AN EVALUATION OF “CANCER SERVICES IN IRELAND: A NATIONAL STRATEGY 1996”

ON BEHALF OF THE NATIONAL CANCER FORUM

Deloitte.

AN EVALUATION OF
"CANCER SERVICES IN IRELAND:
A NATIONAL STRATEGY 1996"

ON BEHALF OF THE NATIONAL CANCER FORUM

Deloitte.

TABLE OF CONTENTS

1

EXECUTIVE SUMMARY

1. EXECUTIVE SUMMARY

1.1 INTRODUCTION

This report presents the outcome of a comprehensive study that evaluated the extent to which the objectives and actions of the 1996 National Cancer Strategy were achieved. The evaluation was commissioned by the Department of Health and Children on behalf of the National Cancer Forum. The field work was carried out by Deloitte and Touche Management Consultants between October 2002 and February 2003.

The terms of reference required the consultants to assess how the Strategy was implemented, to assess the impact of investments made under the Strategy and to determine the key achievements and issues arising under the following key areas:

- Access
- Range of services
- Quality of services
- Integration/co-ordination of services
- Information available to patients
- Identification of the success factors which need to be supported and developed going forward
- Identification of the principal barriers to implementation of the Strategy
- Identification of the principal gaps in the implementation of the Strategy.

Arising from the evaluation, priorities for the future development of cancer services were identified. Consideration of priorities for the future was regarded as critically important as this evaluation study was undertaken in the context of the preparation of a new National Cancer Strategy.

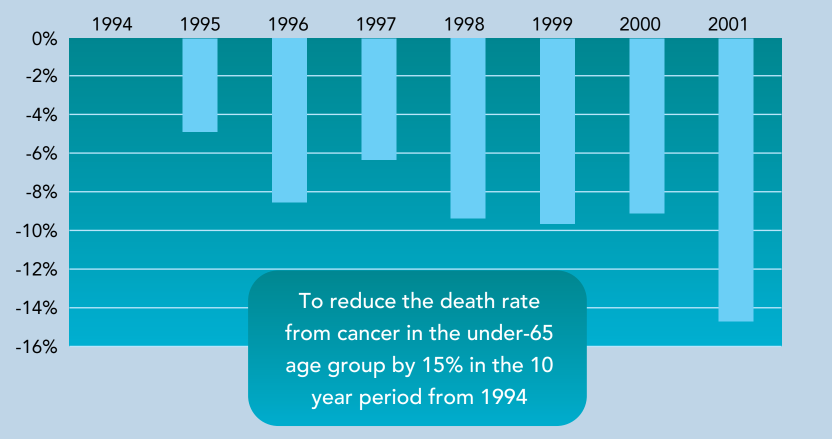
In the course of the evaluation process consultations were held with:

- Members of the National Cancer Forum
- The Chief Executive Officers, Regional Directors of Cancer Services and Directors of Public Health in each of the health boards
- The Department of Health and Children
- Patients and their families (through a public submission process and a patient survey).

1.2 ACHIEVEMENTS AND KEY GAPS

It must be remembered that the key goal of the 1996 National Cancer Strategy was to reduce the death rate from cancer in the under-65 age group by 15 per cent in the ten-year period from 1994. As we can see from Figure 1.1, this was achieved in 2001, which was 3 years ahead of target. It should be noted that despite the big change between 2000 and 2001 (which may be due to reasons other than improved cancer services and care delivery), the underlying trend line is such that this objective would still be on target to be met by 2004.

FIGURE 1.1: CUMULATIVE PERCENTAGE CHANGE IN MORTALITY RATE (ALL MALIGNANT NEOPLASMS) PER 100,000 POPULATION FOR UNDER-65 AGE GROUP



Source: PHIS

Additional objectives of the National Cancer Strategy 1996 can be categorised under seven headings as follows:

- Prevention and Awareness
- Information
- Early Detection and Screening
- Access, Treatment and Quality
- Co-ordination
- Cost Effectiveness
- Research and Education

In Table 1.1 we present an overview of the key achievements of the National Cancer Strategy under each objective. We also identify the key gaps associated with each objective. In considering the achievements of the National Cancer Strategy it is important to highlight that this Strategy represented a very positive development. The Strategy resulted in the allocation of a dedicated budget to cancer services. Up to this point, funding for cancer services was provided through acute hospital budgets. Since the implementation of the Strategy, a cumulative additional sum of approximately €400 million in revenue funding has been invested specifically in cancer services to date. This represents substantial investment in and prioritisation of cancer services and has impacted significantly on the quantity and quality of service provision, e.g. 85 specialist consultants (including 15 medical oncologists) and 245 clinical nurse specialists have been appointed to the services since 1997.

TABLE 1.1: NATIONAL CANCER STRATEGY – ACHIEVEMENTS AND KEY GAPS

	KEY ACHIEVEMENTS	KEY GAPS
Objective: Prevention and Health Promotion	• Key national initiatives: - Establishment of the Office of Tobacco Control - Tobacco Health Act, 2002 - National Age Identification Scheme. • Establishment of health promotion structures within the health boards – appointment of relevant staffing. • Considerable health promotion activity within each health board – initiatives focusing on smoking, alcohol, diet, lifestyle, etc. • In the area of smoking particularly, results from SLÁN have indicated that clearly Health Promotion Initiatives are engaging the target audience and that the audience is relating to the message.	• Absence of a fully co-ordinated approach to health promotion across health boards and the Department of Health and Children. • Role of primary care (GPs, public health nurses, community groups) not sufficiently utilised. • Lack of clear objectives and targets in relation to health promotion activity. • Role of national policies in achieving health promotion objectives needs to be further recognised.
Objective: Information	• Patient Information - Considerable progress in recent years - Appointment of clinical nurse specialists, oncology nurses, cancer liaison nurses, cancer nurse co-ordinators – significant contribution - Patient information material (Irish Cancer Society/ Irish College of General Practitioners). • Clinician Information - Development of clinical protocols - Access to Cochrane Collaboration - Better research facilities (library & on line access) - Development of the work and data of the National Cancer Registry - Appointment of Data Managers in the health boards (on-going).	• No national guidelines in place. • Poor delivery of diagnosis. • Inadequate communications to patients and families. • Need for on-going training in this area has not been recognised to date. • Requirement for transparency in relation to waiting times for services. • Clarity of information is equally important to information provision – not always clarified if patients fully absorb/accept the information received. • Inadequate Management Information Systems (MIS). • All Data Managers not yet appointed. • Need for access to more data by health boards to facilitate decision making.
Objective: Early Detection and Screening	• Two screening programmes: - BreastCheck – national roll-out approved following a successful phase one - Irish Cervical Screening Programme – phase one in progress. • Successful take up rates – by end December 2002, BreastCheck achieved a 75% uptake rate (target rate is 70%).	• Absence of UPI (Unique Patient Identifier) – a mechanism to ensure every patient within the system has an individual identity number so they can be recognised within the system and targeted appropriately. • Integration between development of symptomatic services and screening services needs to be progressed. • Differences in take up rate for screening programmes among different socio-economic groups – key consideration from a targeting perspective in the future. • Need to optimise the role of primary care. • Potential for screening in other site specific cancers needs to be explored.

TABLE 1.1: NATIONAL CANCER STRATEGY – ACHIEVEMENTS AND KEY GAPS (Continued)

	KEY ACHIEVEMENTS	KEY GAPS
Objective: Access, Treatment and Quality	• Recognition of concept of supra-regional centres and regional centres of specialist cancer care. • Appointment of Regional Directors of Cancer Services. • Appointment of increased numbers of clinical specialists, e.g. medical oncologists, surgeons, haematologists, histopathologists, etc. – a total of 85 appointments since 1997. Prior to the Strategy there were 4 medical oncologists in the country; now there are 19. • Appointment of oncology clinical nurse specialists. • Considerable increase in chemotherapy activity – less than 15,000 sessions in 1995; circa 22,000 in 1998; almost 40,000 in 2001. • Considerable increase in radiotherapy activity – 58% increase in the number of new patient episodes for radiotherapy treatment since 1994. • Considerable increase in oncology related surgical activity - 26% increase in the number of patients receiving surgery since 1994. • Significant developments in symptomatic breast disease services. • Significant developments in palliative care.	• Limited application of supra-regional centre and regional centre concepts. • Need for better communication of benefits of specialist centres. • There is dilution of resources by the replication of the same services among many agencies versus benefits of scale and quality at supra-regional centres. • Access to radiotherapy: - significantly under-resourced - waiting times in excess of clinically acceptable parameters - evidence that all patients who need it do not get it (33 per cent actual uptake rate vs. expected 50-60 per cent uptake rate among all cancer patients) - issues re equity of access for non-east coast patients. • Manpower shortages – a priority. • Significantly inadequate counselling and emotional support for patients. • Scope for the development of Quality Assurance procedures, policies, guidelines and protocols – differences between boards. • Insufficient development of community services. • Inability to access waiting times for patients and therefore monitor the waiting times that patients incur. • Audit and evaluation systems have not been developed. • Regular patient surveys to assess their perception of service provision and quality. • Focus to date on breast cancer – some cancers have not received sufficient attention, e.g. bowel, lung, skin, prostate.
Objective: Co-ordination	• Establishment of National Cancer Forum. • Appointment of Regional Directors of Cancer Services. • Appointment of oncology clinical nurse specialists, some of whom have a specific role to co-ordinate all aspects of a patient's treatment and care while within the hospital system.	• Issues raised in relation to the work of the National Cancer Forum according to the following dimensions: - public awareness - representation on the Forum - clarity of role and responsibilities. • The following issues were raised in relation to the work of the Regional Director of Cancer Services: - relationship with National Cancer Forum - the definition of the executive role of the Regional Director of Cancer Services at health board level - administrative support. • Cancer services are regarded as insufficiently co-ordinated within the Department of Health and Children. • Co-ordination between the community, primary and acute services is not sufficient.

TABLE 1.1: NATIONAL CANCER STRATEGY – ACHIEVEMENTS AND KEY GAPS (Continued)

	KEY ACHIEVEMENTS	KEY GAPS
Objective: Cost Effectiveness	• The attainment of better value for money, including new technology assessment is a key element in the letter of determination to Health Boards.	• Equipment under-utilisation (radiography/diagnostics/labs). • Increasing cost of oncology drugs – there is an absence of protocols and guidelines on the use of drugs and the adoption of new treatment approaches. • The absence of performance and outcome measures. • There is a need for investment in IT systems in order to better monitor costs, assess service delivery and monitor treatment outcomes. • Prevention approaches need to be recognised as the most cost effective approach in the long term.
Objective: Research and Education	• Development of the work of the National Cancer Registry. • Health Research Board – active in the area of fellowships and funding of research programmes. • The Health Research Board is working with a Cancer Consortium, which assists co-operation in cancer services between the North and South of Ireland and the United States. • €3.5 million funding for cancer research trials provided by the Department of Health and Children. • Development of multi-disciplinary teams has facilitated on-going education and training.	• The absence of a systematic approach to the implementation of clinical trials – this is being addressed. • The requirement for a continuous approach to education and training.

1.3 BARRIERS TO IMPLEMENTATION

We identified the principal barriers to implementation of the National Cancer Strategy as:

- Lack of definition within strategy – principles versus measurable activity
- Absence of a detailed implementation plan and planned approach
- Absence of a Human Resources plan
- Insufficient information and IT systems (waiting times, etc)
- Key terms were not defined in detail, e.g. supra-regional service
- Provision for public education for strategy buy-in was not given due priority
- Impossible to cost strategy and therefore difficult to trace benefits to particular investment streams

1.4 KEY RECOMMENDATIONS

Table 1.2 summarises our key findings and recommendations following our review of the implementation of the National Cancer Strategy 1996.

TABLE 1.2: SUMMARY OF KEY RECOMMENDATIONS

KEY RECOMMENDATIONS:

1. Radiotherapy services need to be expanded to ensure that all patients have reasonable access to this service. At present, the lack of capacity is such that existing waiting times limit the degree to which doctors can treat their patients according to evidence-based treatment protocols and best-practice guidelines. Addressing this issue must be one of the highest priorities in the new National Cancer Strategy for 2003. This should not mean that radiotherapy services should be located in many centres throughout Ireland, but rather that there should be access arrangements and transfer protocols in place to facilitate patients in accessing these services.

2. The development of BreastCheck has been carried out separately to the development of services to treat symptomatic breast disease. Effective integration of the two services needs to be progressed. In the light of the impact of the national roll out of BreastCheck, an assessment of the appropriate number of centres of excellence for Symptomatic Breast Disease Services should be undertaken.

3. Primary Care, including the role of GPs needs greater development and support, particularly in the areas of:
    - Health promotion and cancer awareness
    - Early detection and screening
    - Palliative care
    - Patient support following discharge from the acute services

4. The Strategy provided for an integrated hierarchy of specialist services involving primary care, and regional and supra-regional hospitals. Dublin, Cork and Galway were recommended as the locations of supra-regional centres. There is a lack of clarity as to the scope, scale and complexity of acute services that should be provided at different levels in the acute sector. There should be a broad understanding within the health system, among providers, general practitioners and patients, of the services that are available and their locations. The essential requirement of assured quality in line with international norms and good practice should be the deciding principle and should not be compromised for geographic reasons. International research has consistently demonstrated that better outcomes are achieved in larger centres through the centralisation of resources, skills and expertise, facilitated by a critical mass of patients.

5. The consultation process clearly highlighted the need for an increase in services to provide emotional and psychosocial support to cancer patients. This service has improved considerably since the introduction of oncology nurse practitioners but there is still a large need for psychologists within the cancer multi-disciplinary team.

6. Health Promotion initiatives have been good, particularly in the area of smoking. Indeed the impending tobacco legislation should see Ireland as a leader in this area within Europe. The health promotion unit in the DOHC needs more interaction with the Acute Hospitals Division in the DOHC. Areas such as sun, alcohol and diet need more focus in the future.

7. Strengthening mechanisms for quality assurance, clinical audit, risk management and health technology assessment are required. The Health Information and Quality Authority (HIQA) should be supported to develop these key areas.

8. In general, very basic information systems are in place. Little audit of waiting lists/times for investigations or results etc. is performed. A common approach is needed to record and analyse this information. It is hard to evaluate programmes, treatments, outcomes etc without appropriate systems to measure and analyse performance. The forthcoming Health Information Strategy should enable this agenda to be pushed forward, not just for cancer services, but also for the entire healthcare system in Ireland.

9. The future role of the National Cancer Forum needs to be examined to build on its successful input into the development and improvement of cancer services. This role should now be reviewed in the light of the experience since the establishment of the first Forum in 1997, its linkages with the Regional Cancer Directors, the Minister for Health and Children, and the Department of Health and Children. An opportunity now exists for this exercise to be progressed and also aligned with the current re-organisation of the health services.

10. Patients are informed of treatment options but no uniformity exists in relation to information given, as very little centrally produced information is available. A much greater emphasis is required centrally in relation to the provision of information for patients on disease causation, treatment and other relevant issues.

11. Evidence based practice should be present in all aspects of cancer control and decision making, including the use of clinical guidelines and integrated care pathways. All patients should be managed through an integrated multi-disciplinary approach.

12. Research should be better integrated across the health sector, rather than individuals or their departments trying to work in isolation in their own facility. This could be achieved through strengthening and developing the role of the Health Research Board, particularly in the area of co-ordination of multi-centred research in the future.

    Most areas/organisations want to be part of a clinical trials programme and this should be facilitated as it raises standards of care and facilitates ongoing continuous medical education programmes.

13. Mechanisms to afford patients, family members and carers an opportunity to be involved in service planning and evaluation should be strengthened and developed.

14. Public debates on health services in general and cancer services in particular should be better informed. In addition, the public needs to be provided with the best evidence to define measures of quality and best practice. Public debate on cancer services needs greater clinical, political and other leadership which reflects that the organisation of services needs to be based on quality and not on geographical considerations. This has proven especially significant in relation to the development of supra-regional and regional centres of specialist cancer care, as well as the location of radiotherapy services, which are discussed later. A related point is that public expectations around service quality must be managed. Whilst it might be understandable that patients would like access to all treatments effectively in their own locality, they do not necessarily consider that this may not be the most appropriate way to deliver quality patient care.

15. The new National Cancer Strategy should reflect the priorities, including investment, for the development of cancer services set out in this report.

1.5 PRIORITIES FOR THE FUTURE

Arising from the evaluation of the National Cancer Strategy and the analysis of the Strategy's key achievements and gaps, we have identified a number of priorities for the future development of cancer treatment services. These are set out in Table 1.3 according to the framework of the National Health Strategy, *Quality & Fairness: A Health System for You*.

TABLE 1.3: PRIORITIES FOR THE FUTURE DEVELOPMENT OF CANCER TREATMENT SERVICES

ORGANISATIONAL REFORM	HEALTH INFORMATION
• Significantly improve the availability of radiotherapy services. • Define supra-regional centres. • Clearly define role for National Cancer Forum and Regional Directors of Cancer Services. • Continue the development of a multi-disciplinary team approach. • Co-ordinate health promotion across the system. • Establish effective linkages between the National Cancer Forum and the revised health structures, viz Health Services Executive, the National Hospitals Office and the Health Information and Quality Authority.	• Facilitate availability of information e.g. waiting times. • Establish the Health Information and Quality Authority. • Develop Performance measures/outcomes. • Improve investment in IT. • Develop a strategy for provision of patient information.
STRENGTHENING PRIMARY CARE	**REFORM OF ACUTE HOSPITAL SERVICES**
• Implement the Primary Care Strategy, specifically targeting: - early detection - screening - health promotion and awareness - patient support following discharge - counselling and emotional support - palliative care.	• Introduce the National Hospitals Office and define how the National Cancer Forum will interface with it. • Effectively integrate the symptomatic breast disease and BreastCheck programmes. • Improve access to: - radiotherapy - screening programmes - clinical trials
FUNDING HEALTH	**DEVELOPING HR**
• Increase investment in: - human resources - radiotherapy - developing symptomatic services in tandem with screening services nationally. • Develop system for assessment of benefits of new treatments and drugs under the aegis of the Health Information and Quality Authority. • Optimise existing resources - equipment under utilisation. • Focus on prevention is key to successfully dealing with the issues of cancer in the long-term (new tobacco laws will have a significant positive impact in this area).	• Develop HR plan. • Resourcing: - direct investment at human resources that support the development of specialist cancer centres for the provision of multi-disciplinary care.

1.6 CONCLUSIONS

The key benefit, most commonly attributed by the stakeholders consulted, of the 1996 National Cancer Strategy was that it provided a framework for the development and funding of cancer services in Ireland. It has also been indicated through the consultation process with health boards and other professionals that cancer services have in many parts of the country developed from a low base in 1996 to a level of regional self-sufficiency and tertiary service provision, although as we have discussed, progress has been variable.

Also, since 1996, the policy context for cancer services has improved considerably at a general and service specific level. As highlighted by section 2, a range of policies has been prepared which impact on cancer services in either a direct or indirect manner. Policy development and the evaluation of that policy have also served to focus attention on service gaps and priorities.

At the same time, new structures emerged to support the development of cancer services at a regional level through the appointment of the Regional Directors of Cancer Services and the introduction of the role of the Cancer Nurse Co-ordinator in the Eastern Regional Health Authority. Research and education across cancer services have also been improved.

While there is and always will be a level of complaint about a level of under-funding in the system to implement the vision and objectives of the 1996 National Cancer Strategy, it must be recognised that cancer services have received an additional cumulative investment of approximately €400m over the lifetime of this strategy. It must also be accepted that economic constraint is likely to continue into the lifetime of the next strategy. Fundamentally, delivery of a new phase of a National Cancer Strategy and its ultimate implementation relies on an ability to reconfigure present structures, enhance system co-ordination and interaction and redefine accepted working practices and service management.

In summary the strategy has delivered:

- A major reduction in cancer mortalities (per 100,000 of population) ahead of target
- An ever increasing spend on cancer services
- Increasing activity in chemotherapy, radiotherapy and surgery
- A considerable improvement in cancer care through a more co-ordinated and structured approach to its delivery
- A significant increase in the number of cancer care professionals.

Clearly substantial investment has been made in cancer treatment services and the system is considerably better today. That said, it cannot be denied that ongoing developments are required, which will impact on services to further improve and enhance patient care with better treatment and facilities in the future.

2

INTRODUCTION

2. INTRODUCTION

2.1 INTRODUCTION

This report presents the findings and recommendations arising from the completion of an evaluation of the 1996 National Cancer Strategy. The purpose of the evaluation is to assess the extent to which the objectives and actions of the National Cancer Strategy have been implemented and achieved. The evaluation was commissioned by the Department of Health and Children on behalf of the National Cancer Forum. The field work was carried out by Deloitte and Touche Management Consultants between October 2002 and February 2003.

2.2 BACKGROUND TO REVIEW

"Cancer Services in Ireland: A National Strategy" was published in 1996, the core objectives of which are as follows:

(i) to take all measures possible to reduce rates of illness and death from cancer, in line with the targets established in *"Shaping a Healthier Future"*
-– reduce the death rate from cancer in the under-65 age group by 15 per cent in the ten year period from 1994.

(ii) to ensure that those who develop cancer receive the most effective care and treatment and that their quality of life is enhanced to the greatest extent possible.

In line with the above, the key thrust of the strategy focused on:

- Effective prevention and screening services
- Information for patients and professionals
- Early detection through screening
- Ensuring all patients have equitable access to effective services which are of uniformly high quality
- Improving and prolonging the quality of life
- Delivering appropriate treatment to a high standard
- Achieving improved co-ordination across primary care, hospital care, rehabilitation and palliative care
- Ensuring that services are delivered in a cost-effective manner
- Providing more and better focused research and development.

Three Ministers for Health have presided over the implementation of the strategy: Michael Noonan (1996-1997), Brian Cowen (1997-2000) and the current Minister for Health and Children, Micheál Martin (2000 to date). The National Cancer Forum is currently in the process of preparing a new strategy. The focus of this report is to evaluate the level of progress made against each of the strategy's objectives so as to inform the thinking of the National Cancer Forum in terms of understanding and quantifying the extent to which the actions and proposed initiatives set out have been implemented, the factors and barriers that have impacted on their implementation, key service gaps and key priorities for the future.

2.3 TERMS OF REFERENCE

The terms of reference for this assignment are as follows:

(i) To examine the extent to which the objectives of the Strategy have been met and in particular to address the following key questions:

(cf Ch.5 and summarised in section 6.2)

- To what extent has the Strategy been implemented as originally planned?
- What impact has the Strategy and associated investment had on cancer care in terms of structures, processes and outcomes?
- What have been the benefits to patients of this investment in terms of:
  - access
  - range of services
  - quality of services
  - integration/co-ordination of services
  - information available to patients
- What are the success factors, which need to be supported, and developed going forward?
- What have been the principal barriers to implementation of the Strategy?
- What have been the principal gaps in the implementation of the Strategy?

(Ch. 5 and summarised in sections 6.2.2, 6.2.3, 6.3.1 and 6.3.3)

(ii) To identify and prioritise areas where future work needs to be done and identify the processes, which will achieve this outcome, in particular in the context of the preparation of the second cancer strategy.

(Ch. 6)

(iii) To make recommendations on priorities for future action with a view to further development of cancer services

(Section 6.3)

2.4 REPORT STRUCTURE

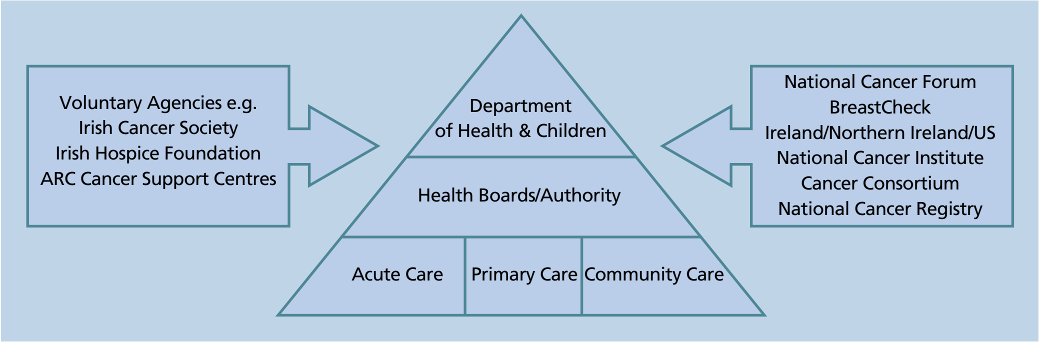
This report is divided into six sections as follows:

- Section 1 is an executive summary, which contains a summary of the key issues arising from this evaluation.
- Section 2 provides an introduction to the background to the report, the terms of reference and the methodology employed.
- Section 3 presents a quantitative analysis of the developments in cancer services over the lifetime of the National Cancer Strategy.
- Section 4 highlights the key patient issues arising from the public submissions and the patient survey facilitated through Reach to Recovery, the Listowel Cancer Support Group and the Bray Cancer Support Group.
- Section 5 collates and analyses the key issues arising from this review according to the objectives of the 1996 National Cancer Strategy.
- Section 6 concludes with our key findings and conclusions arising from the evaluation together with our views on the priorities for the future.

