehensive survivorship programme to address communication issues and information needs of both cancer survivors and healthcare professionals.</p>
38	A partnership framework should be developed between the HSE and the voluntary sector.	<p>Regular meetings take place between the NCCP and the Irish Cancer society, the Marie Keating Foundation and a number of other voluntary groups.</p>

	Recommendation	Update June 2014
39	A code of practice should be developed for self-help groups, support groups and support centres.	Following on from the publication of the 2006 strategy the Irish Cancer Society developed a code of practice for cancer support services and in 2011 it published 'Guidelines for Cancer Support Services in Ireland' <a href="http://www.cancer.ie/sites/default/files/content/attachments/ics_support_groups_guidelines_2011.pdf">http://www.cancer.ie/sites/default/files/content/attachments/ics_support_groups_guidelines_2011.pdf</a>
40	HIQA should establish a National Framework for Quality in Cancer Control.	<p>HIQA published national quality guidelines for Symptomatic Breast Disease in 2007.</p> <p>A national agreed monitoring programme for Symptomatic Breast Disease services is in place in all designated cancer centres to capture and monitor SBD standards and activity.</p> <p>HIQA developed Safer, Better Health Care as a quality framework for health services in 2012 – this will be applicable for all health services including cancer. However in order to implement Safer Better Health care in Breast services the NCCP has specifically developed guidance for quality assurance in Symptomatic breast services. The 2007 Breast standards have now been subsumed into Safer Better Healthcare.</p> <p>The NCCP has developed a number of Key Performance indicators for cancer care which are captured and monitored monthly and reported quarterly.</p> <p>Annual Audit quality and Research days are now held for breast, prostate, pancreatic and lung tumour groups and separately for medical and radiation oncology.</p>
41	HIQA should establish site-specific multidisciplinary groups at a national level to develop guidelines for quality in major cancers.	The NCCP has established expert National Tumour Groups for breast, lung, prostate, GI and gynaecological cancers. These tumour groups are developing multi disciplinary evidence based, guidelines for diagnosis, staging and treatment of the site specific cancers. The Royal College of Physicians and Surgeons have nominated expert consultants to lead this key initiative. These evidence based guidelines are being developed in line with international best practice and to meet the requirements of the National Clinical Effectiveness Committee (NCEC). Three completed draft guidelines (breast, prostate and gestational trophoblastic disease) have gone for stakeholder consultation.
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.	Work is currently underway in the Department on legislative proposals relating to the development of a licensing framework for health facilities, including cancer centres. Such a framework will provide for a mandatory system of licensing for public and private health service providers. It will be designed to improve patient safety by ensuring that healthcare providers do not operate below core standards which are applied in a consistent and systematic way.

	Recommendation	Update June 2014
43	HIQA should develop a cancer surveillance system that will build on the existing system of cancer registration.	<p>The National Cancer Registry of Ireland (NCRI) collects data on every new cancer in public and private hospitals in Ireland, it also has the remit for cancer outcomes such as survival analysis</p> <p>A cancer minimum dataset has been defined and communicated to all cancer centres.</p> <p>An agreed monitoring programme for symptomatic breast diseases (SBD) is in place and all centres have a data capture system for SBD.</p> <p>Some progress has been made in developing KPIs for other tumour groups and treatment modalities</p>
44	Mandatory notification of cancer should be put in place through appropriate legislation.	Legislation has not been enacted to introduce mandatory notification of cancer.
45	HIQA should ensure that a minimum national dataset should be collected for all cases of cancer.	The NCRI collects data on every new cancer in public and private hospitals in Ireland and has a standard dataset that is collated on every cancer case. To align clinical datasets with NCRI data, a core national cancer dataset has been defined by the NCRI and accepted as policy by the NCCP. This has been communicated to all cancer centres and key variables from this dataset form the basis of individual tumour clinical datasets.
46	HIQA should ensure that the public has access to high-quality up to date information about all aspects of cancer.	The NCCP has produced several booklets in relation to cancer prevention and treatment. The Irish Cancer Society has also produced many patient information booklets. The NCCP website is currently being updated and will include additional cancer related information. HIQA's role at present is not focused on informing the public on health related issues.
47	General practitioners should have comprehensive information that enables informed referral and other management decisions.	Standardised referral processes and referral guidelines have been produced for breast, lung and prostate cancers and for pigmented lesions. Electronic referral processes are in place for these cancers. Melanoma guidelines are being piloted in Cork pending national expansion although national rollout is not complete yet for pigmented lesions. Patient booklets have been produced for breast, prostate and lung cancers.