2.5 OVERVIEW OF THE STRUCTURES OF CANCER SERVICE DELIVERY

By means of background information, this section provides an overview of the structures that support the delivery of cancer services in Ireland and describes the associated key responsibilities of the main organisations.

FIGURE 2.1: STRUCTURE FOR THE DELIVERY OF CANCER SERVICES



Department of Health and Children

The Department of Health and Children has overall responsibility for the development of health policy and for the planning of health services.

Health Boards/Authority

The health boards have responsibility for implementation of national policy. Since the implementation of the 1996 Cancer Strategy, a Director of Cancer Services (known as the Regional Director of Cancer Services) has been appointed in each health board. Following its establishment in 2000, the Eastern Regional Health Authority appointed a Regional Cancer Director to each area health board. Each director is responsible for the planning, co-ordination, development and evaluation of cancer services within their area.

Under the 1996 National Cancer Strategy, three supra-regional cancer centres were identified as Dublin, Cork and Galway. The long term objective is for these centres to provide specialist surgery, medical and radiation oncology, rehabilitation and palliative care to cancer patients. In conjunction with this, each health board was requested to designate a regional centre(s) of specialist cancer care (acute hospitals) for the delivery of cancer services.

Acute, Primary and Community Care

Treatment for cancer is provided in two main settings: primary care and acute hospital care. Hospital treatment is provided on an in-patient, day case and out-patient basis. Community based services provide care and support for people with cancer in their homes and through community facilities such as hospices.

Voluntary Agencies

The Irish Cancer Society is the largest voluntary provider of funds for cancer research in Ireland. It is dedicated to the prevention of cancer and improving the quality of life of those living with cancer through patient care, research and education. The main work of the Society is the delivery of nursing and support services to patients with cancer.

Other voluntary organisations include ARC, Canteen Ireland and Reach to Recovery. In addition, there are a range of patient support groups throughout the country that provide invaluable assistance and support to patients.

The National Cancer Forum

In 1994, provision was made for the development of a National Cancer Strategy under the then Health Strategy – *Shaping a Healthier Future.* The 1996 National Cancer Strategy provided for the establishment of the National Cancer Forum. At present, the Forum is working to review and revise the 1996 Cancer Strategy and set out the key investment areas to be targeted for the development of cancer services over the coming years.

The Ireland-Northern Ireland-National Cancer Institute Cancer Consortium

The Ireland-Northern Ireland-NCI Cancer Consortium is a trilateral partnership involving the Department of

Health and Children, the Department of Health, Social Services and Public Safety, Northern Ireland and the National Cancer Institute, United States Department of Health and Human Services. It was conceptualised by cancer physicians in Ireland, Northern Ireland and the United States who took their idea of a collaborative partnership to their respective governments. The Consortium was established in October 1999 on foot of a Memorandum of Understanding signed by the Health Ministers of Ireland and Northern Ireland and the Secretary of State for the United States Department of Health and Human Services. It seeks to bring together in a collaborative way, the cancer communities in all three jurisdictions with a view to enhancing the capacity of our cancer research and service delivery systems. The Department of Health and Children has allocated €3.5 million for cancer clinical trials to the Health Research Board under this initiative. Further details regarding the work of the Consortium and its achievements are set out in section 5.

National Cancer Registry

The National Cancer Registry is a statutory body, which was established in 1991 by the Minister for Health and commenced the recording of cancer cases in Ireland in 1994. The Registry is fully funded by the Department of Health and Children. The information collected is used for research into the causes of cancer, in education and information programmes, in the promotion and facilitation of the use of data in the planning and management of services and in the planning of the national cancer strategy to deliver the best cancer care to the whole population.

2.6 POLICY OVERVIEW

There has been a significant level of policy development impacting on cancer services since the publication of the National Cancer Strategy in 1996. These are summarised in Table 2.1. The majority of policy development has occurred since 1999 with the exception of the Report of the Department of Health Cervical Screening Committee and A Plan for Women's Health.

TABLE 2.1: KEY PUBLICATIONS AND POLICY RELATING TO CANCER

Publications

- Report of the Department of Health Cervical Screening Committee (1996)
- A Plan for Women's Health: 1997-1999
- Implementation of National Cancer Strategy – three separate reports to Minister of Health and Children: 1997, 1999 and 2001
- National Breast Screening Committee: First Report (1998)
- National Development Plan 2000-2006 (1999)
- Report of The Committee on Haematology Services (Comhairle na nOspidéal) (1999)
- Cancer Support Services in Ireland: Priorities for Action (1999)
- Caring about Women and Cancer (1999)
- The National Health Promotion Strategy 2000-2005 (2000)
- Programme for Prosperity and Fairness (2000)
- Partnership 2000 for Inclusion Employment and Competitiveness (1999)
- Development of Services for Symptomatic Breast Disease (March 2000)
- Survey of views and perceptions of women who attended Symptomatic Breast Clinics (2000)
- Quality & Fairness: A Health System for You (2001)
- Your Views About Health: Consultation Report for the Health Strategy (2002)
- Cancer Research Across Borders (2001)
- Review of the Cancer Nurse Co-ordinator Role in the Eastern Region (2001)
- Report of the National Advisory Committee on Palliative Care (2001)
- Primary Care: A New Direction (2001)
- Cancer in Ireland, 1994 to 2002: Incidence, Mortality, Treatment and Survival (2003)
- Cancer in Ireland, 1994 to 1998: Incidence, Mortality, Treatment and Survival (2001)
- BreastCheck: The National Breast Screening Programme Annual Report 2000-2001 (2002)
- BreastCheck: Annual Report 2002 (2003)
- Strategic Task Force on Alcohol: Interim Report (2002)
- Cancer Consortium - A Periodic Update of Progress and Events
- Sustaining Progress - Social Partnership Agreement 2003-2005 (2003)

The main policy developments in the following four key areas have been informed by a number of relevant reports as outlined below:

1. **Health Promotion and Prevention:** National Health Promotion Strategy 2000-2005, Strategic Task Force on Alcohol: Interim Report.

2. **Medical and Nursing Services:** Report of the Department of Health Cervical Screening Committee, A Plan for Women's Health, Report of the Committee on Haematology Services, Development of Services for Symptomatic Breast Disease, Report of the National Advisory Committee on Palliative Care, Review of the Cancer Nurse Co-ordinator Role in the Eastern Region.

3. **Cancer Support Services:** Cancer Support Services in Ireland: Priorities for Action, the Report of the National Advisory Committee on Palliative Care.

4. **Health Services:** Quality and Fairness: A Health System for You, National Development Plan 2000-2006, Primary Care: A New Direction, Programme for Prosperity and Fairness, and Sustaining Progress.

The 1996 National Cancer Strategy served to highlight policy deficiencies in a range of areas within cancer services, for example, palliative care and cancer support services. In highlighting these gaps, policies have subsequently been developed i.e. *Report of the National Advisory Committee on Palliative Care and Cancer Support Services in Ireland: Prioirties for Action*. It is important to recognise that even though these and other policies for cancer treatment services have been formulated outside the National Cancer Strategy, they exist as a consequence of that strategy and have been influenced by it.

Cancer services at the time of the development of the National Cancer Strategy were mainly based around the acute hospital system with insufficient recognition given to the role of primary and community services. Policy development since 1999 has shown a greater awareness of the need to focus on a multi-disciplinary approach towards service delivery with support services now viewed as an essential element of cancer services.

Future policy development will be strongly guided by the principals and objectives of the new health strategy *"Quality and Fairness: A Health System for You".*

2.7 METHODOLOGY

The evaluation of the National Cancer Strategy is primarily based on an extensive consultation process with key stakeholders involved in cancer services in Ireland. Statistical data relating to cancer services was reviewed and analysed, but such information was limited. Our final set of findings and conclusions are therefore largely qualitative in nature.

The study was broken down into four key phases of work:

PHASE I: PROJECT INITIATION

This incorporated:

- Introductory meetings with the Project Steering Committee
- Agreement of stakeholders to be met with
- Development and agreement of the project plan and schedule of consultations
- Development and agreement of stakeholder questionnaire
- Finalisation of public submission process
- General project management planning.

PHASE II: DATA GATHERING

The data gathering phase incorporated the collation and review of both quantitative and qualitative data.

Background Documentation and Literature Review

We carried out an extensive review of all relevant policy documents and reports relating to the 1996 National Cancer Strategy. A summary of the key findings from this review is attached as a separate document to the report.

Quantitative Data Analysis

We carried out a review of relevant statistical data in relation to cancer services as made available through the Department of Health and Children, the Health Boards/Authority and the National Cancer Registry.

Consultations

Consultations comprised a series of meetings with:

- Members of the National Cancer Forum
- Each of the regional health boards comprising meetings with the Chief Executive Officer (or a nominated representative), the Regional Director of Cancer Services and the Director of Public Health
- Representatives from the Department of Health and Children
- The Chief Executive Officer of the Health Research Board.

The interview templates used during these consultations are contained as Appendices 2 and 3. A list of all organisations and individuals met with is included as Appendix 1.

At the request of the Project Steering Committee, participants were requested to respond to a questionnaire on symptomatic breast disease services. This questionnaire as designed by the Project Steering Committee is included as Appendix 4 in conjunction with the presentation of the findings (the level of questionnaire response completeness varies across health boards).

Submissions

The Department of Health and Children ran a series of advertisements inviting members of the public and other interested parties to make submissions to the National Cancer Forum. The purpose of this process was to allow the public the opportunity to present their views on the development of cancer services over the past number of years and on how they could be improved going forward. Individuals and organisations wishing to make a submission were provided with a consultation pack and relevant documentation. A copy of this pack is contained in Appendix 5. A total of 266 submissions were received from patients, their families or friends and patient support groups.

The National Cancer Forum also wrote to over ninety stakeholders, including professional bodies and voluntary agencies seeking submissions. A total of 31 submissions were received. Submissions were analysed in detail using a statistical analysis package.

Patient Survey

Patient input to this report was regarded as being very important from the outset. There was a concern that this might not be forthcoming through the submission process (although this was not the case) and to this end, the assistance of Reach to Recovery Cork, the Listowel Cancer Support Group and the Bray Cancer Support Group was secured in distributing a patient questionnaire, which followed the format of the Department of Health and Children's submission pack (a copy is included in Appendix 6). We are grateful to each of these groups for their assistance and commitment to this process. Fourteen responses were received from patients and their families. These questionnaires contributed valuable additional information as well as providing validation to the responses received from the public submissions.

PHASE III: DATA REVIEW AND EVALUATION

This phase of the study involved a detailed examination of the data gathered as part of Phase II in order to assess the extent to which each of the strategic objectives of the National Cancer Strategy were achieved. On completion of Phase III we presented the key issues to a meeting of the National Cancer Forum for discussion. We subsequently developed our draft report which was presented to the Project Steering Committee for review and comment before the final report was formally presented to the National Cancer Forum.

PHASE IV: FINAL REPORT AND CONCLUSIONS

Finalised following receipt of feedback from the steering committee on the draft report.

2.8 ACKNOWLEDGEMENTS

Deloitte & Touche wish to thank the following for their assistance with this review:

- The members of the Project Steering Committee who provided guidance and assistance during the course of the review
- The members of the National Cancer Forum who gave generously of their time to meet with us and input into the evaluation process
- The Chief Executive Officers, Regional Directors of Cancer Services, the Directors of Public Health and other key staff whom we met with as part of the consultation process with the Health Boards/Authority
- Reach to Recovery, Cork, the Bray Cancer Support Group and the Listowel Cancer Support Group who assisted us in obtaining patient input
- Staff from the Department of Health and Children and the other representatives of organisations who participated in the consultation process
- The individuals and organisations who responded to the public invitation for submissions and provided invaluable input to this evaluation.

3

QUANTITATIVE ANALYSIS OF DEVELOPMENTS IN CANCER SERVICES OVER THE LIFETIME OF THE STRATEGY

3. QUANTITATIVE ANALYSIS OF DEVELOPMENTS IN CANCER SERVICES OVER THE LIFETIME OF THE STRATEGY

3.1 INTRODUCTION

The purpose of this section is to present a quantitative analysis of the key areas of development within cancer services since the implementation of the 1996 National Cancer Strategy. The objective is to understand the extent of financial investment into the Strategy implementation and to quantitatively assess some of the key developments in services and service delivery that have resulted.

The section is structured according to the following headings:

- Overview of Cancer Incidence in Ireland
- Mortality Data
- Cancer Services Funding
- Staff Appointments
- In-Patient and Out-Patient Activity
- Health Board Self-Sufficiency
- Treatment Data
- Conclusions

3.2 OVERVIEW OF CANCER INCIDENCE IN IRELAND

This section quantifies the size of the problem of cancer in Ireland. Consideration of the incidence of cancer provides useful background information and emphasises Ireland's need for a comprehensive National Cancer Strategy which reflects recent developments and best practice in patient management and multi-disciplinary care. This report does not attempt to produce an epidemiological analysis of cancer incidence or other parameters relating to this disease.

Each year there are approximately 19,000 new cases of cancer recorded. About one in three individuals develop cancer in the course of their lifetime with the most common cancers being skin, large bowel, lung, breast and prostate.

Cancer disease is one of the highest contributors to mortality and morbidity rates in Ireland. There are over 7,500 cancer deaths per annum. This accounts for almost one quarter of the annual death toll, making cancer the second most frequent cause of death in Ireland. The largest number of cancer deaths result from lung cancer. Breast cancer is the most common cause of death from cancer in women.

Sixty per cent of patients are aged 65 and over at the time of cancer diagnosis. In addition, the majority of cancer deaths occur in those aged over 65.

Cancer incidence data is recorded and maintained by the National Cancer Registry. It records all malignant cancers and some other early tumours, which are potentially malignant. The average annual number of all new cancer cases is circa 19,000 per annum for the period extending from 1994 to 2001. This data is illustrated in Table 3.1.

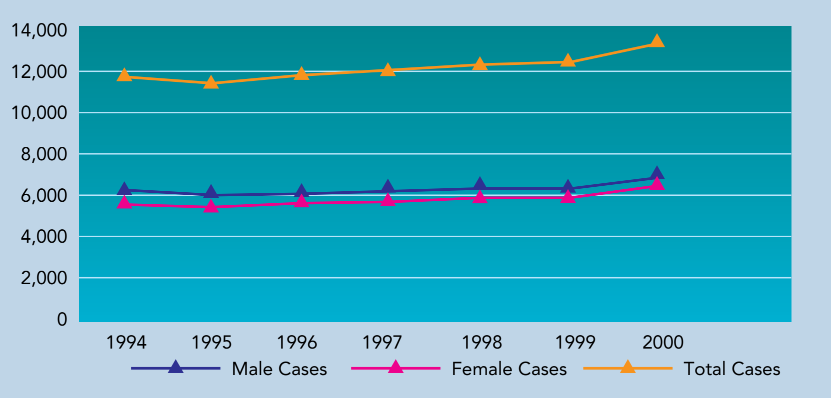
TABLE 3.1: NEW CANCER CASES

YEAR	ALL CANCERS	ALL MALIGNANT CANCERS	ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER
1994	19,063	16,959	11,832
1995	18,684	16,655	11,533
1996	19,528	17,133	11,851
1997	19,870	17,341	12,095
1998	19,836	17,374	12,318
1999	20,093	17,434	12,389
2000	22,117	18,936	13,301

Source: National Cancer Registry Ireland

Figure 3.1 graphically depicts cancer incidence over the period 1994 to 2001 along with a breakdown of incidence between males and females.

FIGURE 3.1: NEW CANCER CASES FOR ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN



Source: National Cancer Registry Ireland

Table 3.1 and Figure 3.1 demonstrate that the incidence of cancer has remained relatively constant over the period 1994 to 2001, although some slight variations do occur. Clearly the burden of cancer is the same today as it was at the launch of the National Cancer Strategy in 1996.

3.3 MORTALITY DATA

A key component of our statistical analysis is an analysis of mortality data. This is important because the overall objective of the National Cancer Strategy was to:

- reduce the death rate from cancer in the under-65 age group by 15 per cent in the ten year period from 1994.

Table 3.2 sets out the cancer mortality rate in the under-65 age group over the period 1994 to 2001.

TABLE 3.2: MORTALITY RATE PER 100,000 POPULATION AGED UNDER 65 FOR ALL MALIGNANT NEOPLASMS

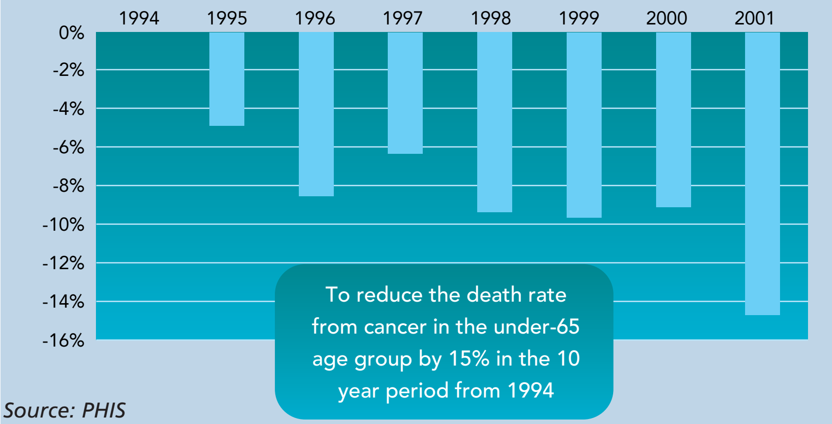
YEAR	MORTALITY RATE PER 100,000 POPULATION < 65	% CHANGE YEAR ON YEAR	% CHANGE ON BASE YEAR
1994	88.97	-	-
1995	84.55	(4.97%)	(4.97%)
1996	81.24	(3.91%)	(8.69%)
1997	83.21	2.42%	(6.47%)
1998	80.46	(3.30%)	(9.57%)
1999	80.25	(0.26%)	(9.80%)
2000	80.80	0.69%	(9.18%)
2001	75.78	(6.21%)	(14.83%)

Source: PHIS

The data contained in Table 3.2 represents positive findings. The overall death rate from cancer in the under-65 age group was 14.83 per cent lower than the death rate in 1994. The death rate has been lower than the rate in 1994 in each year over the period 1995 to 2001. Based on these findings the overall objective of the National Cancer Strategy to reduce the death rate from cancer in the under-65 age group by 15 per cent in the ten-year period from 1994 was achieved in 2001, three years ahead of target.

The percentage cumulative change in mortality in the under-65 age group is graphically depicted in Figure 3.2.

FIGURE 3.2: CUMULATIVE PERCENTAGE CHANGE IN MORTALITY RATE (ALL MALIGNANT NEOPLASMS) PER 100,000 POPULATION FOR UNDER 65 AGE GROUP



To reduce the death rate from cancer in the under-65 age group by 15% in the 10 year period from 1994

Source: PHIS

Table 3.3 sets out the cancer mortality rate for all ages. A similar downward trend is evident for all age groups as for the under-65 age group.

TABLE 3.3: MORTALITY RATE PER 100,000 POPULATION FOR ALL MALIGNANT NEOPLASMS (ALL AGES)

YEAR	MORTALITY RATE PER 100,000	% CHANGE YEAR ON YEAR	% CHANGE ON BASE YEAR
1994	215.64	-	-
1995	214.92	(0.33%)	(0.33%)
1996	208.14	(3.25%)	(3.48%)
1997	208.87	0.35%	(3.14%)
1998	204.65	(2.02%)	(5.10%)
1999	203.75	(0.44%)	(5.51%)
2000	204.66	0.45%	(5.09%)
2001	198.04	(3.23%)	(8.16%)

Source: PHIS

The above analysis shows that the death rate due to cancer in the over-65 age group is higher than that for the under-65 age group. Nevertheless, a consistent downward trend in death rates is evident. The death rate in 2001 is 8 per cent lower than the death rate in 1994.

3.4 CANCER SERVICES FUNDING

Perhaps one of the most notable achievements of the National Cancer Strategy was the separation of the additional cancer care budget allocation to health boards from the budget allocation for general acute hospitals. Prior to the National Cancer Strategy, it was not possible to determine the investment in cancer services. Health boards were allocated a budget for acute hospitals and cancer services fell under that umbrella. The separation of the cancer development budget from the acute hospital budget represented a major development as it ensured that dedicated funding was made available specifically for cancer services and that any changes to this additional funding could be gauged over time. This budget separation was first implemented in 1997.

Over the lifetime of the National Cancer Strategy, there was significant increased investment in cancer services. We have broken down our analysis of funding increases under the following categories:

- Overall Increases in Revenue Funding by Health Board
- Increases in Revenue Funding analysed by Health Board
- Allocation of Funding – Department of Health and Children and Health Boards
- Increases in Capital Funding
- Increases in Palliative Care Funding
- Funding to other Agencies

3.4.1 OVERALL INCREASES IN REVENUE FUNDING BY HEALTH BOARD

Table 3.4 sets out the cumulative spend on cancer services development since 1996 (revenue funding only). These statistics are graphically depicted in Figure 3.3.

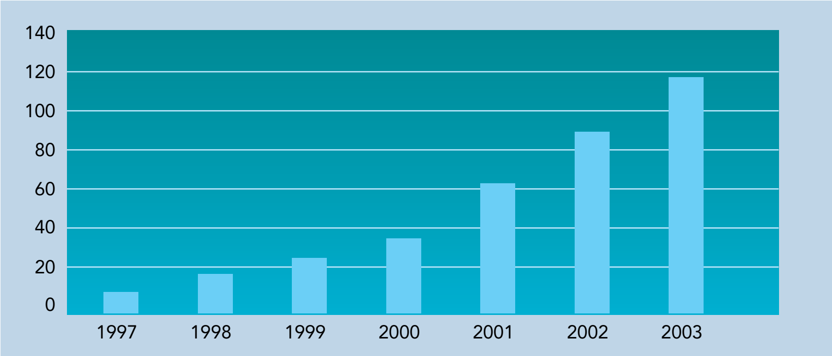
TABLE 3.4: INCREASING SPEND ON CANCER SERVICES DEVELOPMENT BY HEALTH BOARD RELATED TO THE BASE YEAR (1997) (INCLUDES ADJUSTMENTS FOR INFLATION)

YEAR	INCREASING FUNDING (INCLUDES INFLATION ADJUSTMENT)	% INCREASE ON 1997 FUNDING
1997	7.45	-
1998	17.253	132%
1999	25.679	245%
2000	35.568	377%
2001	61.065	720%
2002	87.759	1,078%
2003	117.45	1,477%

Source: Department of Health and Children

This equates to a total cumulative increase in cancer funding across the heath boards of €352.224 million since 1996. This does not include funding allocated to BreastCheck, the National Cancer Registry of Ireland or the Health Research Board.

FIGURE 3.3: **INCREASING SPEND ON CANCER SERVICES DEVELOPMENT BY HEALTH BOARD RELATED TO BASE YEAR (1997) (INCLUDES ADJUSTMENTS FOR INFLATION)**



Source: Department of Health and Children

The most significant conclusion that can be drawn from Table 3.4 and Figure 3.3 is that funding to health boards for cancer treatment services has increased dramatically over the lifetime of the strategy. Funding provided to health boards/authority for cancer services in 2003 is 1,477 per cent greater than funding levels in 1997, a mere six years earlier. The achievement of such a level of funding increase over a relatively short period of time is a major success. It exemplifies the significant commitment of health service providers towards the development of cancer treatment services.

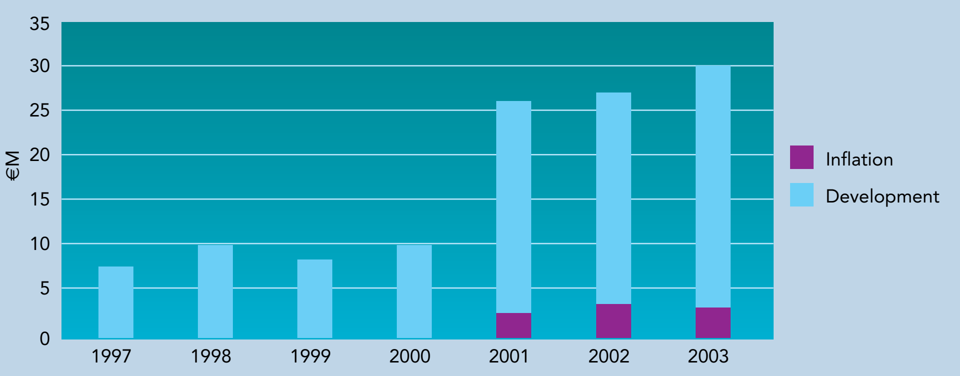
Table 3.5 and Figure 3.4 illustrates the year on year funding to health boards for cancer services over the 1997 to 2003 period. The analysis only covers additions to services for each year.

TABLE 3.5: **YEAR ON YEAR – ANNUAL FUNDING INCREASES BY HEALTH BOARD**

YEAR	DEVELOPMENT FUNDING €MILLION	% CHANGE YEAR ON YEAR	% CUMULATIVE INCREASE ON 1997
1997	7.45	-	-
1998	9.60	28.9%	28.9%
1999	8.01	(16.6%)	7.5%
2000	9.29	16.0%	24.7%
2001	23.13	149.0%	210.5%
2002	23.55	1.8%	216.1%
2003	27.11	15.1%	263.9%

Source: Department of Health and Children

FIGURE 3.4: **YEAR ON YEAR – ANNUAL FUNDING INCREASES BY HEALTH BOARD**



Source: Department of Health and Children

The above data validates the finding that substantial investment has been made into the development of cancer services at health board level since the launch of the National Cancer Strategy. It is clear that additions to service developments were made each year over the Strategy's lifetime. Furthermore, the level of additions increased each year (with the exception of the year 1999). The most significant service additions were made in the years 2001, 2002 and 2003. It has been indicated that the reason for the particular size of additions in these years may be that the increase in staff appointments, which were evaluated and approved in the early years of strategy implementation, began to come on stream in these later years. Overall, the level of health board service additions made amounted to approximately €352 million. The size and substantial nature of this service investment should not be under-estimated.

3.4.2 INCREASES IN FUNDING ANALYSED BY HEALTH BOARD

The purpose of this section is to assess the extent to which a consistent uniform approach was adopted to the allocation of funding across each of the health boards. To this end we have correlated the cumulative cancer budget in each health board with the level of patient activity in each board. We are using number of patient discharges as the indicator of patient activity.

Table 3.6 shows the funding per patient discharge in each health board for each year over the period 1997 to 2001. As can be seen from the table, large variations exist across the health boards. This could imply that the levels of funding allocations may not be consistent across the health boards. Funding per patient can be as much as 75 per cent higher in some health boards than in others.

It is important to recognise that this is a very crude, if not simplistic, approach to assessing the equity of funding between health boards. There are several issues surrounding the validity of the data, e.g. some health boards may not record all day sessions as discharges (e.g. a chemotherapy session) while others do. These differences in recording discharges may result in some health boards having an apparent low number of discharges and hence a higher level of revenue per discharge. These variations must be borne in mind when considering the data contained in Table 3.6.

However given the constraints identified above, there is insufficient data available from the Department of Health and Children to allow appropriate evaluation across health boards of the different levels of investment in cancer services; or performance measures of treatment outcomes.

TABLE 3.6: REVENUE FUNDING PER DISCHARGE BY HEALTH BOARD

YEAR	ERHA (€m)	MHB (€m)	MWHB (€m)	NEHB (€m)	NWHB (€m)	SEHB (€m)	SHB (€m)	WHB (€m)	AVERAGE (€m)
1997	365	80	181	53	297	40	169	223	225
1998	618	177	877	189	579	236	332	550	477
1999	686	416	1,263	317	1,099	366	487	801	652
2000	873	696	1,507	517	1,384	488	664	932	844
2001	1,320	1,218	1,981	897	1,820	1,130	1,352	1,560	1,363

3.4.3 ALLOCATION OF FUNDING – DEPARTMENT OF HEALTH AND CHILDREN AND THE HEALTH BOARDS

The funding information presented in this report has been sourced from the Department of Health and Children. In the course of the consultation process we also received some funding information directly from some of the health boards. It was interesting to note that the health boards' opinion on the size of their allocation did not always correlate with that of the Department. It is important that there is transparency both in terms of allocation of funding to agencies for cancer services and subsequent use of those funds in the delivery of cancer services.

3.4.4 INCREASES IN CAPITAL FUNDING

This section sets out the capital funding allocated to cancer services over the period 1996 to 2002. In considering the increases presented it is important to be aware that they relate exclusively to cancer services. In addition, general acute hospital capital funding that would have impacted positively on cancer services did take place over this period. However, it is not possible to isolate the cancer investment from this funding. As a result we have limited our analysis to consideration of cancer specific capital funding.

Since 1997, approximately €87 million in capital funding has been allocated specifically for the development of cancer related initiatives. This level of capital investment reflects a positive commitment to the development of high quality cancer services. The resulting capital developments have ranged from major new oncology infrastructure projects to minor capital items such as replacement equipment. For example:

Radiation Oncology

Major investment has occurred in the development of radiation oncology services since 1997. In excess of €25 million has been invested in St Luke's Hospital enabling the purchase of significant additional equipment including six new linear accelerators. Cork University Hospital has seen a total investment of almost €15 million in a new radiotherapy unit at the hospital. This involved the commissioning of two new linear accelerators as well as related radiotherapy equipment. A new radiotherapy department is currently under construction at University College Hospital Galway. To date, €14 million has been allocated to this development which will provide services to the Western, Mid-Western and North-Western areas.

Bone Marrow Unit

This expenditure has allowed important capital initiatives to be undertaken in the areas of national specialties with, for e.g., €8.75 million being provided for the Bone Marrow Unit in St James's Hospital.

BreastCheck

A total amount of €12 million in capital funding was made available for the development of the two static BreastCheck units located at St Vincent's Hospital and the Mater Hospital.

Oncology Services

General Oncology services have seen capital investment of almost €3million.

As previously stated this sum of €87 million does not take account of investment in major general capital projects in acute hospitals that also have benefits for cancer services. It also excludes funding given to health boards for minor capital projects, including re-equipping and refurbishing that would obviously have a positive impact on cancer services.

On completion of all of these projects, significant progress will have been made in addressing the major historic deficiencies which have existed in the infrastructure for the delivery of cancer services. There is recognition across the board of the need to continue progress and investment in oncology services.

Table 3.7 presents an overview of some major capital developments since 1997.

TABLE 3.7: EXAMPLES OF SOME MAJOR CAPITAL DEVELOPMENTS SINCE 1997

CAPITAL INITIATIVE	TOTAL € MILLION
St Luke's Hospital – radiation oncology equipment	25
Cork University Hospital – radiotherapy unit	15
University College Hospital Galway – investment to date in radiotherapy department	14
St James' Hospital - Bone Marrow Unit	8.75
BreastCheck	12

Source: Department of Health & Children

It is clear from Table 3.7 that particular emphasis was concentrated on capital investment in cancer services since the implementation of the Strategy. In each of the years 1999, 2000 and 2001, investment was substantially greater than in any previous year. These levels of investment are indicative of the prioritisation that has been attached to improving cancer treatment services.

3.4.5 INCREASES IN PALLIATIVE CARE FUNDING

This section assesses the extent of funding that has been allocated to palliative care over the last number of years. As is the case with the cancer budget, there was no specific palliative care budget prior to the launch of the National Cancer Strategy. Furthermore, it is important to recognise that the palliative care funding presented in this section does not reflect total spending on palliative care, i.e. the funding for palliative care staff (e.g. palliative consultants, palliative nursing, etc,) is included in the cancer revenue funding (section 3.4.1).

In 2001, the Report of the National Advisory Committee on Palliative Care was launched. The Report describes a comprehensive palliative care service and acts as a blueprint for its development. The implementation of the Report has been undertaken as part of the implementation of the National Health Strategy.

That palliative care now has a dedicated budget is indicative of the recognition of the underdeveloped nature of palliative care services and of the need to direct specific attention at their development.

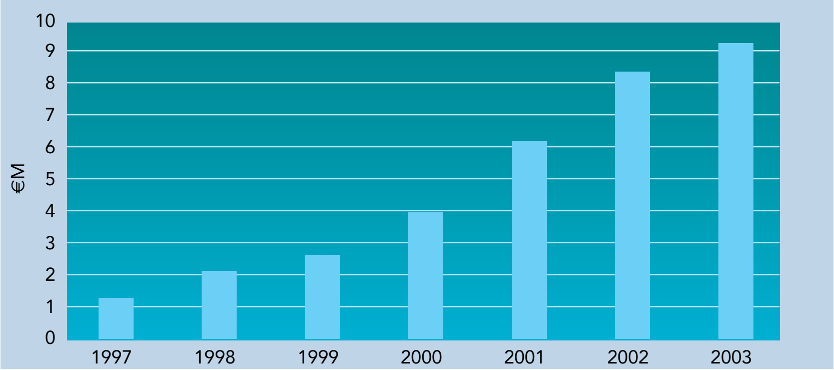
Table 3.8 sets out the cumulative spend on palliative services (including inflation) since 1996. These statistics are graphically depicted in Figure 3.5.

TABLE 3.8: INCREASING SPEND ON PALLIATIVE CARE (INCLUDES ADJUSTMENTS FOR INFLATION) RELATED TO THE BASE YEAR (1997)

YEAR	INCREASING FUNDING (INCLUDES INFLATION ADJUSTMENT) €MILLION	% INCREASE ON 1997 FUNDING
1997	1.181	-
1998	2.11	78.66%
1999	2.668	26.45%
2000	3.986	49.40%
2001	6.262	57.10%
2002	8.405	34.22%
2003	9.34	11.12%

Source: Department of Health & Children

FIGURE 3.5: INCREASING SPEND ON PALLIATIVE CARE (INCLUDES ADJUSTMENTS FOR INFLATION) RELATED TO THE BASE YEAR (1997)



Source: Department of Health & Children

Table 3.8 and Figure 3.5 clearly demonstrate that funding for palliative care has increased steadily over the lifetime of the Strategy.

3.4.6 FUNDING TO OTHER AGENCIES

In addition to increases in revenue funding made to the health boards, increased funding allocations were also made to agencies involved in cancer services development and delivery. Specifically the three agencies under consideration are:

- The National Cancer Registry Board (NCRB)
- The Health Research Board (HRB)
- BreastCheck

The annual increase in funding each year relative to the base year (1996 or the first year of funding) is illustrated in Table 3.9.

TABLE 3.9: INCREASING SPEND ON FUNDING TO AGENCIES (EXCLUDES ONCE OFF ALLOCATIONS) RELATED TO THE BASE YEAR

YEAR	NCRB		HRB		BREASTCHECK	
	INCREASING FUNDING €MILLION	% INCREASE ON BASE YEAR FUNDING	INCREASING FUNDING €MILLION	% INCREASE ON BASE YEAR FUNDING	INCREASING FUNDING €MILLION	% INCREASE ON BASE YEAR FUNDING
1997	0.685	-	-	-	-	-
1998	0.798	16%	-	-	-	-
1999	0.92	34%	-	-	3.74	-
2000	1.08	58%	-	-	7.311	95%
2001	1.271	86%	0.318	-	7.644	104%
2002	1.371	100%	1.621	410%	9.935	166%
2003	1.509	120%	3.028	852%	10.222	173%

Source: Department of Health and Children

As can be seen from Table 3.9, these agencies benefited considerably from increases in funding allocations over the lifetime of the Strategy. This included the allocation of funding for the start-up of BreastCheck and also for the allocation of dedicated funding to the Health Research Board to support cancer clinical trials under the Ireland-Northern Ireland-NCI Cancer Consortium.

3.5 STAFF APPOINTMENTS

In section 3.4 we set out the substantial revenue investments that were directed at cancer service developments over the course of the National Cancer Strategy implementation. In this section we assess where this money was spent. One of the key areas was staff appointments. At the commencement of the strategy manpower shortages were a critical weakness of cancer treatment services. For this reason, the implementation of the Strategy concentrated particular efforts at addressing this weakness.

In this section we set out staffing appointments since the Strategy according to two main headings:

- Consultant Appointments
- Clinical Nurse Specialist Appointments

3.5.1 CONSULTANT APPOINTMENTS

A total of 85 consultant posts have been appointed to the services since 1997. The nature and distribution of these posts is illustrated in Table 3.10.

TABLE 3.10: CONSULTANT APPOINTMENTS SINCE 1997

Health Board	Medical Oncologist	Palliative Care	Histo-pathologist	Radiation Oncologist	Consultant Surgeon (breast surgery)	Gynacologist (interest in oncology)	Radiologist	Haema-tologist	General Surgeon (GI)	Total
ERHA	5	3	5	2	5		6			26
MHB	1		1		1		1	1	1	6
MWHB	1	1	1		1	1		2	1	8
NEHB	2*	1	3		2		2	1	1	10
NWHB	2	1	1		1			2	1	8
SEHB	3	1	1		2		1	1	1	10
SHB	2		3		1		1	1		8
WHB	1	1	4	1	1		1	1	1	11
Total	**15**	**8**	**19**	**3**	**14**	**1**	**12**	**9**	**6**	**87**

**ERHA posts linked to the NEHB*

Source: Department of Health and Children

It is clear from the above table that the extent of new consultant appointments has been very significant. Prior to the Strategy there were just four medical oncologists in Ireland. The Strategy provided for a further 15 appointments which means that the medical oncology manpower has increased by 375 per cent as a result of the Strategy. This positive development has direct implications for issues such as patient access, the range of services available and the quality of service provision.

In relation to the other consultant appointments, the Strategy represented an important move forward. Up to this point, consultants were not dedicated specifically to cancer services. Arising from the Strategy, dedicated consultant appointments were made to cancer services for the first time. Clearly, this development has favourable consequences for the quality of service provision (in addition to improving access).

It is important to remember that 85 consultant appointments brings far more than 85 new personnel to the cancer service. Every consultant appointment involves the appointment of a supporting clinical team. Overall the estimated cost of one consultant appointment and team ranges between €1-€1.5 million. Based on this analysis it becomes evident that the majority of additional finding for cancer services (as set out in section 3.3) was directed at consultant appointments and their supporting teams.

Notwithstanding the high number of consultant appointments, a critical point must be highlighted: three health boards still operate with only one medical oncologist in place: the Mid-Western Health Board, the Western Health Board and the Midland Health Board. This is an important issue which we will explore in further detail in section 5.

3.5.2 CLINICAL NURSE SPECIALIST APPOINTMENTS

As a result of the National Cancer Strategy a significant number of clinical nurse specialist appointments were made across all of the health boards. These appointments were essentially made from a baseline of zero because up until 1999, the concept of specialist nurses did not exist within the services. While there may have been nurses who worked primarily in oncology, breast cancer care, etc., there were no formalised dedicated arrangements in place. The introduction of the clinical nurse specialist role brought nurses, specifically trained in particular areas of care, into cancer services full-time. To date, a total of 245 clinical nurse specialists have been appointed. Predominantly they are involved in the following areas of specialisation:

- Palliative care
- Breast care
- Oncology
- Stoma care

The appointments were made over a three year period over the latter years of the Strategy – 43 in 2000, 170 in 2001 and 32 in 2002. A detailed breakdown of staffing appointments is presented in table 3.11.

TABLE 3.11: BREAKDOWN OF CLINICAL NURSE SPECIALIST APPOINTMENTS

NURSE SPECIALISTS	ECAHB	NAHB	SWAHB	MWHB	MHB	NEHB	NWHB	SEHB	SHB	WHB	TOTAL
Bone Bank Co-ordinator		2		1							3
Bone Marrow Registry Co-ordination			1								1
Bone Marrow Transplant Co-ordinator			1								1
Bone Tumour		1									1
Breast Care	2	1	2	2	1	1	2	1	2	3	17
Cancer Co-ordinator	1	2									3
Chemotherapy			2								2
Colorectal		1									1
ENT/Head and Neck		1									1
Head and Neck Oncology		1	1								2
Interventional Radiology			1								1
Liver Liaison			1								1
Liver Recipient Co-ordinator	2										2
Lung Cancer			1								1
Lung Cancer Nursing			1								1
Lymphodema			1								1
Male Genito - Urinary Cancer			1								1
Mammography		1									1
Oncology		2	1			5	5	3	7	5	28
Oncology Liaison	1		2					1		2	6
Oncology/Breast Care								3			3
Oncology/Palliative Care					1						1
Paediatric Oncology			1								1
Paediatric Oncology Liaison			2								2
Palliative Care	6	2	4	4		1		1	1	6	25
Palliative Care - Learning Disabilities			1								1
Palliative Home Care		13	26	14	7	10	6	16	14	11	117
Stoma Care		2	6			3	2	1	1	2	17
Stoma & Breast Care				1							1
Stomatherapy									2		2
Total	**12**	**29**	**56**	**22**	**9**	**20**	**15**	**26**	**27**	**29**	**245**

Source: Department of Health and Children/National Council for the Professional Development of Nursing and Midwifery.

The achievements arising from the National Cancer Strategy are not only reflected in the actual number of specialist nursing appointments but also in the fact that this new role of nurse specialist was introduced into the services over the lifetime of the strategy.

3.6 IN-PATIENT AND OUT-PATIENT ACTIVITY

The objective of this section is to assess the extent to which the levels of in-patient and out-patient activity have changed over the lifetime of the Strategy. We have structured the section according to the following headings:

- All Patient Activity
- In-Patient Activity and Day Case Activity
- Average Length of Stay

Our analysis in this section and subsequent sections is predominantly based on data obtained from HIPE and PHIS[2].

3.6.1 ALL PATIENT ACTIVITY

The purpose of this analysis is to determine the overall level of activity within cancer treatment services. This is achieved through a review of PHIS cancer discharge data. This data represents the sum of all patient discharges from hospital – discharges occur following an in-patient hospital stay and also following a day case session[3]. The data is presented in Table 3.12.

TABLE 3.12: CANCER DISCHARGES

YEAR	ALL CANCER	ALL MALIGNANT CANCERS	ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER	% YEAR ON YEAR CHANGE (ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER)	% CHANGE RELATED TO BASE YEAR (ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER)
1994	46,125	33,030	29,663	-	-
1995	49,088	33,998	30,230	1.91%	1.91%
1996	52,391	35,479	31,524	4.28%	6.27%
1997	55,202	37,298	33,168	5.21%	11.82%
1998	58,420	40,027	35,764	7.82%	20.57%
1999	62,396	42,889	38,431	7.46%	29.56%
2000	67,526	45,560	40,687	5.87%	37.16%
2001	70,968	46,865	42,182	3.67%	42.20%

Source: PHIS

Table 3.12 clearly illustrates that there has been a substantial and steady increase in patient activity over the lifetime of the Strategy. Each year has shown an increase in patient discharges over the previous year. Data for 2001 shows that there has been a 42 per cent increase in activity since prior to the launch of the Strategy. This increase may be attributable to increases in in-patient activity, increases in day case activity or a combination of both. This is explored in more detail in the following sections.

This increase in patient activity may be indicative of several factors:

- Increased patient access to services due to the greater level of services available.
- Increased quality for patients arising from the greater volume of service provision.

---

[2] The current HIPE (Hospital In-Patient Enquiry) system captures data from all publicly funded acute hospitals, two private hospitals and all 3 Dublin Maternity Hospitals since 2000. Data in the system is case based, therefore the data available is based on patient discharges. As such patients undergoing cancer treatment may have multiple entries in the HIPE system. HIPE data feeds into the Public Health Information System (PHIS), the principal function of which is to report on the health status of the population on an annual basis. Diagnosis counts are based only on patients' principal diagnosis. The key areas on which it reports are population mortality, fertility and morbidity. PHIS also has links to the National Cancer Registry and the CSO data. Data in PHIS originating from the National Cancer Registry pertains to 1994 through to 1997. The current version of PHIS reports on hospital discharges over the 1994 to 2001 timeframe.

[3] However it should be noted that centres may adopt different practices to recording patient discharges, i.e. it has been highlighted to us that not all centres record all day care sessions (e.g. radiotherapy session, chemotherapy session) as patient discharges.

3.6.2 IN-PATIENT ACTIVITY AND DAY CASE ACTIVITY

Table 3.13 sets out the statistics regarding in-patient and day case activity prior to, and over the lifetime of, the National Cancer Strategy. It also shows the year on year changes in activity and the cumulative changes over the 1994 to 2001 period.

TABLE 3.13: IN-PATIENT ACTIVITY AND DAY CASE ACTIVITY

YEAR	DISCHARGES: ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER	IN-PATIENT DISCHARGES	% YEAR ON YEAR CHANGE (ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER)	% CHANGE RELATED TO BASE YEAR (ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER)	DAY CASE DISCHARGES	% YEAR ON YEAR CHANGE (ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER)	% CHANGE RELATED TO BASE YEAR (ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN CANCER)
1994	29,663	23,009	-	-	6,654	-	-
1995	30,230	22,766	(1.06%)	(1.06%)	7,464	12.17%	12.17%
1996	31,524	23,185	1.84%	0.76%	8,339	11.72%	25.32%
1997	33,168	23,591	1.75%	2.53%	9,577	14.85%	43.93%
1998	35,764	23,463	(0.54%)	1.97%	12,301	28.44%	84.87%
1999	38,431	23,582	0.51%	2.49%	14,849	20.71%	123.16%
2000	40,687	24,730	4.87%	7.48%	15,957	7.46%	139.81%
2001	42,182	23,930	(3.23%)	4.00%	18,252	14.38%	174.31%

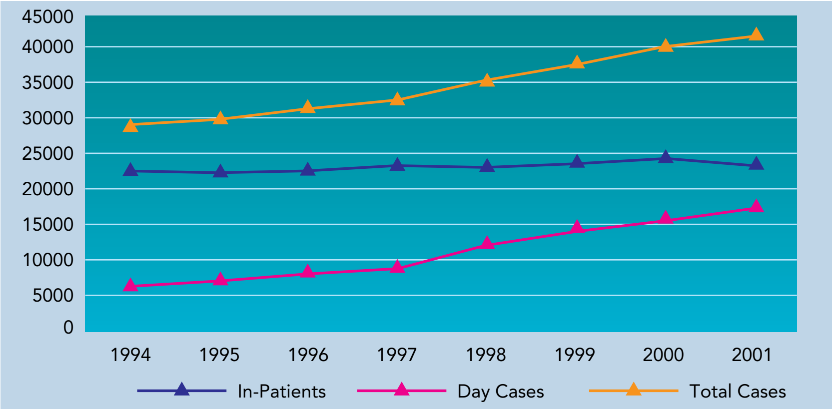
Source: PHIS

One conclusion from Table 3.13 is that the overall increase in patient activity that was evidenced in our analysis in section 3.6.1 cannot be attributed to increases in in-patient activity. Overall the number of in-patient discharges did not change significantly over the lifetime of the Strategy and are not greater than pre-Strategy levels to any large extent. Minor fluctuations did occur from year to year, the largest of which occurred in 2000. The highest level of in-patient activity was recorded in this year.

The reverse is true with respect to day case activity. The number of day cases has increased dramatically over the course of the Strategy. Over the period 1994 to 2001 the number of day cases has increased by 174.31 per cent. This is an important finding and is clear evidence of the impact that the increased funding and staffing appointments are having on the cancer treatment services. As in-patient activity has remained relatively constant, it implies that the increase in day case activity represents the introduction of additional or “new” services and activities to the cancer treatment services (i.e. rather than just a reorganisation of the methods of provision of existing services). This is a critical achievement for the Strategy and highlights the improvements to service range and quality that have been achieved.

Figure 3.6 graphically depicts the data contained in Tables 3.12 and 3.13. By presenting this information in this fashion, it is very clear to see the areas where the Strategy has resulted in increased activity levels. The overall trend is apparent across all health boards over the 1994 to 2001 period i.e. the number of in-patient cases has remained relatively constant, while the number of day cases increased substantially.

FIGURE 3.6: DISCHARGES DUE TO ALL MALIGNANT CANCERS EXCEPT NON-MELANOMA SKIN



Source: PHIS

3.6.3 AVERAGE LENGTH OF STAY

In Table 3.14 we set out the average length of stay for in-patients diagnosed with cancer (all malignant neoplasms except non-melanoma skin).

TABLE 3.14: IN- PATIENT AVERAGE LENGTH OF STAY IN DAYS

HEALTH BOARD	1994	1995	1996	1997	1998	1999	2000	2001
ERHA	15.72	16.5	15.46	14.88	15.03	14.21	13.85	14.12
WHB	15.44	14.58	14.24	12.93	13.48	13.81	13.95	13.57
MHB	13.38	12.71	12.24	12.36	12.31	12.42	12.56	13.02
NWHB	11.82	12.76	12.17	11.6	11.43	12.25	12.35	13.02
NEHB	13.13	12.83	12.59	12.98	13.59	12.63	12.25	12.73
SEHB	12.18	12.24	12.07	11.69	11.72	11.68	11.71	12.64
MWHB	12.32	12.57	12.69	12.23	12.01	12.66	12.03	11.95
SHB	10.19	10.54	10.22	10.49	10.15	10.33	10.69	10.68
Overall Average	13.52	13.73	13.21	12.86	12.95	12.73	12.72	12.97

Source: PHIS

There has been a marginal decrease in the overall in-patient average length of stay over the period 1994 to 2001, i.e. reduced from 13.52 days in 1994 to 12.97 days in 2001. In the previous section we found that in-patient activity had not changed significantly over the course of the Strategy. The above findings show that the length of time cancer patients spend in hospital as in-patients has not changed significantly either. This finding again highlights the point that the increase in day case activity (section 3.6.2) represents additional service provision and not a reorganisation of the methods of provision of existing services. In addition, the provision of increased numbers of day cases has not resulted in a change in the number of days patients are required to spend in hospital.

3.7 REGIONAL HEALTH BOARD ACTIVITY

Table 3.15 illustrates the percentage of patients, resident within different health boards, who receive cancer treatment within their own Health Board area. It gives a reflection of the percentage of total cancer patients, which each health board treats within their own services.