	Recommendation	Update June 2014
48	Information systems and information technology should be developed by the HSE to support the management and delivery of cancer services.	<p>In primary care the NCCP has introduced a system of electronic referrals directly from GPs to designated cancer centres. National electronic referrals have now been embedded in all ICGP accredited software systems. 30% of all breast, prostate and lung cancer referrals are now sent electronically.</p> <p>It is estimated that by the end of 2013, 15,000 electronic referrals will have been received for breast, prostate and lung cancers. This is a 50% increase on 2012 and a seven fold increase since the scheme was introduced in 2010.</p> <p>A key information technology project being progressed by the NCCP's Medical Oncology Programme is the development of a business case for a national medical oncology clinical information system for the optimal and safe delivery of systemic cancer treatment, including computerised ordering, prescribing and administration of these treatments in publicly funded hospitals.</p> <p>The National Cancer Registry of Ireland (NCRI) is a key source of information in relation to cancer incidence and prevalence in Ireland. There are a number of projects underway to improve timeliness of the NCRI data via the electronic transfer of histopathology data project.</p> <p>Key Performance Indicators (KPIs) have been agreed for other tumour groups (including prostate, lung, rectal, pancreas and upper gastro intestinal cancers). Collation of data for pancreatic and upper gastrointestinal cancers commenced in January 2012 and data collection for prostate, lung and rectal cancers is planned to commence in January 2014. All cancer centres have the necessary IT infrastructure to collate data on these cancers though the cost of additional licenses and datasets is challenging for hospitals. Supporting data collection remains a challenge for many hospitals.</p> <p>National collation of data on radiation oncology activity and timeliness commenced in 2012 and on medical oncology activity and timeliness in 2013.</p> <p>Furthermore, there is increased use of other available routine data systems such as Hospital Inpatient Enquiry System (HIPE) and the Patient Treatment Register (PTR) to monitor cancer related activity.</p>
49	HIQA should establish a Cancer Health Technology Assessment Panel.	<p>In 2011 the NCCP established a Technology Review Committee which is responsible for reviewing proposals received from industry or expert groups in Ireland for funding of new drugs, or expanded indications for existing drugs or related predictive laboratory tests.</p> <p>The Committee reports to the Director of the National Cancer Control Programme and make recommendations on the priority for consideration of implementation of a new treatment or test. The recommendations are based on the degree of clinical effectiveness, the acute and chronic toxicity and the cost effectiveness of the proposed technology. A nominee from HIQA has been appointed to the membership of the Committee.</p>
50	The HSE should develop a National Cancer Workforce Plan designed to fully implement national cancer policy.	<p>The NCCP has commenced work with the HSE Medical Education and Training (MET) Body regarding work force planning for cancer services. A strategy has been developed for expansion of medical oncology staffing.</p>



	Recommendation	Update June 2014
51	The third National Cancer Forum, in partnership with the HRB, should advise on the development of a specific plan for cancer research.	<p>High-quality research is an important part of cancer control. The Health Research Board is the lead agency for supporting and funding health research. Funding is provided through the HRB for research areas including cancer incidence, causes and treatment.</p> <p>Ireland is also a participating state in the International Agency for Research on Cancer, which provides valuable research into many aspects of cancer control.</p>
52	There should be improved clinical trial entry for patients, both in terms of the number of trials conducted and the enrolment to them.	The All Ireland Co-operative Oncology Research Group (ICORG) is a North-South organisation that brings cancer clinical research to Ireland. ICORG has succeeded in offering research options to over 10,300 patients in the last fifteen years.
53	Ireland should establish a national tissue bio bank to support research and service delivery.	The Action Plan for Jobs 2013 includes an action “to take steps to establish a national biobanking system and support infrastructure by 2016”. The HRB, in collaboration with other relevant stakeholders is engaged in ongoing discussion in relation to the model and funding for such a system.
54	The HRB should establish a national cancer research database.	The HRB has a database of all funding grants which it has allocated, including cancer related research grants. Other awarding agencies include ICORG and the Irish Cancer Society.
55	The HSE should present a report on policy indicators each year to the National Cancer Forum.	<p>The NCCP captures monthly data on agreed national Key Performance indicators. These are published quarterly as part of the HSE Performance Reports on the Service Plan.</p> <p>The NCCP meets monthly with the Department of Health to provide updates on all relevant matters and to review progress on policy issues;</p>

# Appendix 4

## Cancer Development Funding

- The increasing incidence of cancer, prolonged survival along with the high costs of novel drugs and technologies has resulted in significant challenges in funding cancer care. The majority of funding for cancer services is within the acute hospitals core budget or in the case of oncology drugs is held in primary care.
- Dedicated cancer service development funding and staffing was provided to the NCCP and NCSS between 2007 and 2014. This funding supplemented that which was already within the base funding of the acute hospitals and was allocated towards agreed service priorities.
- Critically, all cancer development funding has continued to remain under the NCCP and is allocated to the relevant agencies on a once off basis each year. This approach has ensured that cancer funding has not been subjected to financial cuts imposed on hospital services.