TABLE 3.15: REGIONAL ACTIVITY ACROSS HEALTH BOARDS

Year	ERHA	MHB	MWHB	NEHB	NWHB	SEHB	SHB	WHB
2001	99.4%	39.4%	60.0%	45.2%	63.5%	63.5%	93.0%	81.5%
2000	99.5%	37.3%	58.7%	47.5%	55.5%	68.9%	90.7%	80.5%
1999	99.4%	39.9%	52.8%	47.4%	57.2%	68.5%	89.2%	78.6%
1998	99.3%	39.4%	58.7%	47.2%	60.5%	58.2%	90.6%	78.7%
1997	99.3%	40.7%	54.5%	45.6%	60.3%	55.7%	92.1%	79.4%
1996	99.3%	44.0%	54.3%	50.0%	60.3%	54.3%	92.8%	78.9%
1995	99.3%	46.4%	53.2%	49.2%	59.9%	51.9%	90.8%	77.8%

Source HIPE[4]

What is clear from the above table is that there has been little change in the percentage of patients travelling outside their own health board area to receive treatment.

3.8 TREATMENT DATA

The three main types of cancer treatment are surgery, chemotherapy and radiotherapy. This section assesses the level of activity under each of these treatment headings. The analysis is carried out using two criteria, i.e. number of patients receiving treatment and secondly the number of treatment sessions provided (e.g. one patient can receive numerous sessions of chemotherapy).

3.8.1 NUMBER OF CASES

Table 3.16 presents data relating to the number of patients receiving chemotherapy, radiotherapy and surgery in respect of all cancers over the period 1994 to 2000[5].

TABLE 3.16: NUMBER OF CASES RECEIVING CHEMOTHERAPY, RADIOTHERAPY AND SURGERY

	CHEMOTHERAPY			RADIOTHERAPY			SURGERY		
YEAR	NUMBER OF CASES	% CHANGE YEAR ON YEAR	% CHANGE ON BASE YEAR	NUMBER OF CASES	% CHANGE YEAR ON YEAR	% CHANGE ON BASE YEAR	NUMBER OF CASES	% CHANGE YEAR ON YEAR	% CHANGE ON BASE YEAR
1994	3,084	-	-	3,273	-	-	9,630	-	-
1995	2,650	(14%)	(14%)	3,318	1%	1%	9,646	0.2%	0.2%
1996	2,395	(9%)	(22%)	3,401	3%	4%	10,301	7%	7%
1997	2,571	7%	(17%)	3,253	(4%)	(0.6%)	10,353	0.5%	8%
1998	2,690	5%	(13%)	3,349	3%	2%	10,193	(2%)	6%
1999	3,116	16%	1%	3,691	10%	13%	12,137	19%	26%
2000	3,175	2%	3%	3,257	(12%)	(0.5%)	12,120	(0.1%)	26%

Source: National Cancer Registry Ireland

The above statistics show that the number of patients accessing chemotherapy and radiotherapy services has not increased over the course of the Cancer Strategy implementation.

In the years 1995, 1996, 1997 and 1998, the number of patients receiving chemotherapy was actually less than the number of patients who had received chemotherapy in 1994. By 2000 the number had increased by just 3 per cent on 1994 levels.

---

[4] This data is based on records where the Principal Diagnosis Codes are 'All Malignant Neoplasms Except Non-Melanoma Skin' and includes in-patients and day cases. It should be noted that numbers of cases is not equivalent to the number of patients since HIPE is case based and not patient based.

[5] Data for 2001 is not yet complete so it has not been included in the analysis.

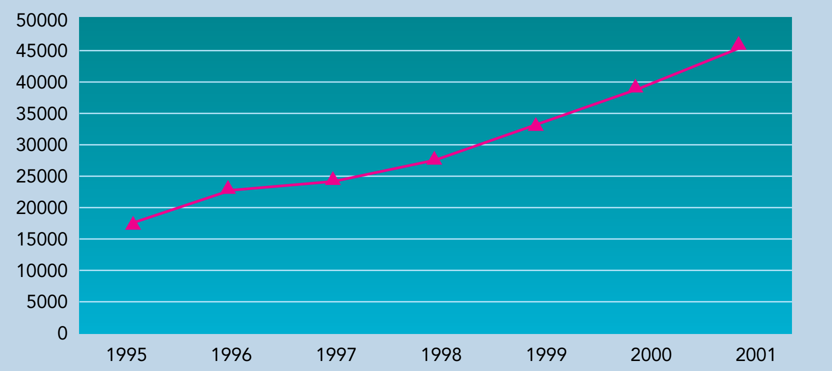
In relation to radiotherapy the number of patients receiving radiotherapy in 2000 was 0.5 per cent lower than the number who had received radiotherapy in 1994. During the period 1994 to 2000 there were some fluctuations in numbers accessing radiotherapy services. However, no significant improvements were evident.

Surgery was the single treatment type where there were increased numbers of patients accessing the service. By 2000, the numbers of patients receiving surgery was 26 per cent greater than the number in 1994.

3.8.2 NUMBER OF SESSIONS

Figure 3.7 shows an increasing trend in the number of chemotherapy sessions in the period 1995 to 2001. The number of chemotherapy sessions has almost trebled over the period.

FIGURE 3.7: NUMBER OF CHEMOTHERAPY SESSIONS



Source HIPE[6]

That the number of chemotherapy sessions has increased over the lifetime of the Strategy with no comparable increase in the number of patients receiving chemotherapy may suggest that the overall quality of treatment provided has increased.

HIPE data shows that the number of new patient episodes per annum for radiotherapy treatment has increased from 2402 in 1994 to 3809 in 2000. This represents an increase of 58 per cent nationally. The 2002 Annual Report for St Luke's Hospital shows that in 2002 there were 76,398 radiotherapy treatments at the hospital compared with 69,420 in 2000. This represents a 10 per cent increase in the number of radiotherapy treatments.

---

[6] Data is based on either a diagnosis of "Encounter for Chemotherapy" for any diagnostic field or procedure code "Injection or Infusion of Cancer Chemotherapeutic Substance" for any procedure field.

3.9 CONCLUSIONS

The data presented throughout this section is evidence of the level of prioritisation and commitment that has been directed at cancer treatment services since the launch of the National Cancer Strategy. This is illustrated by the substantial and increasing levels of investment that have been made in the development of dedicated cancer services since the launch of the Strategy.

The area where the effects of this investment are most visible is staffing. The Strategy provided for the appointment of 85 specialist consultants (with supporting teams) and 245 clinical nurse specialist posts. The achievement of the Strategy not only relates to the actual appointment of these staff; equally important is the fact that these staff appointments represented the first time that dedicated nurses were appointed to the area of cancer care. In addition, the significant increase in consultant oncologists will have contributed enormously to better patient care. This represents a critical step forward and has important consequences for the quality of patient care.

The majority of staff appointments began to come on stream mid-way through the Strategy implementation. Therefore, it is not possible to assess their long term implications. However, we have identified a number of areas where significant achievements have been made. These include:

- Increases in the level of patient activity – particularly day case activity.
- Increases in the numbers of patients receiving surgery.
- Increases in the numbers of chemotherapy sessions.
- Increases in radiotherapy activity.

It emerged that the mortality rates are improving and that the Strategy achieved its overall objective, i.e. to reduce the death rate from cancer in the under-65 age group by 15 per cent in the ten year period from 1994.

4

REVIEW OF PATIENT SUBMISSIONS AND PATIENT SURVEY

4. REVIEW OF PATIENT SUBMISSIONS AND PATIENT SURVEY

4.1 INTRODUCTION AND BACKGROUND – PATIENT SUBMISSIONS

In November 2002, the Department of Health and Children ran a series of advertisements inviting members of the public and other interested parties to make submissions to the National Cancer Forum. The purpose of the submission process was to allow interested parties give their views on how cancer services have been developed over the past number of years and how they could be improved in the future. Individuals and organisations wishing to make a submission were provided with a consultation pack and relevant documentation. Respondents were not required to answer every question but were asked to give answers to the questions that were important or relevant to them. A copy of the consultation pack is contained in Appendix 5.

Submissions generally came from patients, their families and friends, and patient support organisations. As a result they generally addressed patient issues and concerns. These submissions have been statistically analysed and the findings are presented in section 4.2, in addition to being incorporated into the evaluation of research findings presented in section 5.

The National Cancer Forum also wrote to over ninety professional and public bodies, voluntary agencies, charities and research/advisory bodies seeking submissions. These submissions did not follow the format of the consultation pack but rather were presented in letter and report format. They addressed a range of issues including patient issues and service quality. A total of 31 submissions were received. As the information received was in qualitative rather than quantitative format, it was not possible to undertake any form of statistical analysis on the findings. As such, we have extracted the key points made under each submission for incorporation into the evaluation of research findings in section 5.

There is always an element of risk associated with carrying out submission/survey processes. For this reason the findings should be interpreted with a degree of caution. Examples of possible risks include:

- Respondents sometimes regard this type of process as an opportunity to highlight areas of dissatisfaction only. This may result in respondents not communicating the areas where they were satisfied. The outcome of the process may therefore be skewed in an overly negative direction.
- In general, individuals are more likely to respond to a submission process/survey if they have negative feelings rather than if they have positive feelings.
- The questions may not be clearly understood and therefore may elicit the wrong information.
- The submission form can sometimes be answered quickly and the questions may not be fully read, thus leading to inaccurate responses.
- It may be hard for participants to recall information about services, which they used in previous years.
- Responses can sometimes be blurred by the most recent incident experienced. If this is negative, it can result in a response being skewed negatively even though the overall view may in fact be positive.

While the submission form (and patient survey) were carefully designed and clearly worded to avoid some of the above problems arising, the risks cannot be fully eliminated. It is also important to remember that the findings presented represent the perceptions of a sample of individuals who have experience of cancer treatment services, i.e. a significantly higher number of individuals have experience of these services than responded to the submission process/patient survey.

We also reviewed and analysed the contents and opinions recorded in the two reports: Caring about Women and Cancer and the Women's Cancer Report.

The remainder of this section is dedicated to the presentation of findings. The objective is to present the views of patients that emerged from the patient consultation process. In sections 5 and 6 we explore and comment on these findings in greater detail and set out the priorities for the future.

4.2 KEY FINDINGS – SUBMISSIONS FROM PATIENTS AND FAMILIES

A total of 266[7] submissions were received for analysis. A detailed statistical analysis was carried out and the findings are presented according to the following headings in the pages that follow:

- General Demographics
- Use of Cancer Services
- Satisfaction with Cancer Services
- Strengths of Cancer Services
- Weaknesses of Cancer Services
- Priorities for the Development of Cancer Services

4.2.1 GENERAL DEMOGRAPHICS

Questions 1 to 4 asked respondents to provide personal information on gender, age and county of residence. The purpose of this information was to assess the extent to which views from different parts of the country and different age groups were collated.

The majority of responses were from individuals and health service workers. A small percentage (14 per cent) of responses were from organisations[8].

TABLE 4.1: GENERAL DEMOGRAPHICS OF RESPONDENTS

GROUP	FREQUENCY	PERCENT
Individual	153	57.5%
Health Service Worker	44	16.5%
Family	31	11.7%
Health Organisation	21	7.9%
Other Organisation	16	6.0%
Unknown	1	0.4%
Total	**266**	**100.0%**

The majority of respondents were female (68 per cent) in comparison to a 25 per cent response rate from males. It should be noted that a number of questionnaires were not filled in by patients, but by spouses and other family members of patients. Therefore, the response may be from a female but relate to a male cancer experience in the family.

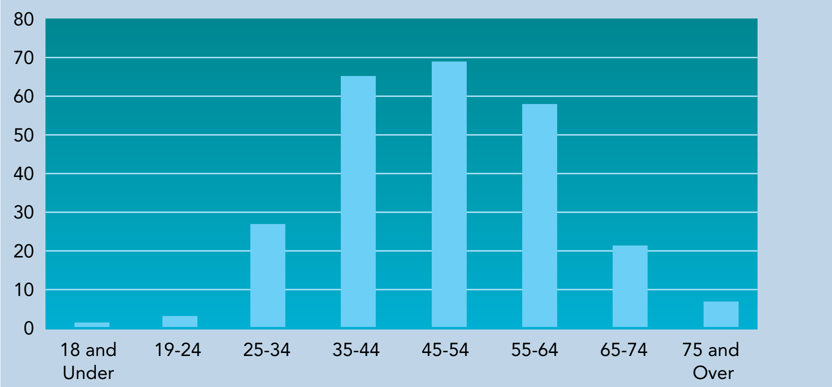
Over 70 per cent of respondents fell within the 35 to 64 age bracket. Ten per cent of respondents were between 25 and 34 years of age and 9 per cent were in the 65-74 age category. The age category of 13 respondents was unknown.

---

[7] Three submissions related to cancer services outside Ireland and one submission was received after the cut off date for analysis of Friday 10th January. These were not included in the analysis.

[8] These are patient representative organisations, which addressed patient issues.

FIGURE 4.1: AGE PROFILE OF RESPONDENTS



In terms of regional representation, 26 of the 32 counties were represented. 26.7 per cent of respondents were from Dublin, 7.5 per cent from Cork, 6 per cent from Galway and 5.3 per cent from Waterford. Longford is not represented in Leinster and Down is the only county represented in Northern Ireland.

TABLE 4.2: REGIONAL REPRESENTATION OF RESPONDENTS

PROVINCE	NO. OF COUNTIES REPRESENTED	FREQUENCY	PER CENT
Leinster	11	133	50.0%
Munster	6	71	26.7%
Connaught	5	30	11.3%
Ulster	4	22	8.3%
Unknown		10	3.8%
Total	**26**	**266**	**100.0%**

A reasonable balance of representation from urban and rural areas was received with 56 per cent of respondents from urban areas and 41 per cent from rural areas.

4.2.2 USE OF CANCER SERVICES

Question 5 asked respondents if they or their families used cancer services in recent years. If respondents answered positively, they were asked to give the year in which they used cancer services.

72 per cent (192) of respondents stated that they or their families had used cancer services in recent years. Of these, almost 45 per cent used cancer services during 2002. Table 4.3 gives a breakdown of the findings:

TABLE 4.3: YEAR OF EXPERIENCE WITH CANCER SERVICES

YEAR	FREQUENCY	PER CENT
2002	86	44.8%
2001	24	12.5%
2000	18	9.4%
1999	13	6.8%
1998	8	4.2%
1997	5	2.6%
1996	6	3.1%
Pre 1996	29	15.1%
Unknown	3	1.6%
Total	**192**	**100.0%**

The high percentage of responses related to experiences in 2002 and 2001, thereby implying that the findings generally reflect patients' views of current cancer services. However, it may be fair to state that the majority of respondents who had experience with cancer services in 2002 are still actively undergoing treatment and are involved with cancer services.

4.2.3 SATISFACTION WITH CANCER SERVICES

Question 6 asked respondents to rate their satisfaction with cancer services. 23 per cent of all respondents were very satisfied with cancer services and 58 per cent were either very satisfied or moderately satisfied. Almost 27 per cent of respondents were dissatisfied with the services.

TABLE 4.4: SATISFACTION LEVELS WITH CANCER SERVICES

	FREQUENCY	PER CENT
Very Satisfied	62	23.3%
Moderately Satisfied	92	34.6%
Dissatisfied	71	26.7%
Unknown	41	15.4%
Total	**266**	**100%**

4.2.4 STRENGTHS OF CANCER SERVICES

Question 7 asked respondents to list what they regard as the three most important strengths of cancer services.

TABLE 4.5: STRENGTHS OF CANCER SERVICES

STRENGTH	FREQUENCY	PER CENT
Staff	101	37.9%
Support Group	50	18.8%
Quality of Treatment	32	12.0%
Other	70	26.3%

(i) Staff

The dedication and motivation of staff working in cancer services was listed as the principal strength. Many respondents stated that staff, in spite of limited resources, always did their best for patients. Nurses in particular were very helpful, courteous and efficient, and in some cases, patients regarded nurses as being more sensitive than doctors to their needs.

(ii) Cancer Support Groups

18.8 per cent of respondents stated that the support groups were very helpful and essential throughout their treatment. Volunteers in hospitals provided support to patients with cancer and were available to talk. Support groups such as the Irish Cancer Society, ARC Cancer Support, Hodgkin's United Group and Reach to Recovery were identified as providing excellent support services. The excellent care provided by the Irish Hospice Foundation was also commented upon in the submissions.

(iii) Quality of Treatment

11.9 per cent of respondents classified the quality of treatment and care received as a strength of cancer services. Some respondents were satisfied with the oncology units in hospitals. They also noted that better treatment drugs were now available with enhanced ability to control pain and sickness.

(iv) Other

A range of other strengths were referenced and included the information and literature available on cancer especially that provided by the Irish Cancer Society. The BreastCheck programme, although not available nationally at the time of this evaluation was mentioned as an excellent service.

4.2.5 WEAKNESSES OF CANCER SERVICES

Respondents were asked to identify the three greatest weaknesses of cancer services in question 8. The main weakness related to the accessibility of cancer services.

TABLE 4.6: WEAKNESSES OF CANCER SERVICES

WEAKNESS	FREQUENCY	PER CENT
Access	163	61.3%
Resources	83	31.2%
Emotional Support/Information	71	26.7%
Counselling/Follow Up Support	65	24.4%
Travel and Transport	61	22.9%
Alternative Treatments	20	7.5%
Co-ordination of Services/Treatment	18	6.8%
Other	92	34.6%

(i) Access

Difficulties in accessing cancer services and the lack of dedicated cancer clinics were listed as a weakness by over 61 per cent of respondents. The opinion among many respondents is that there is no universal treatment protocols and that regional differences are prevalent. The following table illustrates patient satisfaction levels with cancer services, broken down by the county of residence. Respondents living outside Cork and Dublin had a higher level of dissatisfaction with cancer services. Access is an issue that we will explore in further detail in section 5.

TABLE 4.7: PATIENT SATISFACTION BY REGION

	VERY SATISFIED	MODERATELY SATISFIED	DISSATISFIED	UNKNOWN	TOTAL
Cork and Dublin (frequency)	23	32	20	16	91
Outside Cork and Dublin (frequency)	39	60	51	25	175
Cork and Dublin (%)	25.3%	35.2%	22.0%	17.6%	100%
Outside Cork and Dublin (%)	22.3%	34.3%	29.1%	14.3%	100%

The principal recurring issue for patients and families referenced throughout the submissions was the belief that radiotherapy services and specialist multi-disciplinary cancer centres should be located countrywide. It was the view of patients and families that radiotherapy services should be available in most health boards.

The speed at which patients could access cancer services was frequently listed as a weakness. Patients cited long delays for tests, test results and treatments. Some patients had difficulty getting referrals to specialists from their General Practitioners. Others experienced long waiting lists leading to delays in intervention and treatment. Respondents also expressed dissatisfaction with outdated equipment, which regularly broke down, resulting in the rescheduling of appointments and thus additional waiting time and stress.

(ii) Resources

The lack of resources in cancer services was listed as a weakness by 31.2 per cent of respondents. The main issue identified was the shortage of oncology nurses and the high turnover of personnel in cancer services. A need for more specialist doctors and consultants was identified. Also, the shortage of dedicated units and beds for cancer patients is an issue for patients. It was considered that there was insufficient money spent on equipment, with a lot of equipment being old and outdated. Cancer patients were dissatisfied with the lack of privacy in units while undergoing treatment.

(iii) Emotional Support/Information

The emotional support and information category encapsulates comments respondents made in relation to the support and information that patients received while undergoing treatment. Respondents felt that although information was available on cancer, the information given to them in relation to cancer treatments and their side effects was inadequate. In some cases they were unable to make an educated choice on the type of treatment to undergo. Respondents felt that doctors and consultants did not always provide the necessary support, sensitivity and compassion when dealing with cancer patients. Opportunities to improve doctor-patient relationships were identified. Many patients were of the view that a low level of psychological support was available during treatment.

(iv) Counselling/Follow Up Support

Approximately 25 per cent of patients listed counselling and follow up support as a weakness post treatment. Once patients were discharged, it was considered that there was limited support available to them and their families with regard to community nurses and home-help.

(v) Travel and Transport

The need to travel long distances for treatment was categorised as a weakness by over 22 per cent of patients. As a result of having to travel long distances, beds were sometimes occupied for up to six weeks for radiotherapy treatment that only lasted a few minutes per day. Patients from a range of counties including Galway and Donegal highlighted the requirement to travel to Dublin for treatment. This was noted as being extremely difficult and uncomfortable, particularly for patients who were unwell. Leaving family and friends and the expense incurred in travelling for treatment also added to the stress of patients.

(vi) Alternative Treatments

Some respondents perceived there to be a lack of alternative treatments and non-conventional treatments available. It was suggested that these should be incorporated into the treatment options available and presented to patients.

(vii) Co-ordination of Services/Treatments

The co-ordination of services and treatments was regarded as being poor by almost 7 per cent of respondents. The lack of communication between doctors was an issue for many patients. Patients claimed there was poor communication between hospital teams, GPs and public health nurses. Poor administration was cited by some respondents, for example, files sometimes misplaced and patient details lost.

(viii) Other

A variety of other weaknesses were listed. The two most recurring of these related to public and private patient access to services and the availability of screening services. It was claimed that public patients were subject to longer waiting times, with private patients having speedier access to cancer services. Respondents commented on the limited availability of the BreastCheck Programme (an announcement to extend the programme nationally has subsequently been made). Furthermore, the age groups to which these services were offered were considered too narrow. Respondents also commented on the lack of resources directed at preventative measures.

4.2.6 PRIORITIES FOR THE DEVELOPMENT OF CANCER SERVICES

Question 9 asked respondents to list their three priorities for the development of cancer services in the future. These are listed in Table 4.8.

TABLE 4.8: PRIORITIES FOR THE DEVELOPMENT OF CANCER SERVICES

PRIORITY	FREQUENCY	PER CENT
Access	162	60.9%
Follow Up/Counselling	97	36.5%
Screening Services	71	26.7%
Emotional Support/information	67	25.2%
Staffing	56	21.1%
Medical Cards	19	7.1%
Travel Services	16	6.0%
Other	87	32.7%

(i) Access

Among the suggestions put forward to improve service access included:

- Decentralised treatment centres including the provision of more radiotherapy facilities; Respondents requested radiotherapy centres in the Western, Midland, South Eastern and North Eastern Health Boards
- Develop more centres of specialist cancer care around the country
- Develop the availability of paediatric services and facilities for adolescents on a regional basis
- Improved and quicker access to tests, test results and treatments
- Privacy for patients receiving chemotherapy
- Develop chemotherapy services so that more out-reach chemotherapy units can provide this service
- Provide more wards and beds dedicated to cancer patients and extend the opening hours of treatment centres to shorten waiting time
- The availability of community based oncology nurses in each health board for taking blood, and support rather than patients having to travel to acute hospitals
- Development of more support groups nationwide.

(ii) Follow Up/Counselling

There were a number of priorities listed in relation to counselling and support services following cancer treatment:

- Practical, financial and emotional support for families and carers
- Improved resources for individuals who choose to stay at home in terms of the provision of carers, hospice teams and respite beds
- Extension of hospice care so patients can be treated within their own area
- Development of a national cancer help-line.

(iii) Screening Services

Over one quarter of respondents made suggestions for developing screening services in the future.

- Extend the BreastCheck programme (subsequently announced) and cervical screening programme nationally
- Increase awareness of men’s health and aim to reduce the incidence of prostate cancer
- Expand the age range at which screening programmes are targeted.

(iv) Emotional Support/Information

One quarter of respondents highlighted the importance attached to emotional support during their treatment process. Many respondents who did not come in contact with support groups said that it would have been extremely beneficial to meet with individuals who have gone through treatment for the same type of cancer. Other suggestions included:

- Make information available on all treatments and services available
- Improved sensitivity towards patients and families
- The development and improvement of psychological support for patients and family ensuring that it is part of a scheduled process arranged for all patients.

(v) Staffing

Suggestions in relation to staffing included the following:

- Increase the staff-patient ratio
- Assign more palliative care nurses to rural areas
- Make additional staff available to talk to patients
- Increase the number of oncology nurses.

(vi) Medical Cards

Some respondents commented on the expense of drugs and the treatment. Six per cent of respondents suggested that oncology patients should be given a medical card while undergoing treatment.

(vii) Travel Services

Travelling for treatment incurs expense and inconvenience on patients and their families. While patients are undergoing treatment it was suggested that they and their families could have access to free travel. It was also suggested that an ambulance service should be available for some patients who have difficulty in travelling to treatment centres.

(viii) Other

A variety of other priorities were identified for the development of cancer services in the future:

- Incorporate unconventional and alternative treatments into conventional treatments
- Improve the co-ordination of the care pathway
- Government funding for Hospices
- Develop nutritional plans
- Equity of care for both public and private patients
- Better communication from treatment centres to G.P.s
- Greater public education and the introduction of informational sessions to secondary schools to improve cancer awareness
- Develop the availability of clinical trials
- Use of a national information system to reduce repetitive administrative demands on patients, for example, the need to fill out same forms at outpatient clinics.

4.3 PATIENT SURVEY – RESULTS AND FINDINGS

Patient input to this report was regarded as being very important from the outset. In addition to the public consultation undertaken by the DoHC, we secured the assistance of Reach to Recovery Cork, the Listowel Cancer Support Group and the Bray Cancer Support Group in distributing a patient questionnaire, the format for which followed the format of the Department of Health and Children's submission pack (a copy is included in Appendix 6). We are grateful to each of these groups for their assistance and commitment to this process.

The responses to the patient survey validated the issues emerging from the patient submissions while also providing some valuable additional information.

There were a number of areas that were highlighted as important strengths of cancer treatment services. These were:

- The professionals with responsibility for patient care and treatment. The majority of patients reported that they had total confidence in the professionals in charge of their care
- The way in which the diagnosis was delivered
- The care and support provided by the nursing staff
- The quality of support groups. Patients are of the view that it is critically important to meet other patients and families who have had similar experiences
- The dedicated centres of specialist cancer care, focusing on particular types of cancer, for example, breast cancer, child cancers.

The key areas where patients identified weaknesses in cancer treatment services were the following:

- Difficulties in obtaining information and having questions answered
- The absence of an adequate counselling service for patients and families (family counselling is particularly important in child cancer cases)
- The absence of practical supports for patients, for example, travel facilities, overnight accommodation for patients travelling long distances for treatment.

4.4 CONCLUSIONS

Overall, there is a moderate level of satisfaction with cancer services in Ireland. However, circa 27 per cent of respondents to the submission process (over a quarter) indicated a level of dissatisfaction.

Table 4.9 summarises the range of strengths and weaknesses of cancer treatment services. In reflecting these findings due consideration should be given to the usual risks and limitations that apply to public surveys and submission processes.

TABLE 4.9: STRENGTHS AND WEAKNESSES AS IDENTIFIED BY PATIENTS

STRENGTHS	WEAKNESSES
• Staff – particularly nursing staff • BreastCheck screening programme • Quality of treatment provided in oncology units • Voluntary support groups • Information provided by the Irish Cancer Society	• Access to services • The under-provision of radiotherapy services • Requirement to travel long distances to receive treatments and the absence of supports, e.g. financial assistance, home help, etc. • Staff resources • Low numbers of specialist consultants • Low numbers of specialist nurses • The limited availability of counselling and emotional support services • Insufficient provision of information • Differences in practices across health boards • Co-ordination of services, e.g. between hospital teams and GPs • Absence of dedicated acute beds

5

THE NATIONAL CANCER STRATEGY: REVIEW AND EVALUATION OF FINDINGS

5. THE NATIONAL CANCER STRATEGY: REVIEW AND EVALUATION OF FINDINGS

5.1 INTRODUCTION

5.1.1 OVERVIEW OF NATIONAL CANCER STRATEGY

The National Cancer Strategy first and foremost should be credited with raising the profile of cancer services across the health system and with providing a clearer focus and direction in terms of the planning process. In essence, resources have been allocated; investment has been made in people, equipment and facilities; a range of initiatives have been implemented to improve service quality and the structures to support cancer services are continuously evolving.

While progress has been made, this has not been consistent across all of the health boards. There are variations between tertiary services and between the secondary services outside of Dublin, Cork and Galway.

The foundations to provide quality cancer services have been established but much remains to be done. Pockets of best-practice are to be found across different aspects of cancer care but unfortunately the mechanisms, structures or resources to roll these out on a more universal scale are not in place with the result that regional variations exist. To coincide with this, patient and public expectations have increased considerably over the last seven years.

5.1.2 REVIEW AND EVALUATION OF FINDINGS

This section of the report evaluates the findings from the research programme and the associated issues arising. This includes our meetings with the members of the National Cancer Forum, the Chief Executive Officers of the Health Boards, the Regional Directors of Cancer Services, the Directors of Public Health and representatives of the Department of Health and Children. Submissions received from patients, patient families and other stakeholder organisations within the health sector with an interest in cancer services are also included. The object of this report is to examine the extend to which the objectives of the National Cancer Strategy have been met given the level of investment in cancer services over the past five years – an increase of approximately €400 million.

We have considered our findings in the context of the objectives of the 1996 National Cancer Strategy namely: prevention; information; early detection; access, treatment & quality; co-ordination; cost effectiveness, and research and education. Discussion on each objective opens with a table, which summarises the key achievements of the 1996 Cancer Strategy for that area and highlights relevant gaps in cancer services that still need to be addressed. This is followed by a more detailed consideration of the key achievements and issues arising over the past five years. We conclude our analysis of each objective by setting out the activities that were planned under the Cancer Strategy and assessing the extent to which they were achieved.

In considering our analysis of the objectives of the National Cancer Strategy and their implementation to date, we took into account the measures and objectives of service delivery and different models of patient care adopted by other countries whose practices we researched to inform our review and findings. It would appear that there are a number of criteria, in line with international best-practice, necessary to ensure good cancer treatment and care for all patients. These can be summarised as follows:

- All patients should have access to uniformly high quality of care. While this should be as close to the patient's home as possible the priority should always be high quality, safe and effective treatment. This principle is consistent with the development of supra-regional centres and specialist centres for cancer care
- Delivery of public and professional education to help early recognition of symptoms of cancer plus the availability of national screening programmes
- Patients, families and carers should be given clear information and assistance about all aspects of their care
- Development of cancer services should be patient focused
- Primary care teams are a central and continuing element
- A recognition of the psychosocial impact of cancer care on patients and families
- Cancer registration and careful monitoring of treatment and outcomes are essential
- Increased specialisation in cancer management
- A multi-disciplinary multi-professional team approach
- Provision of services, which are research-based and submitted to regular formalised outcome assessment.

In presenting our evaluation findings it is important to reiterate that the 1996 National Cancer Strategy contained only one single tangible measure of performance, i.e. to reduce the death rate from cancer in the under-65 age group by 15 per cent in the ten year period from 1994. As was highlighted in section 3, Figure 3.2, this objective was achieved as the death rate from cancer in the under-65 age group fell from 88.97 per 100,000 population in 1994 to 75.78 per 100,000 population in 2001, i.e. a reduction of 14.83 per cent. It should be noted that despite the significant change between 2000 and 2001 (which may be due to reasons other than improved cancer services and care delivery), the underlying trend line is such that this objective would still be on target to have been met by 2004. It is likely that in the future different objectives will be set to measure the success of the new National Cancer Strategy, which would reflect an increased focus on the systems and processes involved in service delivery.

The absence of additional quantifiable performance indicators in the National Cancer Strategy has complicated the process of evaluation. There is a need for clear definition of specific measurable parameters to facilitate the evaluation of the achievements of any strategy in the first instance. Future performance indicators should be focused on measurable, tangible parameters. In essence goals should be SMART: Specific, Measurable, Agreed, Realistic and Time Bound.

5.1.3 ISSUES IMPACTING ON POLICY DEVELOPMENT, IMPLEMENTATION AND EVALUATION

Although there has been a significant amount of policy development, the implementation of that policy has been inconsistent and fragmented. There are a number of core factors, as outlined below, which have impacted on policy development, implementation and evaluation.

(i) Funding

In 1996, it was estimated that the cost of implementing the 1996 National Cancer Strategy would be in the order of IR£25m. Over the course of the strategy, it emerged that the original costs had been completely underestimated and by 2002, approximately €400m had been invested in the development of services for the treatment and care of cancer patients. As identified in previous sections of this report, there remain significant service gaps to be addressed.

A more detailed analysis of the funding that has been made available for cancer services since 1996 has been made in section 3.4.

(ii) Under-development of Primary/Community Care Services

The principal vehicle for the delivery of health services in an Irish context has historically focused on the acute sector. The new Primary Care Strategy has identified the role that primary and community services should have in the provision of an enhanced and quality health service in the future. In essence, the strategy sees primary care as the central focus for the delivery of health and personal social services in Ireland. This will have an important bearing on cancer services and their future development. Investment in infrastructure and resources for primary care is regarded as a key success factor in the provision of a comprehensive and quality service to patients.

(iii) Accountability and Performance Management

The service planning process that was introduced by the Department of Health and Children in 1999 is highly regarded as a valuable management tool that has facilitated improvements in the areas of policy planning and evaluation as well as expenditure control. However, performance measurement and in particular, outcome measurement remains at an early stage of development. As is widely reported upon, the deficiencies in management information systems have been a key contributor to this. However, custom-built IT systems are being developed for the National Breast Screening Programme and the data analysis and research programmes provided through the National Cancer Registry will help alleviate this problem. That said, the on-going monitoring and evaluation of the effectiveness and efficiency of national policies remains a mainly qualitative exercise in most cases.

(iv) Human Resources

The effective implementation of policy is dependent on the appropriate mix and numbers of skilled resources being made available. The shortage of appropriately trained staff, both medical and nursing has had an impact on service delivery across all levels of the system. A targeted National Human Resources Strategy for cancer services should help identify and address these issues.

(v) Co-ordination and Communication Across Stakeholders

There is a clear requirement for the development of better linkages and relationships between key players in the health system. The lack of co-ordination and integration between primary and acute hospital care, as well as health boards, government departments and other key players need to be addressed if policy is to be effectively integrated. The current reorganisation of structures and systems in the Irish healthcare system will have a bearing on this.

5.2 PREVENTION

TABLE 5.1 SUMMARY OF OBJECTIVES IMPLEMENTED AND KEY GAPS IN CANCER PREVENTION STRATEGIES FROM THE NATIONAL CANCER STRATEGY, 1996

	FACTORS INFLUENCING ASSESSMENT	
	KEY ACHIEVEMENTS	KEY GAPS
Objective: Prevention and Health Promotion	• Key national initiatives: - Establishment of the Office of Tobacco Control - Tobacco Health Act, 2002 - National Age Identification Scheme. • Establishment of health promotion structures within the health boards – appointment of relevant staffing. • Considerable health promotion activity within each health board – initiatives focusing on smoking, alcohol, diet, lifestyle, etc. • In the area of smoking particularly, results from SLÁN have indicated that clearly health promotion initiatives are engaging the target audience and that the audience is relating to the message.	• Absence of a fully co-ordinated approach to health promotion across health boards and the Department of Health and Children. • Role of primary care (GPs, public health nurses, community groups) not sufficiently utilised. • Lack of clear objectives and targets in relation to health promotion activity. • Role of national policies in achieving health promotion objectives needs to be further recognised.

5.2.1 PREVENTATIVE ACTIVITIES

- There is no one measure that has been shown to be effective in isolation in the prevention of cancer. National strategies such as the Health Promotion and Cardiovascular Strategies have and continue to provide a framework for the development of health promotion initiatives for diseases such as cancer and heart disease. The 1994 Health Strategy "Shaping a Healthier Future" provided a major stimulus for adopting an expanded role for health promotion in providing improved standards of health in Ireland. The Health Promotion Strategy 1995 – 1999 outlined a detailed plan for the promotion of health in Ireland and indeed the area of health promotion and prevention has, at national and regional level received significant investment since the launch of this Strategy.

  The new Health Promotion Strategy 2000-2005 and Cardiovascular Strategy 1999 have built on the success of the first Health Promotion Strategy. Now each health board has an established Health Promotion Department headed by a qualified Health Promotion Manager supported by a team of health promotion specialists. The Health Promotion Managers and senior officials from the Health Promotion Unit meet on a regular basis to ensure integration of the many health promotion programmes and campaigns at national and regional level.

  The National Cancer Strategy acknowledges that the cause of most cancers is multifactorial but that there is strong evidence that lifestyle and environmental factors play an important role in particular smoking, alcohol and diet. The promotion of healthy lifestyles is a key element of the work of the Health Promotion Unit. Smoking, alcohol and nutrition are significant risk factors for both cancer and heart disease. The Health Promotion Strategies 1995-1999 and 2000-2005 identified specific strategic aims and objectives affecting lifestyle behaviours and the Health Promotion Unit in association with the health boards continues to expand and develop programmes to achieve these aims and objectives.

  It is widely acknowledged that cancer services have benefited from the activities initiated under both the National Cardiovascular Strategy and the National Health Promotion Strategies owing to the similarity of risk factors and thus the similarity of preventative interventions required. In that context, the Health Promotion Unit remains committed to the implementation of the National Cancer, Alcohol and Cardiovascular Strategies.

- A key focus of health promotion activity in recent years has been in the area of smoking cessation. Among the most notable developments in recent times has been the implementation of the Public Health (Tobacco) Act 2002, which included the establishment of the Office of Tobacco Control, the introduction of improved restrictions for the marketing and promotion of tobacco products and the implementation of more stringent penalties for retailers who sell to under-age customers. While it is not possible to detail all of the anti-smoking activities at health board level, suffice to say a significant amount of activity has been instigated at community level and across both primary and post primary schools including the Smoking Target Action Group (STAG) programme, which is co-ordinated across all health boards.

  There is a general consensus that smoking should continue to receive priority attention as part of any cancer prevention programme given that smoking is the single most important factor that is attributable to incidences of cancer in Ireland. It remained a source of frustration among those interviewed that a universal embargo on smoking in hospitals has not been implemented. However, from early 2004, a ban on smoking in the work place will come into effect. This will include hospitals. The targeting of activities and resources at schools was also identified as requiring further attention and priority.

  In recognition of smoking being the single most important factor that is attributable to incidences of cancer, a number of strong measures have been introduced to reduce tobacco consumption particularly among young persons.

- Advertising of tobacco products in newspapers and magazines has been ended

- Sponsorship of events by the tobacco industry has been ended

- Nicotine Replacement Therapy products are available without cost to those on low incomes trying to quit smoking

- Sustained media advertising campaigns directed at preventing young persons and particularly young girls from taking up smoking have been run

- Additional funding has been provided to regional health boards to improve compliance with anti-tobacco laws

- An Office of Tobacco Control has been established to oversee implementation of a national tobacco control programme. The Office has been a very effective catalyst in highlighting the importance of cross sectoral participation in tobacco control measures

- The price of tobacco products is kept high in Ireland. This is intended to prevent young people taking up smoking and to encourage smokers to quit. Cigarette prices in Ireland are among the highest in the EU and taxes account for 80% of the price of a packet. This is in line with the level recommended from the WHO and the World Bank

- More recently the Minister for Health and Children has announced that smoking will be banned in all workplaces from early 2004. This ban will include the hospitality industry. This ban is on foot of a Report by the Office of Tobacco Control and the Health and Safety Authority and is in an effort to protect employees and the public from the harmful effects of toxic tobacco smoke.

In addition to smoking cessation, prevention initiatives have also been implemented in the areas of alcohol, diet, lifestyle and sun exposure, again all very relevant to cancer. Once again, a multitude of initiatives have been developed at health board and national level.

Smoking has been the topic most focused upon by the Health Promotion Unit. The national campaigns were developed in partnership with the Irish Cancer Society and the regional health boards. These campaigns target the whole population at one level and specific subgroups at another e.g. teenage girls. Other campaigns have been promoted at European Union level such as The ‘Feel Free to Say No’ campaign.

The first SLÁN Survey (The National Health and Lifestyle Survey) identified the high prevalence of smoking in women and particularly, in teenage girls. The Health Promotion Unit’s ‘NICO’ campaign specifically targeted this population group. This campaign focused on factors that are of importance to young people in the immediate term (e.g. effects on teeth & complexion, unattractive odours etc.). The second SLÁN survey has shown that across all demographic categories smoking rates have fallen (Overall 27 per cent (31per cent in 1998) of respondents reported being regular or occasional smokers, representing a 4 per cent decrease in smoking since 1998) but this trend has been most marked among girls and young women, the key target group for the anti-smoking campaign.

There is certainly no shortage of health promotion or preventative activity driven primarily by the frameworks established under the Health Promotion Strategy, the National Cardiovascular Strategy, European Union legislation and to a lesser degree the National Cancer Strategy. However, a number of recurring concerns and issues were raised with associated implications for the efficiency and effectiveness of cancer services:

– Health promotion/prevention activities and strategies have not been afforded equal priority or resourcing at health board level

  - The extent to which health boards work together in exchanging information/best practice and in co-ordinating activities is limited. The establishment of HeBE (Health Board Executive Agency) is seen as having a potentially positive impact in this regard. Likewise, at a national level there is a perceived lack of co-ordination between relevant strategies and also between different Government Departments
  - Health promotion/prevention activities are by their very nature long-term. However, appropriate outcome measures and an evidence-based approach to the development and implementation of initiatives should be strengthened
  - Although health promotion and prevention were defined as a key objective of the National Cancer Strategy, there is a view that insufficient attention has been given to this area vis-à-vis cancer services.

- Primary Care is regarded as having a pivotal role to play in health promotion, prevention and screening. In the future the implementation of the Primary Care Strategy and the development of Primary Care teams are seen as providing a more cohesive structure for the administration of health promotion activities at this level. Obviously, the availability of funding will impact on the planned roll-out of the strategy but so too will cultural issues. However, the Department of Health and Children is optimistic that there is sufficient commitment within the system to overcome the obstacles that exist.

- The mobilisation of community resources (health board staff and volunteers) in raising awareness of health promotion issues is an area that can be further developed. Community resources operate close to the ground and are in day-to-day contact with target populations and as a result are a valuable medium for health promotion.

5.2.2 EVALUATION OF HEALTH PROMOTION/PREVENTION ACTIVITIES

- The last number of years have been characterised by a high level of activity and progress in terms of developing the appropriate structures and in putting in place a range of health promotion initiatives and programmes. National strategies such as the Health Promotion, Cardiovascular and Alcohol Strategies have provided the framework for the development of these health promotion initiatives. The strategies have set down clearly defined objectives that are measurable and allow for continuous evaluation and assessment of the various initiatives. However, as referred to above, it is perceived that the evaluation, evidence-based approach and outcome measurement functions need to be strengthened.

- In this respect considerable progress has been made through the commissioning of the SLÁN/HBSC surveys. These surveys were commissioned to provide baseline information on a range of lifestyle related health behaviours in the Irish adult population and school-going children, with sufficient power to detect differences across age, gender and social strata. SLÁN is a comprehensive piece of research into health and lifestyle. It has enabled the Health Promotion Unit and the Health Promotion Departments in each of the boards to bring a greater degree of focus to the Unit's work and to target particular population groups. The first SLÁN/HBSC survey was commissioned in 1998, the second followed in 2002 and the survey will be repeated at four year intervals thereafter.

- Promotional campaigns and programmes are specifically targeted at identified audiences through the use of the most appropriate medium. For instance the Alcohol Awareness Campaign, launched in February 2001, was the beginning of a three-year initiative aimed at promoting awareness of alcohol and attitudes to drinking across all age groups in Ireland. The first year of the campaign focused on young people and under-age drinkers.

The most recent phase of the campaign launched in November 2002 is intended to target the 18- 29 year old “binge drinker”. Two radio advertisements and a television advertisement have been developed.

The Framework for Developing a College Alcohol Policy is a document designed to assist colleges to develop campus alcohol policies, which promote sensible drinking among students and limit alcohol-related harm on campus. It was developed using a holistic approach where the relevant stakeholders in the colleges were given a voice to express their concerns and opinions with regard to alcohol use in colleges.

‘How’s the liver today?’ was also a significant phase of the “Less is More – It’s Your Choice” alcohol awareness campaign. This phase targeted third level students and involved the distribution of a disposable, paper tray insert to be used in the restaurants of those colleges involved in the development of the College Alcohol Policy.

Given the concern about the increased prevalence of smoking particularly among teenage girls, a special component of the Break the Habit campaign was developed during 2000 to target teenagers. This campaign called NICO concentrates on the simple message that smokers are less attractive than non-smokers. As part of this campaign smokers are encouraged to contact a free-phone Quitline, or to text message, for a comprehensive stop smoking advice kit, free of charge.

In the area of smoking particularly, results from SLÁN have indicated that clearly health promotion initiatives are engaging the target audience and that the audience is relating to the message.

5.2.3 NATIONAL POLICY

- The importance of enforcing national policies and legislation that underpin health promotion was highlighted as a critical success factor throughout the consultation process, particularly in relation to cigarettes and alcohol. In recent years stricter penalties have been introduced for selling alcohol to underage persons. Likewise the Public Health (Tobacco) Act 2002 will enforce greater penalties in relation to the selling and marketing/promotion of tobacco products and will include a ban on smoking in all workplaces from early 2004. This ban will include the hospitality industry.

- The sponsorship of sporting/other events by the alcohol and tobacco companies was widely regarded as being inappropriate. Again, positive progress has been made in this area with the introduction of the Public Health (Tobacco) Act 2002. Progress has also been made on the issue of alcohol advertising and the sponsorship of sporting events. Preparatory work has begun on drafting legislation with the aim of limiting the exposure of young people and adolescents to alcohol marketing, sponsorship and advertising.

5.3 INFORMATION

TABLE 5.2 SUMMARY OF OBJECTIVES IMPLEMENTED AND KEY GAPS IN CANCER INFORMATION SYSTEMS FROM THE NATIONAL CANCER STRATEGY, 1996

	FACTORS INFLUENCING ASSESSMENT	
	KEY ACHIEVEMENTS	KEY GAPS
Objective: Information	• Patient Information - Considerable progress in recent years - Appointment of clinical nurse specialists, oncology nurses, cancer liaison nurses, cancer co-ordinators – significant contribution - Patient information material (Irish Cancer Society/ Irish College of General Practitioners). • Clinician Information - Development of clinical protocols - Access to Cochrane Collaboration - Better research facilities (library and on line access) - Development of the work and data of the National Cancer Registry Appointment of Data Managers in the health boards (on-going).	• No national guidelines in place. • Poor delivery of diagnosis. • Inadequate communications to patients and families. • Need for on-going training in this area has not been recognised to date. • Requirement for transparency in relation to waiting times for services. • Clarity of information is equally important to information provision – not always clarified if patients fully absorb/accept the information received. • Inadequate Management Information Systems (MIS). • All Data Managers not yet appointed. • Need for access to more data by health boards to facilitate decision making.

5.3.1 PATIENT INFORMATION

Our discussions with clinical and health board staff highlighted the perception that significant improvements have been made in the provision of information to patients and their families since the launch of the Cancer Strategy in 1996. The appointment of oncology nurses and the establishment of the Cancer Nurse Co-ordinator role in the ERHA region are seen as positive developments in this regard, although the latter is not universal across all health boards. The role played by the Irish Cancer Society in producing patient information booklets covering areas such as diagnosis, treatment, side effects, etc was also highly regarded.

Notwithstanding the positive progress that has occurred, there are clearly further opportunities for developments and improvements, particularly given the high priority attached to information provision by patients and families as part of the submission process.

- There remains an absence of a systematic and planned approach to the provision of patient information about treatments, and their impact etc. Opposing arguments were put forward as to whether a structured approach to communication is required or whether the level and format in which information is provided to patients should be assessed on a case-by-case basis. However, the feedback we received would suggest that communication is not consistently delivered in a manner most appropriate to patient needs. Examples of practice not consistent with the delivery of a quality patient-centred service include patients receiving their diagnosis on a trolley, by telephone and by a junior NCHD doctor (Intern or Senior House Officer). While there is no evidence to suggest that such practices are widespread, their occurrence is unacceptable. Equally important, the quality of information provision and communication should not vary significantly: by region; individual consultants; the availability of oncology nursing staff; access to voluntary support groups etc. On balance, it must be remembered that time constraints and commitments of consulting staff and the individual patient circumstances vary considerably. That said it would appear that there is a requirement for national guidelines to uphold and support quality practices but which also accommodate a degree of flexibility.

- Patient views on the communication process would appear to be slightly at odds with those presented by health board and clinical staff. In particular, patients were of the view that medical consulting staff need to show a higher level of sensitivity and understanding in the manner in which they provide information to patients (nurses were regarded as being more effective in this role). However, once again the time constraints on medical consulting staff must be recognised, particularly in those areas where there is a lack/absence of nursing staff to co-ordinate the communication process. The lack of trained social workers and counsellors in terms of supporting the patient after treatment is a further deficit, a role which the medical consulting staff are sometimes expected to fulfil in their absence. None of this is to say that further attention is not needed in improving and enhancing the communication skills of clinical staff. Indeed, we understand that communication training is now incorporated into the curriculum of the Royal College of Surgeons in Ireland. However, on-going training is also required and the differences in opinion expressed between patients and health board/clinical staff also serves to highlight the importance of collating patient views on a regular basis as a means of understanding and addressing their expectations around service quality.

  A further related issue is the extent to which patients/families fully understand the information that is provided to them (the Cancer Nurse Co-ordinator in the ERHA region generally fulfilled this role but considerable variations exist across the other health boards). The timing of information is also a key concern; for example, a patient may not be in a position to absorb or comprehend the information following receipt of a diagnosis (e.g. information on care pathways, treatments, side effects, etc.) and therefore ideally should be given the opportunity and mechanisms to ask for further information or verify the information at a later stage.

- Patient surveys are by no means an intrinsic component of cancer services in Ireland. In general, patient/family input into the planning and evaluation of services is missing. However, this is changing – recently their input was sought for the palliative care needs assessment analysis that has taken place at health board level. A number of patient surveys have been completed but for the most part these tend to focus on a small population base and are not updated on a regular basis.