### Dedicated Development Funding and Resources for the National Cancer Control Programme and the National Cancer Screening Services, 2007-2014

Agency	Year	WTEs	Budget (M)	Priorities for Funding
National Cancer Control Programme	2007		3.5	Symptomatic Breast Cancer Services
	2008	51	10.0	Symptomatic Breast Cancer Services
	2009	88	13.3	Rapid Access Clinics & Neuro-oncology
	2010	25	8.0	Surgical and medical oncology & dermatology
	2011	28	1.5	Theatre and critical care support
	2012	0	0	
	2013	0	17	Oncology Drug Funding
	2014	0	3.5	Oncology drug funding & molecular testing

Agency	Year	WTEs	Budget (M)	Priorities for Funding
National Programme for Radiation Oncology	2007	0	3.25	
	2008	39	5.0	
	2009	12	1.7	
	2010	54	8.0	
	2011	0	8.0	
	2012	-	-	After 2011 radiation oncology services were directly funded for development priorities
	2013	-	-	
	2014	-	-	
National Cancer Screening Services	2007	-	-	Prior to 2012 the NCSS were directly funded for development priorities
	2008	-	-	
	2009	-	-	
	2010	-	-	
	2011	-	-	
	2012	20	3.4	BowelScreen & Diabetic RetinaScreen
	2013	0	9.2	BowelScreen & Diabetic RetinaScreen
	2014	0	6.5	BowelScreen & Diabetic RetinaScreen

# Appendix 5

## Designated Cancer Centres

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

## Centres with Medical Oncology/Haematology Consultants

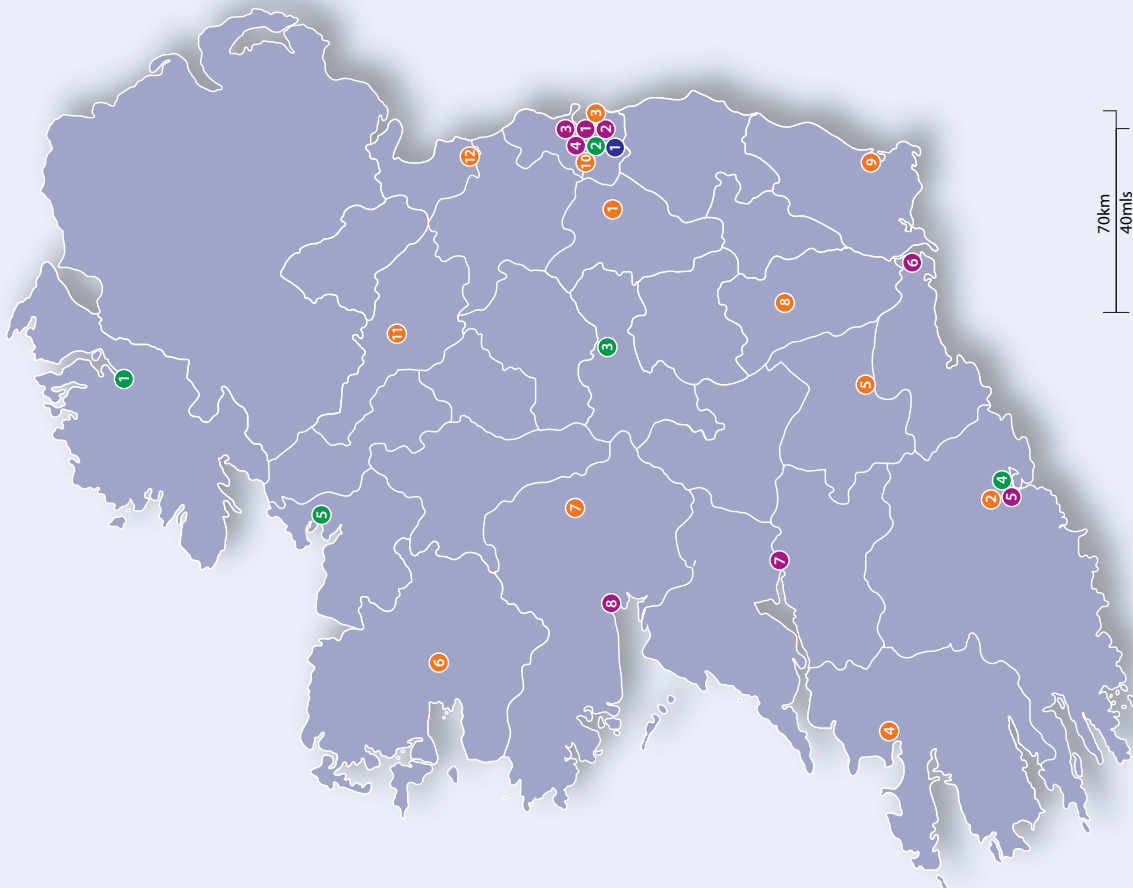
- 1 Letterkenny General Hospital
- 2 Adelaide and Meath Hospital, Tallaght
- 3 Midlands Regional Hospital, Tullamore
- 4 Mercy University Hospital, Cork
- 5 Sligo General Hospital

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

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

## Paediatric hospital

- 1 Our Lady's Children's Hospital Crumlin



<http://cancercontrol.hse.ie>

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