- The consultation and submission processes identified the requirement for:

  (a) reliable and comprehensible information on cancer treatments and options

  (b) information on how and where to access secondary and tertiary cancer services.

- The proliferation of the Internet has greatly increased patient/public access to general information on cancer treatments. However, the issue is not so much the depth of information available as the quality and reliability of that information. In particular, it was suggested that patients and in fact some healthcare professionals require direction in terms of reliable information sources. The role of the voluntary sector in the provision of such information was given due recognition. We recognise that there are some highly developed practices in the area of patient information in place, such as the National Children's Cancer Unit, Crumlin where patient's passports were developed. These are folders of information, prepared for the parents of cancer patients, incorporating information on the drugs used for treatments, their side effects, guidelines on how to use them, etc.

- Information on access to cancer services is regarded as deficient.

- Public debates on health services in general and cancer services in particular have not been sufficiently informed. In addition, the public has not been provided with the best evidence to define measures of quality and best practice. This has proven especially significant in relation to the development of supra-regional and regional centres of specialist cancer care, as well as the location of radiotherapy services, which are discussed later. Whilst it might be understandable that patients would like access to all treatments effectively in their own locality, they do not necessarily consider that this may not be the most appropriate way to deliver quality patient care.

5.3.2 MACRO LEVEL INFORMATION

- The reported deficiencies in health related Management Information Systems (MIS) have been well documented in recent years. Information systems, at agency level integrated to national systems, to gather cancer-related data and statistics need considerable strengthening. Ad-hoc, stand-alone systems are certainly in place but information from these is primarily only applicable to local service planning and evaluation. Information on waiting times, access to services, etc is not systematically recorded or tracked on a cancer specific basis. Likewise, patient quality of life data is not collated. Furthermore, the appointment of Data Managers[9] has not consistently happened across all hospitals.

  The primary source of information on cancer in Ireland is the National Cancer Registry[10]. Information from HIPE, PHIS and Casemix is also used. The information collected and analysed by the Registry is used in a variety of ways, in the areas of cancer prevention, detection and treatment. There was a general view that the information available is extremely valuable. However, arising from our discussions, a number of key issues were raised:

  - The quality of the information/research produced by the National Cancer Registry is dependent on the quality of health records/MIS systems within the various hospitals and centres. This includes the extent to which hospitals accurately record and complete all of the required data according to the Registry's standardised coding methodology. However, it is widely understood that there is a general lack of processes and systems to audit hospital data or the data entry process.

  - Health boards expressed the desire for additional and more up-to-date information through the National Cancer Registry including:

    (a) More detailed information by cancer type
    (b) Access by healthcare managers and practitioners to data from other hospitals both within their own health board area and other health boards. This was regarded as critical for the purposes of audit, peer review, macro comparisons and outcome comparisons (e.g. comparison of outcomes in bigger units and smaller units).

- Accurate costing information was another key area where information gaps were identified, for example, in the area of drugs and treatment options. This creates difficulties in terms of the planning and budgeting of services, particularly for health boards where it is widely reported that increasing drug costs are impacting on their overall budget for cancer services.

- Due to some funding deficiencies, the National Cancer Registry is in arrears with its information processing. The NCRI is currently addressing this with the DoHC. It should be noted that health boards would welcome information from the National Cancer Registry broken down into data that is specific to their region, which should facilitate their needs assessments and service planning.

---

[9] The role of the Data Manager is to collate patient information and reports.

[10] Identifies, collects, classifies, records, stores and analyses information relating to the incidence and prevalence of cancer in Ireland. It also gathers information on morbidity rates.

5.4 EARLY DETECTION

TABLE 5.3 SUMMARY OF OBJECTIVES IMPLEMENTED AND KEY GAPS IN EARLY DETECTION PROGRAMMES FOLLOWING THE NATIONAL CANCER STRATEGY, 1996

	FACTORS INFLUENCING ASSESSMENT	
	KEY ACHIEVEMENTS	KEY GAPS
Objective: Early Detection and Screening	• Two screening programmes: - BreastCheck – national roll-out approved following a successful phase one - Irish Cervical Screening Programme – phase one in progress. • Successful take up rates – by end December 2002, BreastCheck achieved a 75% uptake rate (target rate is 70%).	• Absence of UPI (Unique Patient Identifier) – a mechanism to ensure every patient within the system has an individual identity number so they can be recognised within the system and targeted appropriately. • Integration between development of symptomatic services and screening services needs to be progressed. • Differences in take up rate for screening programmes among different socio-economic groups – key consideration from a targeting perspective in the future. • Need to optimise the role of primary care. • Potential for screening in other site specific cancers needs to be explored.

- There have been very positive developments in the area of early detection and screening since the launch of the 1996 Cancer Strategy particularly with the introduction of the breast and cervical screening programmes on a phased basis. Both programmes while well regarded, are also the subject of wide-spread criticism because of the failure to roll them out on a nation-wide basis (the rollout of BreastCheck has subsequently been announced). (An opposing view was presented that screening programmes should not be rolled out and did not represent value for money based on medical evidence. This is a fundamental issue, which needs to be addressed by the next strategy).

  In terms of refining both services in the future, it was further recommended that good information gathering components be built into each programme. The establishment of a population register is a further critical component in providing an effective screening programme.

- Attention must be given to the differences in take-up rates in the two screening programmes among the different socio-economic groups. This is being addressed by the Programme. It was also argued that the target age range of these programmes was too narrow and needed to be expanded.

- The Minister for Health and Children announced the extension of BreastCheck to the remaining counties in the West and South in March 2003. This development is a welcome and significant contribution to cancer care. It also removes the inequity in breast screening services whereby women in the East, Midland and Northeast had access to BreastCheck and women outside these areas had no such access. In relation to the future organisation of cancer care, especially surgery, submissions have been made about how best to organise services for women with symptomatic breast disease and screen detected breast cancer. These submissions relate to the development of BreastCheck independently of the symptomatic services.

Current policy as regards symptomatic services is prescribed in the Report of the Sub-Group to the National Cancer Forum entitled Development of Services for Symptomatic Breast Disease, commonly referred to as the O'Higgins Report. The Report recommended the establishment of fourteen specialist breast units throughout the country based on a population of 250,000 to 300,000 from which it is expected that there will be a minimum of 100 new primary breast cancers per annum. The Report concludes that this level of workload is necessary to sustain the collective workload of the multi-disciplinary team involving surgeon, radiologist, pathologist, medical oncologist, radiation oncologist and clinical nurses. The Report recommends that quality assurance structures are put in place to ensure that women receive the highest standard of care.

BreastCheck, the National Breast Screening Programme, was established in 1998 and currently provides screening services at two static sites in Dublin and a number of mobile units. The static units are located at St Vincent's Hospital and the Mater Hospital, Dublin. In respect of women who require follow up, BreastCheck also provides primary treatment at the two static units and follow up care is provided either at these units or at more local breast units. The programme is organised with decentralised multi-disciplinary clinical units for screening, recall and assessment and for follow up primary treatment. It has developed a multi-disciplinary QA system and the programme's high quality has been validated by the European Network of Reference Centres for Breast Cancer Screening (EUREF).

BreastCheck's proposal for expansion of the programme sets out that women who are screened by the programme will receive treatment, if required, in the relevant host hospital of the programme, despite the existence of a centre of excellence in their health board area. BreastCheck gives as a basis for this decision the respective purposes and differences of screening and symptomatic services, the different skills and expertise involved in the services and the need to preserve the integrity of the programme from a quality assurance point of view.

In preparing this analysis, detailed discussions have taken place with cancer care experts throughout the country. The common theme of the respective submissions is that quality should underpin the organisation and delivery of services for women with breast cancer regardless of whether they are treated by the symptomatic services or at BreastCheck host hospitals. There is widespread support for the breast screening programme and a general recognition of the expertise required. Submissions concern the treatment and follow up of screen detected women and the role of the symptomatic services in surgical care and follow up care. Based on an analysis, our considered views are:

(i) The content of both programmes by their nature should be interrelated and interdependent, targeting the same disease process, albeit at different stages of development. The consequence of having two separate programmes will result in unnecessary overlap, duplication and costs.

(ii) Organising primary breast treatment under two separate organisational models is without international precedent.

(iii) The objective in the O'Higgins Report and in the BreastCheck programme is to ensure that women who access breast services have the highest standard of care. A compromise on this principle is not acceptable. The attainment of this objective involves the various modalities of care, radiology, pathology, surgery and medical oncology delivering care on a multi-disciplinary basis.

(iv) Considerable investment has taken place in recent years to develop the symptomatic services along the lines set out in the O'Higgins Report. This was not the case at the time of the launch of the BreastCheck Programme in 1998. Subsequently, in 2000 the O'Higgins Report was published. A true centre of excellence on the O'Higgins model with an effective multi-disciplinary team, sufficient case volume and a quality assurance structure should be capable of meeting all the requirements of treating screen detected lesions and the delivery of a symptomatic breast disease service.

(v) With the clear intention of rolling out BreastCheck to the entire eligible population in the very near future, one must consider the resultant impact this will have for symptomatic breast disease centres. When the national breast screening programme is up and running, it may undermine the numbers of patients presenting to some symptomatic breast disease centres, thus reducing their patient turnover. This could be due to patients diagnosed within BreastCheck, being treated within that system as opposed to being referred to their regional symptomatic centre of excellence. Effective integration of the two services needs to be progressed. In the light of the impact of the national roll out of BreastCheck, an assessment of the appropriate number of centres of excellence for Symptomatic Breast Disease Services is now required. From a quality and value for money perspective, if one is to continue to invest in developing centres of excellence for the treatment of breast cancer such investment should be capable of meeting all the requirements for treating screen detected lesions and the delivery of a symptomatic breast disease service.

In conclusion, an opportunity now exists given the commitment to the national extension of BreastCheck to assess the best model to deliver integrated breast care for women with breast cancer that is in line with international best practice. The Forum is ideally placed to recommend on integration that should not delay the rollout of the screening programme.

- In the course of the consultation process the issue of screening services for other specific cancers were raised, for example, colo-rectal cancer and prostate cancer. This is currently being reviewed by a Sub-Group of the National Cancer Forum.

- GPs are the starting point for the patient referral process to symptomatic services. Since the launch of the 1996 Cancer Strategy progress has been made in the development of GP referral guidelines. However, there remains much to be done with varying levels of progress reported across the different health boards. It would appear that the majority of guidelines developed to date have been for symptomatic breast disease services with key gaps across other cancers (with some notable progress in prostate cancer). A further related problem arises from GPs referring patients to services outside of their own health board area. This appears to occur most frequently in those health boards that are on the geographic periphery of tertiary services. Consequently, questions and issues arise in relation to bed capacity, the extent to which the funding follows the patients and the implications for the development of local services.

  The role undertaken by GPs in screening and detection must also be subject to the appropriate quality controls.

- Public health nurses also have an important role to play in early detection and the promotion of screening. However, as with their health promotion responsibilities, it is acknowledged that the volume of workload placed on them makes it very difficult for them to proactively pursue this agenda. Furthermore, the majority of people with whom they come into contact are young mothers and the elderly. These groups are not necessarily representative of the target population for screening programmes.

5.5 ACCESS, TREATMENT AND QUALITY

TABLE 5.4 SUMMARY OF OBJECTIVES IMPLEMENTED AND KEY GAPS IN ACCESS, TREATMENT & QUALITY ASSESSMENT AFTER THE NATIONAL CANCER STRATEGY, 1996

	FACTORS INFLUENCING ASSESSMENT	
	KEY ACHIEVEMENTS	KEY GAPS
Objective: Access, Treatment and Quality	• Recognition of concept of supra-regional centres and regional centres of specialist cancer care. • Appointment of Regional Directors of Cancer Services. • Appointment of increased numbers of clinical specialists, e.g. medical oncologists, surgeons, haematologists, histopathologists, etc. – a total of 85 appointments since 1997. Prior to the Strategy there were 4 medical oncologists in the country; now there are 19. • Appointment of oncology clinical nurse specialists. • Considerable increase in chemotherapy activity – less than 15,000 sessions in 1995; circa 22,000 in 1998; almost 40,000 in 2001. • Considerable increase in radiotherapy activity – 58% increase in the number of new patient episodes for radiotherapy treatment since 1994. • Considerable increase in oncology related surgical activity - 26% increase in the number of patients receiving surgery since 1994. • Significant developments in symptomatic breast disease services. • Significant developments in palliative care.	• Limited application of supra-regional centre and regional centre concepts. • Need for better communication of benefits of specialist centres. • There is dilution of resources by the replication of the same services among many agencies versus benefits of scale and quality at supra-regional centres. • Access to radiotherapy: - significantly under-resourced - waiting times in excess of clinically acceptable parameters - evidence that all patients who need it do not get it (33 per cent actual uptake rate vs. expected 50-60 per cent uptake rate among all cancer patients) - issues re equity of access for non-east coast patients. • Manpower shortages – a priority. • Significantly inadequate counselling and emotional support for patients. • Scope for the development of Quality Assurance procedures, policies, guidelines and protocols – differences between boards. • Insufficient development of community services. • Inability to access waiting times for patients and therefore monitor the waiting times that patients incur. • Audit and evaluation systems have not been developed. • Regular patient surveys to assess their perception of service provision and quality. • Focus to date on breast cancer – some cancers have not received sufficient attention, e.g. bowel, lung, skin, prostate.

5.5.1 SUPRA-REGIONAL CENTRES/REGIONAL CENTRES OF SPECIALIST CANCER CARE

- The development of the concept of 'supra-regional' centres, introduced in the 1996 Cancer Strategy, was deemed a major development. International research has consistently demonstrated that better outcomes are achieved in larger centres through the centralisation of resources, skills and expertise, facilitated by a critical mass of patients. There is widespread evidence to support the view that an effective and efficient cancer service requires the input of a multi-disciplinary team, preferably working within the same location.

While the concept of supra-regional centres has been accepted by policy-makers, limited progress has been made on their establishment on the ground and the manner by which they interconnect with secondary services:

- The three designated centres in Ireland: Dublin, Cork and Galway are all at various stages of development in terms of service provision and quality. As reported, Galway regards itself as being significantly behind the other two centres
- The level of service to be managed through each centre is unspecified, although there was a general level of consensus in the consultation process that Galway and Cork should be able to deal with almost all cancer treatments in their regional centres, with only very complex cases requiring specialised treatment referred to Dublin, such as paediatrics. However, this has not been completely formalised
- Within Dublin, it has been argued that a greater level of clarity is required in terms of which hospitals are the "dedicated centres for specialist care" for particular treatments. The strategy specified Dublin city as a supra-regional centre but no reference was made to specific hospitals
- As will be discussed in greater detail later, clinical pathways from secondary services to tertiary services have not been clearly defined.

- The capacity of health boards to develop regional centres of specialist care for secondary services showed considerable variation. In some health boards, it was established that cancer services are spread across a number of hospital sites. Part of this is attributable to geographic and demographic considerations. However, it is also a result of political influence and the desire to have "all services in all hospitals".

  The approach to implementation, which has been adopted over the life-span of the strategy, clearly goes against the thrust of the recommendations set out in the National Cancer Strategy, resulting in the dilution of human capital and funding resources. It also has a derived impact on referral patterns to tertiary services from the regions, with patients or their GPs opting for those centres that provide a more comprehensive service.

  While significant issues remain, progress has been made under the National Cancer Strategy. Centres of specialist care for symptomatic breast disease services have been set up (although as seen, these are not always located within the designated regional centre for specialist care). In the course of consultations, evidence was presented that in one board there were 16 surgeons performing breast cancer operations prior to the establishment of the centre; now this clinical practice is restricted to just three surgeons dedicated to breast cancer surgery, who have had specialist training in this area. Likewise, the centralisation of paediatric services has occurred as a direct consequence of the support given by the National Cancer Strategy. With the exception of Cork, all solid tumours and most brain tumours are treated in Our Lady's Hospital for Sick Children in Crumlin within the National Paediatric Cancer Services Unit. The vast majority of Paediatric Leukaemia patients are treated in the Mercy Hospital in Cork from the Southern Region, while children from other regions are sent directly to Crumlin.

- All regional health boards strive for a degree of independence in terms of cancer service provision. Similar to the point made above, there is a lack of clarity and definition as to what precisely self-sufficiency incorporates and whether there is a standardised definition or whether this definition needs to vary to take account of regional differences. Again, this is seen as requiring greater clarity in terms of the development of the structures to support future service provision. The data shows that regional self-sufficiency has not improved to any significant degree within the health boards outside of the ERHA (section 3.7).

  It is obvious across many of the health boards that cancer-related surgery is being undertaken by general surgeons who perhaps perform only small numbers of similar operations on an annual basis. This activity, to the best of our understanding, is not tracked or monitored to any significant degree except perhaps through the Casemix system.

This raises the issue that a minimum or adequate patient caseload is required to maintain standards of quality care, e.g. as identified in the O'Higgins report on Symptomatic Breast Disease. It will be necessary to ensure that these standards or recommendations are in place and subject to on-going assessment.

Again this raises questions in relation to the relationship and communication processes between secondary services and tertiary centres of cancer care. In particular, can mechanisms and structures be developed to ensure that those performing operations in the regional centres have access to the expertise and knowledge of the tertiary services, as required?

- The public should be informed of the benefits and merits of a structure of supra-regional and regional centres of care, particularly in the areas of comprehensive treatment and facilities, including ancillary specialist services. While it is recognised that maintenance of high performance and quality standards is linked to a high patient caseload, the public should also be aware that spreading services throughout a large number of acute hospitals actually makes it more difficult to achieve and keep these targets. The Department of Health and Children, the National Cancer Forum, the health boards, clinicians and media all have roles to play in this process.

5.5.2 STAFFING

- Since 1996, a sizeable number of staff appointments have been made including Medical Oncologists, Radiation Oncologists, Haematologists, Histopathologists, etc. Additional appointments are expected in the future as the Health Boards strive to develop and enhance their levels of service quality and self-sufficiency. However, an important point to note is that not all of the increases in staffing can be attributed to the National Cancer Strategy.

  Despite these appointments there remains key staffing shortfalls within the system. All of the Health Boards that we met with were able to identify key gaps. Haematology is one area that was identified where although the numbers have more than doubled in the last three years (to circa 29 / 30), it falls short of what was recommended in the 1999 Comhairle Report (1 per 100,000 population). The number of Medical Oncologists is also regarded as too low. Other specialties where shortages have been identified were Thoracic Surgeons (lung cancer), Urologists (prostate cancer), Radiographers and Radiotherapists.

  The shortages of staff across the support services (including primary and community care) was repeatedly flagged as an issue including specialist nurses, social workers, counsellors, dieticians, palliative care staff, occupational therapists, etc. Head and neck cancer in particular needs an increase in support services, as a greater number of patients are now surviving complex surgery and are returning home to the community needing care for issues such as trachyostomy or enteral nutrition. Psychiatry was another gap that is not widely regarded as a core specialty within the cancer treatment services (although only a minority of patients require access to such resources).

  All these issues around staffing of cancer services point to the need for a detailed National Human Resources Strategy for Health Care to recruit key staff in the future, e.g. Radiation Oncologists etc. This should also address issues such as the appointment of a Medical Oncologist, or any cancer specialist for that matter, to what would be a single-handed practice in regional hospitals. Our consultation process clearly identified this as an issue of considerable dissatisfaction to those physicians appointed to these posts and their professional colleagues.

- Continued reference was made to insufficient services to address the area of emotional support and counselling. This came from our direct consultation process, the patient survey, the patient focus groups and the organisation submission process. There is insufficient attention given to this area at present. Most often, this is due to the lack of a dedicated resource to focus on this area of care. It is acknowledged that the appointment of clinical nurse specialists for cancer has made a significant difference in this area, but the perception is that more needs to be done to support patients and their families during the difficult time of cancer diagnosis, treatment and recovery.

- The provision of specialist nursing resources was an area that frequent reference was made to. There is by all accounts a level of confusion as to the role that is undertaken by different nurse specialists within the system, with variations in the same role dependent on the health board or hospital being discussed. However, there was general agreement that specialist nurses have a greater role to play within cancer services, particularly in terms of the co-ordination of services and the development of care pathways for patients. Differences of opinion were expressed in terms of the benefits of having oncology nurses attached to a designated consultant/service.

  The concerns of the nursing community in terms of their involvement and participation in the planning and development of cancer services was a further issue communicated to us. In particular, they would like to move to the fore in terms of the decision-making process, including their level of representation on the National Cancer Forum (refer to 5.6.1 below).

5.5.3 RADIOTHERAPY

- Radiotherapy has increasingly become the focus of attention with an Expert Review Group established in 2000 by the Minister for Health and Children. The delay in provision of sufficient radiotherapy capacity to meet patient needs has contributed to the present access difficulties, which are repeatedly discussed in the public domain.

- From the consultation process, access to radiotherapy was cited as the most critical area where cancer services are underprovided. There are currently two public radiotherapy units – one located in Dublin and the second in Cork with two privately operated facilities in Dublin (Mater Private and St. Vincent's Hospital). The recommended World Health Organisation's (WHO) provision for radiotherapy units is 1 per 625,000 population. Ireland clearly falls substantially short of this target. In turn, there are only 8 Consultant Radiation Oncologists servicing the Republic of Ireland with two more expected to be appointed this year. Owing to the low numbers, the caseload per consultant is three to four times above the WHO recommended average. If international best practice were to be followed (Denmark, Australia, Canada, US), the required compliment of Radiation Oncologists would be in the order of 30 to 36. An increase in the number of Radiation Oncologists along these lines would facilitate the development of a more specialist model in Ireland.

  The low numbers of Radiation Oncology Consultants also results in the service being very much consultant-led as opposed to being consultant-delivered, with an over-reliance on Non-Consultant Hospital Doctors to support it. New Specialist Registrar (SPR) mechanisms will commence this year, as agreed with the Department of Health and Children and Comhairle na nOspidéal. This will see 1 Consultant per Specialist Registrar.

  In the short-term, it is inevitable that the existing crisis in radiotherapy will continue in terms of medical manpower and patient caseload. It is estimated that of the 50 per cent to 60 per cent of cancer patients who require radiotherapy treatment, only about 33 per cent actually receive it. We understand that patients living outside Dublin or Cork have particular difficulties in accessing radiotherapy services and more especially those living in peripheral geographic regions.

- In the area of radiotherapy, it was perceived that a disproportionate focus has in the past been given to equipment rather than to people. In Ireland, and indeed right across Europe there are shortages in professional staff including:
  - Radiation Oncologists
  - Radiation Therapists
  - Oncology Nurses
  - Physics and Engineering support.

The capacity to attract personnel to Ireland over the last few years has improved. A further key challenge relates to the retention of staff on a long-term basis.

- The location of radiotherapy services is a contentious issue and one that will be addressed by the Report on the Development of Radiation Oncology. The report has looked extensively at international best practice in the context of a needs assessment and capacity assessment (personnel and equipment) for Ireland. Although, the recommendations are not available, it is anticipated that they will fall in line with best practice, which advocates the development of clinical networks around the large treatment centres, taking account of both equity and access. The first priority is likely to concentrate on achieving a critical mass in patient numbers and ensuring that quality as opposed to convenience guides the service development. That said, if patients cannot access radiotherapy, this will have a negative impact on particular patient treatment programmes.

  A fundamental issue that was brought to our attention was the development and provision of radiotherapy services in Galway. While the physical infrastructure is near completion it will be 2005 at the earliest before services can be offered through the newly constructed centre. In particular, there are concerns that the people resources will not be put in place in a timely manner to accommodate service delivery. The Department of Health and Children has recently issued approval for the appointment of key staff necessary to commission the radiotherapy unit. Additional resources to roll-out the services are essential. To date, the processes and planning to resource an integrated team of nurses, NCHDs, consultants, etc has not yet commenced. Furthermore, no plan has been developed to specify how services will be rolled out within a given timeframe. Delivery of radiotherapy services in Galway is regarded as a major priority by the Department of Health and Children.

  Until the unit is operational, there will continue to be a knock-on affect on the services in Dublin and, equally important, a requirement for people from the region to continue to travel relatively long distances to access services. Organisation and management of these radiotherapy services will need to address issues such as referral and treatment protocols and integration with regional services and will require the co-operation of both management and clinicians on a multi-disciplinary basis.

- A further issue to be addressed in the context of radiotherapy services relates to St. Luke's Hospital in Dublin. The question arises as to whether St. Luke’s should continue as a stand-alone oncology service or whether it should be further developed either in terms of the range of services (e.g. surgery) it provides on site or as part of the service provision of one or more acute hospitals within the Dublin area. There are advantages and disadvantages associated with each approach.

  The options for the future development of St. Luke’s Hospital are not an issue that can or should be directly addressed by the next Cancer Strategy. However, it does need to be considered in the context of the development of radiotherapy services in conjunction with the forthcoming report.

5.5.4 WAITING TIMES

- In the course of our study we endeavoured to explore the waiting times that patients experienced for consultant appointments, tests, test results, surgery and chemotherapy. There is an absence of IT systems to collect and report on this type of data and in many cases, while overall waiting times for treatment are available, these are not available on a cancer specific basis. In order to develop a culture of continuous improvement in service quality, improvements in this area must be realised. That said, examples of successful organisation of data collection and analysis did exist, e.g. the Cancer Information System in St. James’s Hospital, South Western Area Health Board.

5.5.5 EQUIPMENT

- Overall there was a considerable level of satisfaction with investment in CT and MRI scanners since the 1996 Cancer Strategy. Each of the Health Boards reported progress in this area but a number of concerns were expressed. There remains a view that there is an insufficient number of MRI scanners, particularly in those hospitals where large numbers of cancer patients are treated. However, it was also acknowledged that in some cases greater use could be made of existing resources through extended working days, etc. There is a need for a dedicated programme of capital replacement across all hospitals with obvious implications for service quality and patient safety. This may be reflected in the findings from the submission process where patients were in some instances dissatisfied with the standard of equipment in place.

- An important issue raised is the pressure on the health care system to provide new and emerging technologies as early as possible. During our consultations, PET scanners to provide enhanced diagnostic images to support cancer diagnosis and decisions on treatment were referred to specifically by hospital consultants. PET scanning is available privately at the moment and is availed of by public hospitals that send patients to private facilities for PET scans. The specific questions, which need to be addressed within the health system in relation to new technologies, relate to how the health care system should adequately determine whether, where and when such technologies should be provided. There is currently no formal assessment mechanism in the public health system, which can properly develop answers to these questions, the objective of which is to introduce proven technologies that can offer significant benefits to the hospital system.

  Health Technology Assessment (HTA) is a key input to policy determination and is considered a valuable evidence based tool to support decision making in other countries. HTA is a multi-disciplinary field of policy analysis, which studies the implications of health technology and makes recommendations for its development, diffusion and use. The Health Strategy (Action 111) provides for the establishment of an independent Health Information and Quality Authority which will oversee the development of capacity for health technology assessment. This structure should be established and utilised to determine the appropriateness of new technologies. A cautionary note is required in that the introduction of new technologies must be viewed against the competing demands for health sector resources including the need to ensure that existing technologies are available in suitable locations and in the numbers required for the effective and equitable provision of cancer care.

5.5.6 COMMUNITY SERVICES

A key finding throughout the study is the requirement for cancer services to be holistic in nature. Community services for cancer patients emerged as a key issue in the course of our study and are regarded by all as being underdeveloped. As mentioned previously, the implementation of the Primary Care Strategy will form an important cornerstone in the development and strengthening of community resources. Fundamentally, there is a widespread view that the emphasis of cancer services must move towards integration of the acute system with the community and primary care services. Primary and community care are seen as the most appropriate channel for the delivery of services such as: health promotion; cancer prevention, awareness and education; recovery and certain aspects of palliative care. A greater recognition of this role for Primary Care within cancer treatment is required. At present, that input is underdeveloped and needs expansion to take on its appropriate role. Ultimately, cancer care should involve the successful working and integration of the full continuum of treatment: Primary Care (early detection and screening); Acute Care and Community Care.

5.5.7 PALLIATIVE CARE

Considerable progress has been made in this area including the recent publication of the Report of the National Advisory Committee on Palliative Care (2001). Regional Consultative and Regional Development Committees have been established in each health board area and these Committees are representative of all stakeholders. The Development Committees also recommend how funding for palliative care services should be allocated.

All Health Boards have been allocated funding for the development of these services although once more there remains a marked regional variation in terms of the current state of development. Part of this is attributable to the role that has been played by the voluntary sector in spearheading and funding service initiatives.

One of the key events in recent times has been the completion of the needs assessment study within each health board which will provide the framework for service development going forward in conjunction with the 2001 report. The needs assessment studies are expected to be completed for all boards in 2003. It also seems likely that the future will see the emergence of a more structured and formalised arrangement between the health boards and the voluntary sector in terms of service provision.

5.5.8 AUDIT AND EVALUATION

Audit and evaluation is significantly underdeveloped throughout the Irish Health System and consequently cancer services. This point was consistently highlighted in the course of our consultations. It was reported that audit methodologies were part developed, in the process of development or not developed at all. Likewise, with regard to risk management, pockets of best-practice were identified (chemotherapy would appear to be one area where there are well developed risk management practices) but there are no mechanisms or structures to roll these out on a wider basis. One of the key obstacles to progress in this area is seen to be the lack of a national system of clinical audit. However, the roll-out of the National Hospital Accreditation Programme in the major academic teaching hospitals was recognised and welcomed.

There is a consensus view that going forward there must be a stronger focus placed on the evaluation process and in particular an evidence-based approach to service development and decision-making. This also upholds the requirement for multi-disciplinary teams working together, within the context of supra-regional centres and centres of specialist care.

5.5.9 TRAVEL

An important aspect of quality of patient care that manifested itself through the submission and consultation process related to the physical travelling requirements for patients in accessing services (frequently mentioned for radiotherapy and also applicable to paediatric patients). The issue is not so much the travel involved but the absence of an appropriate infrastructure and support system that would go towards minimising patient trauma. Potential solutions that would assist included:

- Identifying possible opportunities for sharing transport facilities with patients from other areas within the health service who are also required to travel, e.g. cardiovascular patients
- Provision of more residential accommodation at the main hospital centres
- Provision of home care supports, e.g. child minding
- Co-ordinating appointments so that time spent travelling is minimised for patients
- Ensuring that appointments are not cancelled at short notice.

At a practical level, while every effort should be made to minimise the disruption and discomfort to patients, this needs to be balanced in the context of patients having to travel in order to avail of the best quality of services available.

5.5.10 CANCER STRATEGY PRIORITIES

There is a view that some cancers (e.g. bowel, lung, skin, prostate) did not receive sufficient prioritisation under the 1996 Strategy. Significant focus has been directed at breast cancer and success and progress has been achieved in this area. A requirement emerged from consultations to concentrate similar efforts on the other cancers over the course of the next cancer strategy.

5.5.11 SERVICE ACCESS

- Differences in terms of equity of access to cancer services at a regional level was put forward as an issue. Evidence was presented of variations between health boards in relation to the granting of medical cards to cancer patients. Some health boards have a policy that all cancer patients are entitled to a medical card irrespective of their income.

- There is a widely held belief that waiting times for private patients is quicker than for public patients. While this may be a valid viewpoint for some services, for example, in the case of private radiotherapy services, for the most part it is considered that patients are treated on the basis of "need" rather than on their ability to pay. Indeed, in some instances public patients are reported as having better access to services. Furthermore, it was noted that evidence to support the true reality of the situation is not available.

- The care pathways that support a streamlined service for cancer patients have for the most part not been developed although some specific examples were to be found. In the case of Paediatrics, the care pathways are reportedly well defined.

5.6 CO-ORDINATION

TABLE 5.5 SUMMARY OF OBJECTIVES IMPLEMENTED AND KEY GAPS IN CANCER SERVICES COORDINATION FOLLOWING THE NATIONAL CANCER STRATEGY, 1996

	FACTORS INFLUENCING ASSESSMENT	
	KEY ACHIEVEMENTS	KEY GAPS
Objective: **Co-ordination**	• Establishment of National Cancer Forum. • Appointment of Regional Directors of Cancer Services. • Appointment of oncology clinical nurse specialists, some of whom have a specific role to co-ordinate all aspects of a patient's treatment and care while within the hospital system.	• Issues raised in relation to the work of the National Cancer Forum according to the following dimensions: - public awareness - representation on the Forum - clarity of role and responsibilities. • The following issues were raised in relation to the work of the Regional Director of Cancer Services: - relationship with National Cancer Forum - the definition of the executive role of the Regional Director of Cancer Services at health board level - administrative support. • Cancer services are regarded as insufficiently co-ordinated within the Department of Health and Children. • Co-ordination between the community, primary and acute services is not sufficient.

5.6.1 STRUCTURES

- It is widely acknowledged that the Regional Directors have contributed enormously to the improvement of cancer treatment services and that such a role should be maintained going forward. In essence, the role is seen very much as a planning role in conjunction with the health boards and also as a co-ordinating role in communicating and co-ordinating the input of key stakeholders. Other points that were raised were as follows:

  - It is appropriate that the role should have clinical input. However, following clear definition of the role and expectation of the performance, it may be appropriate to provide some administrative/other support to the Regional Director in carrying out their duties.
  - Improved mechanisms are required to ensure that the views of the Regional Directors are properly articulated at National Cancer Forum level or that there are opportunities for the Regional Directors to meet as a group on a regular basis. However, for such meetings to be effective, it requires that discussions focus on national/common issues rather than regional specific issues.
  - In terms of the changing structures of the Irish healthcare system it is not obviously clear where the National Cancer Forum will sit in the future. In our view, the Forum should provide an advisory role to the proposed Health Services Executive.

- The National Cancer Forum is seen as having played a pivotal role in the development and improvement of cancer services. There is a perceived need for such a co-ordinating body, working in conjunction with the Department of Health and Children. In particular, the Forum is seen as having played a very effective role in terms of bringing and highlighting key issues to the Department. However, a number of concerns were raised:

  - Awareness of the Forum is not consistent across all stakeholders. The consultation process established that there may be issues with respect to the levels of awareness among GPs. Against this, it was suggested that the profile of the Forum needed to be raised with a greater focus on external communications.

  - It was suggested that the scope and remit of the Forum may be too broad and that there may be merit in it adopting a narrower focus. The extent that this is possible given the range of areas that fall under cancer services is an issue for debate.

  - As part of the consultation process, we received feedback that there are insufficient nursing representatives on the Forum. However, following our examination of the board, we are of the view that they are adequately represented.

  - Further clarification and delineation of the roles and responsibilities of the Department of Health and Children, the National Cancer Forum, the Regional Directors of Cancer Services and the health boards is required in relation to cancer services. It is not always clear who the decision-maker is or where the lines of accountability should be drawn.

- The organisation and structures of cancer services in the Department of Health and Children reflect the diverse nature of cancer within the health care system. Responsibilities for cancer services are therefore shared among several divisions including:

  - Acute Hospitals Division (National Cancer Strategy & BreastCheck)
  - Community Health Division (Cervical Screening)
  - Health Promotion Unit
  - Services for the Elderly Division (Palliative Care)
  - Medical and Nursing Policy Divisions

  The Department's Management Advisory Committee comprises top Departmental Officers who have overall management responsibility in the Department involving all functions, including those which relate to cancer. In addition, good linkages on an informal basis occur involving divisions in relation to cancer specific policies and programmes. However, consideration should be given to a more formal co-ordination of policies within the Department insofar as cancer is concerned.

5.6.2 CO-ORDINATION OF SERVICES

- One of the key objectives of the 1996 National Cancer Strategy was the further development of an integrated cancer care service, where there would be a seamless progression of patients through from primary care to the acute care services and so forth. At a national and regional level, the National Cancer Forum and the appointment of the Regional Cancer Directors are perceived to have brought about improvements in this regard. However, from an operational/service delivery point of view, there remains significant work to be done. Quite obviously the level of co-ordination and co-operation between the community, primary and acute systems varies by health board region. A range of initiatives have been implemented including the standardisation of patient referral forms to outpatient departments. However, a series of core issues remain including:
  - inappropriate referrals from GPs into the acute system.
  - the level and timing of communication from the acute system to GPs/community care practitioners particularly in the area of discharge planning e.g. handwritten discharge letters that include insufficient information on treatments, etc, discharge letters not being issued promptly, etc.
  - the development and strengthening of community care services.

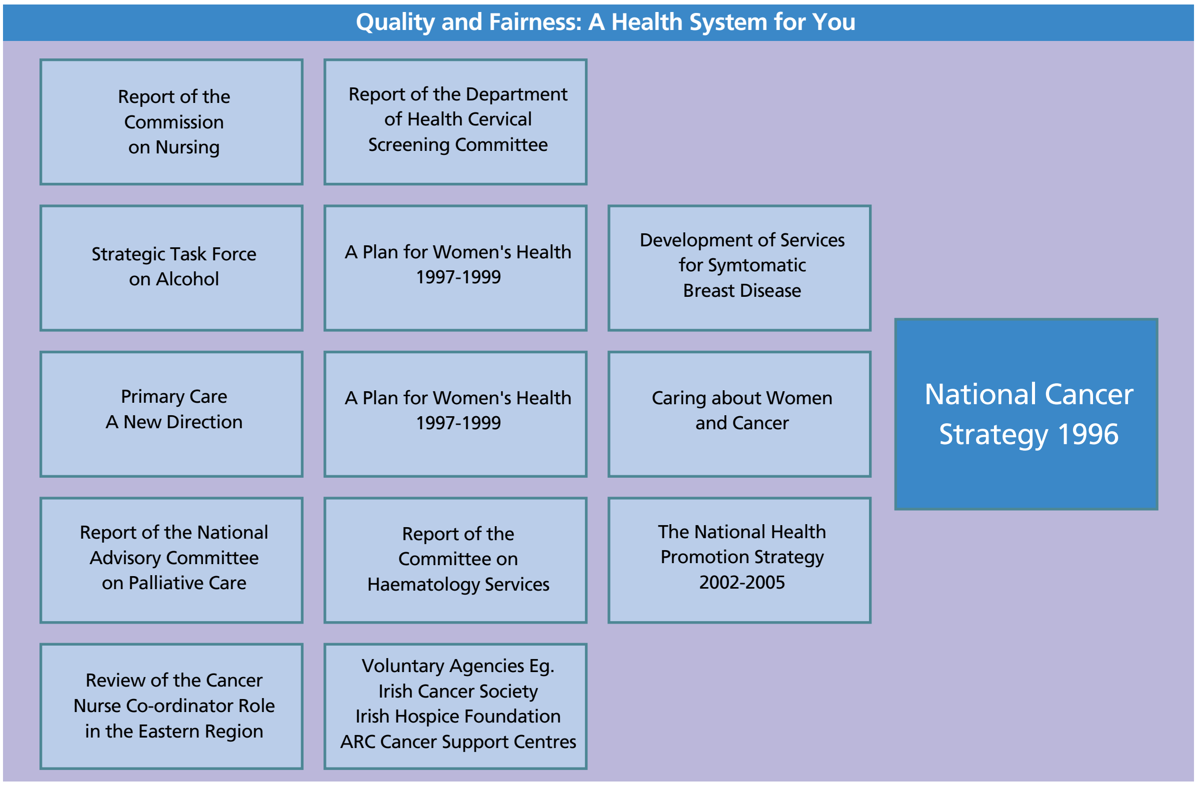
  There are obvious cultural issues to be addressed in the realisation of improvements across the co-ordination of services. Likewise, the application of IT and ICT systems will influence service delivery. While development and investment in IT is an on-going issue that cuts right across the health sector, there was general agreement that insufficient use has been made of ICT technologies such as videoconferencing, etc in terms of service co-ordination but also service efficiency.

- The delivery and organisation of cancer services remains largely centred around geographic boundaries notwithstanding the progress that is being made between the North Western Health Board and the Northern Ireland Health Authorities. Communication and co-ordination across Health Boards remains poor across the planning and delivery of cancer services despite the fact that service requirements do not naturally marry with current health board boundaries.

- The voluntary sector has played a key role in cancer services particularly in driving developments in the area of palliative care. The relationship between the voluntary sector and the respective health boards is by all accounts quite good including examples of where the health boards now pay the salaries of staff from the voluntary organisations and the implementation of jointly funded posts. Many health boards expressed the view that they would like to see the relationship with the voluntary sector more formalised primarily through service level agreements. Ultimately, service provision is seen as the responsibility of the health board and a concern was expressed that there should not be an over-reliance on the voluntary sector to bridge service gaps especially in the area of palliative care.

- The co-ordination of the National Cancer Strategy with other relevant strategies such as the Health Promotion Strategy and the National Palliative Care Strategy is regarded as an important factor in the overall efficiency and effectiveness of cancer care given the range of services and areas covered by cancer. At a general level, it is perceived that the National Cancer Strategy has not been formally linked to other strategies except in an ad-hoc fashion, as demonstrated in Figure 5.1. For the next strategy, it is seen as important that key elements of other national strategies, as applicable to cancer, are incorporated and formally referenced. One such example, is the review of all paediatric services in Ireland, as planned in the National Health Strategy.

FIGURE 5.1: SUMMARY OF STRATEGIES IMPACTING ON CANCER SERVICE DELIVERY



- Various opinions were expressed as to the role of the private sector in the provision of cancer services. Among many stakeholders, they are seen as having a role to play, and already do so in terms of acute hospital care and radiotherapy services. However, it was also widely recommended that service provision should be in conjunction with rather than independent to the public sector.

5.7 COST EFFECTIVENESS

TABLE 5.6 SUMMARY OF OBJECTIVES IMPLEMENTED AND KEY GAPS IN COST EFFECTIVENESS AFTER THE NATIONAL CANCER STRATEGY, 1996

	FACTORS INFLUENCING ASSESSMENT	
	KEY ACHIEVEMENTS	KEY GAPS
Objective: **Cost Effectiveness**	• The attainment of better value for money, including new technology assesment is a key element in the letter of determination to Health Boards.	• Equipment under-utilisation (radiography/diagnostics/labs). • Increasing cost of oncology drugs – there is an absence of protocols and guidelines on the use of drugs and the adoption of new treatment approaches. • The absence of performance and outcome measures. • There is a need for investment in IT systems in order to better monitor costs, assess service delivery and monitor treatment outcomes. • Prevention approaches need to be recognised as the most cost effective approach in the long term.

- One of the main areas where opportunities for improved cost effectiveness were identified related to the use of equipment and treatment facilities. It emerged that equipment (e.g. CT scanners, MRI scanners), laboratory facilities, radiotherapy facilities, etc. operate standard working hours (there are some exceptions) with associated knock-on implications for patient access to services. Changes in HR practices is one of the key challenges to be addressed if the working day is to be extended.

- The increasing costs of oncology drugs is a key area of concern within cancer treatment services given its impact on the total level of base funding available for service delivery in other areas. There was strong support for the development of protocols and guidelines for evidence-based best practice in patient care. Particular concerns were raised about the increasing costs of drugs and the need to ensure that hospital budgets adequately reflect this. However, we would emphasis that consultants must play a key role in the development of protocols and also accept that they have a responsibility to become involved in developing any solution or initiative to address the cost of oncology drugs. In this context, it was noted that Ireland is unique in not having a National Technology Assessment Centre. The proposed Health Information and Quality Authority will have a role in overseeing accreditation and the development of HTA.

- There is a need to evaluate the role for PET scanning in cancer treatment in Ireland by an independent body. It is proposed that this function will fall under the remit of the Health Information and Quality Authority.

  Public expectations in relation to the different treatment options available is a further area highlighted as requiring management and control. Once again, the role of a co-ordinator of information to patients on treatment options (e.g. Cancer Nurse Co-ordinator) and public access to reliable information sources were referenced as potential options.

- One of the perceived weaknesses of the 1996 National Cancer Strategy was the lack of performance measures and outcomes. At the time the strategy was instigated, performance measurement across the health sector was at a very early stage of development. In the intervening period progress has been made but the culture of performance measurement and evaluation remains under-developed as do the IT systems to support it. Therefore, the evaluation of the 1996 National Cancer Strategy is largely based upon a qualitative assessment of stakeholders' views. For the next strategy, it has been recommended that more specific targets need to be defined and a framework for performance measurement set out if its overall effectiveness is to be properly defined. In conjunction with this, a detailed implementation plan is required that clearly stipulates how the strategy will be translated into practice so as to set clear milestones, and to reduce any ambiguity that exists in terms of its objectives and how they are intended to be applied.

- A key concern emerging from consultations with health boards is that the process of allocating funds from the Department of Health and Children makes it difficult for the Health Boards to adopt a strategic approach to budgeting and the development of services, including cancer services.

5.8 RESEARCH AND EDUCATION

TABLE 5.7 SUMMARY OF OBJECTIVES IMPLEMENTED AND KEY GAPS IN RESEARCH & EDUCATION FOLLOWING THE NATIONAL CANCER STRATEGY, 1996.

	FACTORS INFLUENCING ASSESSMENT	
	KEY ACHIEVEMENTS	KEY GAPS
Objective: Research and Education	• Development of the work of the National Cancer Registry. • Health Research Board – active in the area of fellowships and funding of research programmes. • The Health Research Board is working with a Cancer Consortium, which assists co-operation in cancer services between the North and South of Ireland and the United States. • €3.5 million funding for cancer research trials provided by the Department of Health and Children. • Development of multi-disciplinary teams has facilitated on-going education and training.	• The absence of a systematic approach to the implementation of clinical trials – this is being addressed. • The requirement for a continuous approach to education and training.

5.8.1 RESEARCH

- The work of the National Cancer Registry is central to the development of the research and planning agendas for cancer services in the future. As identified previously, issues do exist in relation to the quality, depth and timeliness of data produced, although it would be incorrect to say that all of these issues are directly attributable to the National Cancer Registry. Questions were also raised in relation to the funding of the activities of the Registry and in particular whether the Registry receives sufficient funding to analyse data as well as collect it.

- To date the HRB has received €3.5m in funding from the Department of Health and Children for cancer research trials. A further €0.5m has been invested by the HRB in staff training.

- The Health Research Board is involved in the Ireland-Northern Ireland-National Cancer Institute Cancer Consortium to facilitate links between the North and South of Ireland and the United States of America. In addition, it has facilitated the introduction of the Cochrane Library for access by all health professionals in Ireland.

- The Ireland-Northern Ireland-NCI Cancer Consortium is a trilateral partnership involving the Department of Health and Children, the Department of Health, Social Services and Public Safety, Northern Ireland and the National Cancer Institute, US Department of Health and Human Services. It was conceptualised by cancer physicians in Ireland, Northern Ireland and the Unites States who took their idea of a collaborative partnership to their respective governments.

- The Consortium was established in October 1999 on foot of a Memorandum of Understanding signed by the Health Ministers of Ireland and Northern Ireland and the Secretary of State for the U.S. Department of Health & Human Services. It seeks to bring together in a collaborative way, the cancer communities in all three jurisdictions with a view to enhancing the capacity of our cancer research and service delivery systems.

- A Board of Directors consisting of the Chief Medical Officers of Ireland and Northern Ireland and the Director of the National Cancer Institute governs the Consortium. The Board meets at least twice a year.

- The Board is supported by a board-appointed Implementation Group, which meets at least four times per year and makes recommendations to the Board. Membership includes representatives from the various disciplines – nurses, clinicians, scientists, palliative care, prevention, and epidemiology- from all three jurisdictions.

- The Implementation Group is supported by Working Groups, tied to specific initiatives of the Board. Current groups include:

  - Clinical Trials
  - Cancer Registries
  - Scholar Exchange Groups in Nursing and Medical Oncology
  - Information Technology, and
  - Prevention.

- The Consortium is guided by the requirements of the Memorandum of Understanding and operating procedures defined in an Implementation Plan developed by the Board.

- The major goals of the Consortium are as follows:

  - Share the best technology available to enhance clinical research
  - Conduct joint clinical research studies involving people from all three jurisdictions
  - Sponsor formal training exchanges to immerse Irish and American medical, nursing, and scientific scholars in the cancer programmes of partner institutions
  - Implement the use of teleconferencing, Telesynergy, and other information technology capabilities to facilitate all-island and U.S. education and interaction
  - Consolidate the cancer registries of Ireland and Northern Ireland so that more can be learned about cancer incidence on the entire island.

- The Consortium's main achievements are regarded as follows:

  - **Clinical Trials:** Agreement has been reached on the most appropriate model for the development of a clinical trials infrastructure in Ireland. The objective is to fund a number of centres to carry out high quality research clinical trials to a similar level as that already achieved in Belfast City Hospital and to fund an all-island clinical trials group to co-ordinate the trial activity of funded hospitals, North and South.
  - Under the first phase of this scheme, awards to the value of €1.9m were made through the Health Research Board to 6 hospitals in November 2001 as follows: St. Vincent's University Hospital and St. Luke's Hospital, Dublin; University College Hospital, Galway; Cork University Hospital; Beaumont Hospital, Dublin; Limerick Regional Hospital and Mater Misericordiae Hospital, Dublin.
  - Under the second phase of the scheme, further awards to the value of €1.6m were made available through the Health Research Board in 2002 to the following four hospitals: St. James's Hospital Dublin; Mater Hospital, Dublin; The Adelaide and Meath incorporating the National Children's Hospital Tallaght and Waterford Regional Hospital.
  - The Director of the US National Cancer Institute launched the first all-Ireland Cancer Network in February 2003. The network will ensure that Irish patients have access to the latest and most effective cancer therapies. The network is being formed by the Irish Clinical Oncology Research Group (ICORG) based in Dublin and the Clinical Research Support Centre (CRSC) located in Belfast.

- The new cooperative group will be jointly funded by the Health Research Board in Dublin and the Research and Development Office in Belfast. The group will receive €1m over the next two years to carry out its work. Its principal role will be to initiate and coordinate clinical trials in cancer hospitals in both parts of the island.

- **Cancer Registries** – Released the All-Ireland Cancer Statistics Report, a first-time co-ordination of cancer statistics for the island's entire population from the cancer registries of Ireland and Northern Ireland.

- **Scholar exchange** – Two fellows, one from Ireland and one from Northern Ireland, are in the final year of a three year epidemiology fellowship after spending the first year at NCI and two years back at the National Cancer Registries.

- **Information Technology** – the complete telesynergy system, developed by the NCI and the Centre for Information Technology of the NIH, was physically assembled in Belfast in July 2002 and was completed in Dublin in August 2002. This project allows for enhanced communications between the participating centres for the transmission of complex images and large volumes of research data. It enables scientists and clinicians at multiple laboratories and hospitals to interact simultaneously with one another. Its installation in Ireland is the first time the system has been used outside of the United States.

- **Prevention** – Plans are underway for the running of a series of annual prevention workshops in Ireland, with the first (on smoking cessation) having taken place in May 2003.

- **Cancer Conference 2003:** Planning is underway for the Consortium's Second International Cancer Conference, which is scheduled to be held in Cork on 20-22 October 2003.

5.8.2 EDUCATION

- As part of our consultation process, medical educational standards in Ireland were repeatedly praised and it was stated that they were among the best in terms of international standards. That said, the recent report from the Irish Medical Council has stated that the IMC sees a need to raise the standards of education in medical schools in Ireland even further.

  A key theme that cut across the consultations was the requirement for a greater emphasis on on-going and continuous education programmes. The rapid pace of development in cancer treatments and disease necessitates that medical professions are kept up-to-date with developments especially in the area of primary care where they are not to the forefront of cancer treatment. The structures that are currently in place to keep primary care professionals informed are underdeveloped at a regional level although, as highlighted through our discussions with the health boards, efforts have been targeted at implementing a range of initiatives. One of the key deficiencies in this area, is the lack of communication/information sharing between GPs and specialist cancer consultants. The greater involvement of GPs/other primary care professionals in multi-disciplinary patient case meetings was advocated. However, the feasibility of this option in terms of time commitment is questionable unless, as mentioned previously, greater use can be made of such technologies as video-conferencing.

- Multi-disciplinary team working is, by all accounts, an area that has received increased recognition over the last number of years. Across all of the health boards, it was reported that this approach has been adopted in the acute hospital system. However, we were unable to validate how comprehensively it has been rolled out. It also emerged that different models of multi-disciplinary team working are in place in terms of the stakeholders involved and the frequency at which these meetings occur. It has been argued that there is a greater need for more patient and primary care involvement (as mentioned above the feasibility of this needs to be assessed).

Outside of the acute hospital system, multi-disciplinary team-working is not as prevalent. Again, the Primary Care Strategy should bring about improvements at a primary care/community level.

5.8.3 CLINICAL TRIALS

- The consultation process identified that mechanisms to involve patients in clinical trials are ad-hoc and dependent on locality. Furthermore the extent to which clinical trials are offered to patients is unclear. There is a view that a systematic approach to the allocation of trials to different hospitals needs to be adopted and therefore there is an associated requirement for a body to oversee this – perhaps the Health Information and Quality Authority.

- Many stakeholders were of the view that the size of Ireland does not justify it developing/leading its own clinical trials, rather it would be more effective for us to participate in international trials. The Health Research Board argued that participation in clinical trials should be encouraged so as to support the on-going education of clinical staff as well as the development of best practice policy and procedures.

- Linked to the previous point, it has been argued that research activity across the health services in Ireland is unco-ordinated despite the common areas of interest that exist, for example, research in other areas may yield results that, while not specific to cancer, will impact upon it. The Minister for Health and Children has thus requested that the major objectives of the Irish health system are examined (e.g. decreased mortality) in conjunction with the organisation and structures that support research activity. It is anticipated in the future that people engaged in publicly funded research activity would be requested to select a project from a project listing and subsequently compete for funding from the Health Research Board. Such an approach would necessitate increased collaboration among researchers from different disciplines.

5.9 CONCLUSIONS

5.9.1 PREVENTION

- The National Cardiovascular Strategy has been the driver in this area, which has resulted in less prioritisation being given towards measures to target skin cancer. This needs to be addressed in future plans.
- Measures to target smoking cessation have been successful, such that the proposed new legislation should see Ireland positioned as a leader in this area within Europe.
- There should be a greater role for Primary Care in this area.
- Appropriate performance measures should be developed to assess the success of these initiatives in the future.

5.9.2 INFORMATION

- Significant improvements have been made in the provision of information to patients and their families since the launch of the Cancer Strategy in 1996.
- There remains an absence of systematic and planned approaches to the provision of patient information about treatments, and their impact.
- Certain aspects of communication with patients need to be strengthened.
- There is potential to increase the use of the National Cancer Registry to enhance the availability of information to health boards etc. in order to guide future service development and delivery.

5.9.3 EARLY DETECTION

- There have been very positive developments in the area of early detection and screening since the launch of the 1996 Cancer Strategy particularly with the introduction of the breast and cervical screening programmes on a phased basis.
- In terms of refining both services in the future, it was further recommended that good information gathering components be built into each programme. The establishment of a population register is a further critical component in providing an effective screening programme. As yet this is not available.
- Given the differences in demands and protocols associated with the various programmes/units, there is a critical need to ensure that BreastCheck and the symptomatic breast disease services are integrated in the future.

5.9.4 ACCESS, TREATMENT AND QUALITY

- The concept of "Supra-Regional" needs to be defined in relation to the development of regional/supra-regional centres of specialist cancer care. Considerable ambiguity exists surrounding this area and definition. The National Cancer Forum should also clearly define their concept of supra-regional centre: is it multi-site services within a single region or multi-services from a single hospital.
- The capacity of health boards to develop regional centres of specialist care for secondary services showed considerable variation.
- Since 1996, a sizeable number of staff appointments have been made including Medical Oncologists, Haematologists, Histopatologists, etc. Despite this, key staffing shortfalls still exist within the system. Continued reference was made to insufficient services to address the area of emotional support and counselling.
- Specialist nurses have played a key role in improving services available to patients.
- Access to radiotherapy was cited as the most critical area where cancer services are underprovided. In addition, the location of radiotherapy services is a contentious issue expected to be addressed in the Report on the Development of Radiation Oncology Services.
- Health Technology Assessment is required for input into policy determination and as an evidence based tool to support decision making.
- Community services for cancer patients emerged as a key issue in the course of our study and are regarded by all as being underdeveloped.
- Considerable progress has been made in the area of Palliative Care, including the recent publication of the Report of the National Committee on Palliative Care (2001).
- Audit and evaluation is significantly underdeveloped throughout the Irish health system and consequently cancer services.
- The absence of an appropriate infrastructure and support system that would go towards minimising patient trauma in relation to the physical travelling requirements for patients in accessing cancer services is a key area which needs to be addressed.

5.9.5 CO-ORDINATION

- It is widely acknowledged that the Regional Directors of Cancer Services have contributed enormously to the improvement of cancer treatment services and that such a role should be maintained going forward.
- The National Cancer Forum is seen as having played a pivotal role in the development and improvement of cancer services.
- One of the key objectives of the 1996 National Cancer Strategy was the further development of an integrated cancer care service, where there would be a seamless progression of patients through from primary care to the acute care services and so forth. At a national and regional level, the National Cancer Forum and the appointment of the Regional Directors are perceived to have brought about improvements in this regard. However, from an operational/service delivery point of view, there remains significant work to be done.

5.9.6 COST EFFECTIVENESS

- One of the main areas where opportunities for improved cost effectiveness was identified related to the use of equipment and treatment facilities.
- The increasing costs of oncology drugs is a key area of concern within cancer treatment services given its impact on the total level of base funding available for service delivery in other areas.
- There is a need to evaluate the role for PET scanning in cancer treatment in Ireland by an independent body. This function of health technology assessment will be overseen by the Health Information and Quality Authority.
- One of the perceived weaknesses of the 1996 National Cancer Strategy was the lack of performance measures and outcomes.

5.9.7 RESEARCH AND EDUCATION

- The work of the National Cancer Registry is central to the development of the research and planning agendas for cancer services in the future.
- To date the HRB has received €3.5m in funding from the Department of Health and Children for cancer research trials. A further €0.5m has been invested by the HRB in staff training.
- The Health Research Board is involved in the Ireland-Northern Ireland-National Cancer Institute Cancer Consortium to facilitate links between the North and South of Ireland and the USA. In addition, it has facilitated the introduction of the Cochrane Library for access by all health professionals in Ireland.
- Multi-disciplinary team working is, by all accounts, an area that has received increased recognition over the last number of years.
- Mechanisms to involve patients in clinical trials are ad-hoc and dependent on locality.
- It would appear that it would be more effective for Ireland to participate in international trials as opposed to developing its own. The Health Research Board argues that participation in clinical trials should be encouraged so as to support the on-going education of clinical staff as well as the development of best practice policy and procedures.
- Research activity across the health services in Ireland is described as unco-ordinated despite the common areas of interest that exist.

6

CONCLUSIONS AND PRIORITIES FOR THE FUTURE

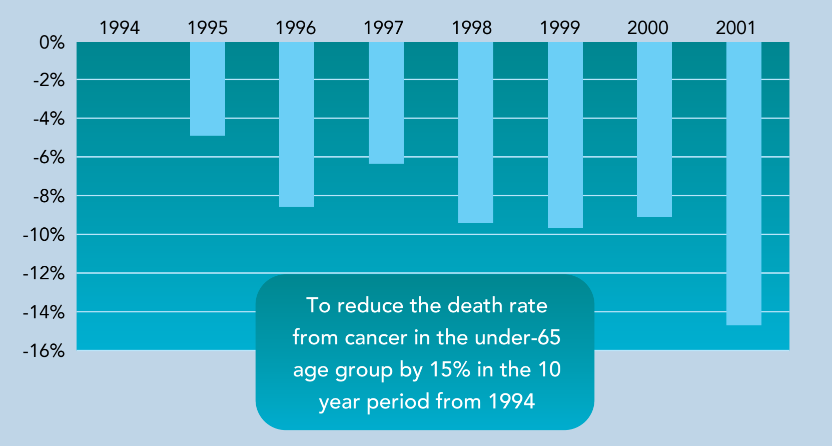
6. CONCLUSIONS AND PRIORITIES FOR THE FUTURE

6.1 SECTION OVERVIEW

Having presented and reviewed the key findings from the data gathering programme, this section sets out our conclusions and observations in relation to the achievements and work left to be done in implementing the 1996 National Cancer Strategy. Following on from this, we set out our views on the priorities for the next Cancer Strategy in the context of the issues raised.

It must be remembered that the key goal of that strategy was to reduce the death rate from cancer in the under-65 age group by 15 per cent in the ten-year period from 1994. As we can see from Figure 6.1 below, this figure was achieved in 2001, which was 3 years ahead of target.[11]

FIGURE 6.1: CUMULATIVE % CHANGE IN MORTALITY RATE (ALL MALIGNANT NEOPLASMS) PER 100,000 POPULATION FOR UNDER 65 AGE GROUP



Source: PHIS

In summary the key findings of this report are set out in the Table 6.1 overleaf:

---

[11] It should be noted that there was a significant change between 2000 and 2002, which may be a statistical aberration. However if this is discounted the underlying trend still indicates that the objective would be reached by 2004

TABLE 6.1: KEY FINDINGS AND RECOMMENDATIONS FROM THE REVIEW OF THE IMPLEMENTATION OF THE NATIONAL CANCER STRATEGY, 1996

KEY RECOMMENDATIONS:

1. Radiotherapy services need to be expanded to ensure that all patients have reasonable access to this service. At present, the lack of capacity is such that existing waiting times limit the degree to which doctors can treat their patients according to evidence-based treatment protocols and best-practice guidelines. Addressing this issue must be one of the highest priorities in the new National Cancer Strategy for 2003. This should not mean that radiotherapy services should be located in many centres throughout Ireland, but rather that there should be access arrangements and transfer protocols in place to facilitate patients in accessing these services.

2. The development of BreastCheck has been carried out separately to the development of services to treat symptomatic breast disease. Effective integration of the two services needs to be progressed. In the light of the impact of the national roll out of BreastCheck, an assessment of the appropriate number of centres of excellence for Symptomatic Breast Disease Services should be undertaken.

3. Primary Care, including the role of GPs needs greater development and support, particularly in the areas of:
   - Health promotion and cancer awareness
   - Early detection and screening
   - Palliative care
   - Patient support following discharge from the acute services

4. The Strategy provided for an integrated hierarchy of specialist services involving primary care, and regional and supra-regional hospitals. Dublin, Cork and Galway were recommended as the locations of supra-regional centres. There is a lack of clarity as to the scope, scale and complexity of acute services that should be provided at different levels in the acute sector. There should be a broad understanding within the health system, among providers, general practitioners and patients, of the services that are available and their locations. The essential requirement of assured quality in line with international norms and good practice should be the deciding principle and should not be compromised for geographic reasons. International research has consistently demonstrated that better outcomes are achieved in larger centres through the centralisation of resources, skills and expertise, facilitated by a critical mass of patients.

5. The consultation process clearly highlighted the need for an increase in services to provide emotional and psychosocial support to cancer patients. This service has improved considerably since the introduction of oncology nurse practitioners but there is still a large need for psychologists within the cancer multi-disciplinary team.

6. Health Promotion initiatives have been good, particularly in the area of smoking. Indeed the impending tobacco legislation should see Ireland as a leader in this area within Europe. The health promotion unit in the DOHC needs more interaction with the Acute Hospitals Division in the DOHC. Areas such as sun, alcohol and diet need more focus in the future.

7. Strengthening mechanisms for quality assurance, clinical audit, risk management and health technology assessment are required. The Health Information and Quality Authority (HIQA) should be supported to develop these key areas.

8. In general, very basic information systems are in place. Little audit of waiting lists/times for investigations or results etc. is performed. A common approach is needed to record and analyse this information. It is hard to evaluate programmes, treatments, outcomes etc without appropriate systems to measure and analyse performance. The forthcoming Health Information Strategy should enable this agenda to be pushed forward, not just for cancer services, but also for the entire healthcare system in Ireland.

9. The future role of the National Cancer Forum needs to be examined to build on its successful input into the development and improvement of cancer services. This role should now be reviewed in the light of the experience since the establishment of the first Forum in 1997, its linkages with the Regional Cancer Directors, the Minister for Health and Children, and the Department of Health and Children. An opportunity now exists for this exercise to be progressed and also aligned with the current re-organisation of the health services.

10. Patients are informed of treatment options but no uniformity exists in relation to information given, as very little centrally produced information is available. A much greater emphasis is required centrally in relation to the provision of information for patients on disease causation, treatment and other relevant issues.

11. Evidence based practice should be present in all aspects of cancer control and decision making, including the use of clinical guidelines and integrated care pathways. All patients should be managed through an integrated multi-disciplinary approach.

12. Research should be better integrated across the health sector, rather than individuals or their departments trying to work in isolation in their own facility. This could be achieved through strengthening and developing the role of the Health Research Board, particularly in the area of co-ordination of multi-centred research in the future.

    Most areas/organisations want to be part of a clinical trials programme and this should be facilitated as it raises standards of care and facilitates ongoing continuous medical education programmes.

13. Mechanisms to afford patients, family members and carers an opportunity to be involved in service planning and evaluation should be strengthened and developed.

14. Public debates on health services in general and cancer services in particular should be better informed. In addition, the public needs to be provided with the best evidence to define measures of quality and best practice. Public debate on cancer services needs greater clinical, political and other leadership which reflects that the organisation of services needs to be based on quality and not on geographical considerations. This has proven especially significant in relation to the development of supra-regional and regional centres of specialist cancer care, as well as the location of radiotherapy services, which are discussed later. A related point is that public expectations around service quality must be managed. Whilst it might be understandable that patients would like access to all treatments effectively in their own locality, they do not necessarily consider that this may not be the most appropriate way to deliver quality patient care.

15. The new National Cancer Strategy should reflect the priorities, including investment, for the development of cancer services set out in this report.

6.2 THE 1996 NATIONAL CANCER STRATEGY – POSITIVE OUTCOMES

6.2.1 POSITIVE IMPACT OF THE 1996 NATIONAL CANCER STRATEGY ON STRUCTURE OF SERVICES OF DELIVERY OF CANCER CARE

The impact of the strategy on cancer care can be summarised under three separate headings: structure, process and outcome:

- Structure:
  - Development of regional centres
  - Development of supra-regional centres
  - Introduction of Regional Directors of Cancer Services
  - Introduction of specialist clinical resources
  - Introduction of screening programmes
  - Clinical trial co-ordination body

- Process:
  - Examples of best practice in service structure and organisation:
    - IT Systems
    - Cancer Liaison Nurses
    - Multi-disciplinary care pathways
    - Protocols for diagnosis and treatment
    - Referral and discharge processes for full integration of patient care

- Outcomes:
  - Potential to exceed target reduction in death rate from cancer in the under 65 age group
  - More appropriate treatment of patients
  - Significant increase in chemotherapy, radiotherapy and surgical activity
  - Better patient information
  - Awareness of relationship between critical mass and improved outcomes.

6.2.2 PATIENT BENEFITS FROM INVESTMENT IN THE 1996 CANCER STRATEGY

Considerable debate has centered on whether the investment into cancer services has actually impacted on the quality of patient care and resulted in tangible benefits to patients. Table 6.2 demonstrates how this investment has actually benefited patients and their care.

TABLE 6.2 PATIENT BENEFITS FROM INVESTMENT IN THE NATIONAL CANCER STRATEGY

Benefits	Access	Range of Services	Quality of Services	Integration/ co-ordination of services	Information Available to Patients
Significant increase in activity (Chemotherapy, Radiotherapy and Surgery despite relatively static figures on incidences)	✓				
Access to specialist Medical Oncologists	✓		✓		✓
More appropriate treatment			✓		
Introduction of Oncology Nurse Practitioners - positive impact on patient and family experience			✓	✓	✓
Development of multi-disciplinary approach		✓	✓	✓	
Developement of clinical protocols based on Evidenced Based Medicine			✓	✓	
Significant increase in Health Promotion (lifestyle)					✓
Increased cancer awareness					✓

6.2.3 SUCCESS FACTORS TO BE SUPPORTED AND DEVELOPED IN THE FUTURE

In addition to the positive impacts described above, successful projects resulting from the National Cancer Strategy, 1996 also include the following:

- Introduction and development of Human Resources
  - Establishment of health promotion structures within the health boards.
  - Appointment of nurse specialists – oncology nurses, cancer liaison nurses, cancer nurse co-ordinators.
  - Appointment of data managers in the health boards (on-going).
  - Appointment of Regional Directors of Cancer Services.
  - Appointment of increased numbers of clinical specialists, e.g. medical oncologists, haematologists, laboratory experts, histopathologists, etc. – a total of 85 appointments since 1997. Prior to the Strategy there were 4 medical oncologists in the country; now there are 19.
  - Development of multi-disciplinary teams have facilitated on-going education and training.
- Establishment of the National Cancer Forum
- Development of the work and data of the National Cancer Registry
- National roll-out of BreastCheck
- Irish Cervical Screening Programme – Phase one
- Establishment of the Office of Tobacco Control
- Tobacco Health Act, 2002
- Clinical Developments and research
  - Development of clinical protocols – Evidence Based Medicine
  - Access to Cochrane Collaboration
  - The Health Research Board is working with the Cancer Consortium to facilitate links between the North and South of Ireland and the US.
  - €3.5 million funding for cancer research trials provided by the Department of Health and Children

6.3 KEY LESSONS LEARNT

Cancer as a disease, involves many areas of health services including health promotion, screening/diagnosis, treatment and patient aftercare and support. In addition, services span the acute hospital system, the primary care system and community care. As such, the first National Cancer Strategy took on a complex and challenging task in endeavouring to address the range of issues that needed to be addressed against the background of an under-developed service infrastructure. Although issues and gaps remain, a baseline has now been established for the further refinement and development of services in the future. The key task at hand involves assessing what lessons can be learnt from the implementation of the previous strategy and identifying areas to be addressed in terms of the development of the new National Cancer Strategy. These are classified as follows:

- Analysis of gaps in current service delivery
- Key issues identified and summarised under the four principles of the National Health Strategy, and
- Principal barriers to implementation of the National Cancer Strategy.

6.3.1 SUMMARY OF ANALYSIS OF GAPS IN CURRENT DELIVERY OF CANCER SERVICES

The key issues to be addressed primarily relate to:

- The standardisation of service capacity and access across all health boards, in both the primary treatment specialities and also ancillary services such as physiotherapy or emotional support and counselling. Patients should not be disadvantaged in terms of the service they receive depending on their geographic location.
- The concentration of resources, competencies and skills in regional and national centres of specialist cancer care.

- Matching investment in equipment and infrastructure with a corresponding investment in people and skills.
- Access to radiotherapy services. This issue will be addressed by the Report on the Development of Radiation Oncology Services.
- The further development and implementation of quality protocols and standards in conjunction with a national system of clinical audit.
- The development of clinical pathways particularly in accessing tertiary services.
- The development and improved utilisation of IT systems and resources.
- Improvement in the timeliness, relevance and reliability of statistical and patient quality of life data to inform the service planning, monitoring and evaluation processes.
- Expanding and developing the role that primary and community care services play in the delivery of cancer services and the co-ordination of this role with the acute system.
- Enhancing the level of structured and regular communication between the various professionals involved in the administration of services at different levels in the system.
- The development of patient support services across information provision, counselling, etc.

6.3.2 SUMMARY OF KEY ISSUES TO BE ADDRESSED IN FUTURE SERVICE DEVELOPMENT, CLASSIFIED ACCORDING TO THE FOUR PRINCIPLES OF THE NATIONAL HEALTH STRATEGY, 2002.

In some respects, the 1996 National Cancer Strategy was too broad in scope and attempted to address too many areas against a relatively low level of established service provision. As a result efforts and resources have been diluted. Progress has been made in many areas and it is obvious that staff are attempting to deliver the best care possible within the current service structure, system organisation and allocated resources. The next National Cancer Strategy needs to be more specific and targeted in terms of its objectives, goals and the focus of its priorities. The adoption of such an approach is deemed as being even more important in light of the current economic climate and the demands on funding that exist.

With the benefit of hindsight, it is now realised that the 1996 National Cancer Strategy concentrated on certain elements of cancer care, with less attention elsewhere. This was reasonable given the level of service development at the time but the next phase of a national cancer strategy should redress this imbalance. The most commonly referenced areas for increased focus were: radiotherapy; health promotion; patient inclusion in the planning and evaluation processes and the role of primary/community care. This highlights once again the importance of prioritisation and the clear specification of how and where the strategy can support development and progress in conjunction with other national policies and plans.

Table 6.3 summarises the key issues we think need to be addressed in the future following our review of the implementation of the National Cancer Strategy, 1996. They are grouped under the four principles of the National Health Strategy, published in 2001.

TABLE 6.3 SUMMARY OF KEY AREAS OF CANCER SERVICES WHERE MORE WORK IS REQUIRED IN THE FUTURE

EQUITY	ACCOUNTABILITY
• Access • Variability in take up rate of screening programme across different socio economic groups • Inter regional/board service agreements for supra-regional centres • Clinical pathways (supra-regional, primary – secondary – tertiary)	• Role of National Cancer Forum • Role of Regional Director of Cancer Services • Co-ordination across boards • Organisation of cancer services within DoHC
QUALITY	**PATIENT CENTREDNESS**
• Quality assurance, clinical audit, risk management and health technology assessment • Need for framework for performance measurement and outcome measurement • Supracentre quality of treatment not recognised by general public • Protocols and guidelines • Education and training • Dilution of resources in agencies	• Community care support needs strengthening • Support mechanisms (e.g. transport, accommodation) • Role of primary care • Palliative care • Emotional counselling and support • Patient involvement in service planning • Health promotion targeting right audience groups • Delivery of diagnosis

6.3.3 PRINCIPAL BARRIERS TO IMPLEMENTATION OF THE NATIONAL CANCER STRATEGY

We identified the principal barriers to implementation of the National Cancer Strategy as:

- Lack of definition within strategy – principles versus measurable activity:

  The 1996 strategy lacked clear outcome and performance measures. This makes it very difficult to ascertain the effectiveness of current treatment programmes, service delivery and evaluate whether treatment programmes and support services offer value-for-money.

- Absence of a detailed implementation plan and planned approach:

  While the 1996 strategy did not actually include an implementation plan that detailed how its objectives would be implemented in practice across the health boards and agencies, this was the first task tackled by the National Cancer Forum. Because of the devolved nature of the health system, the health boards have in the absence of clear direction, developed and interpreted their own approach to implementation, resulting in different areas of emphasis. A more integrated approach is required. In turn, it is seen that in some instances in the past, political influence has had too much sway over the location of services and the distribution of resources. As identified, this has resulted in variation in the way in which cancer services are delivered and organised and the quality and extensiveness of service provision.

  The development of an implementation plan would also assist in defining improved lines of responsibility for the different roles associated with the planning, management and evaluation of cancer services. Section 5 highlights the need for greater definition in relation to the role of the National Cancer Forum, the health boards and the Regional Directors of Cancer Services.

- Absence of a Human Resources plan:

  The need for the development of a Human Resource plan in conjunction with an implementation plan and detailed costs has been identified as a clear need, following on from the 1996 Strategy. The regional distribution of resources aligned with an overall development plan to support appropriate regional self-sufficiency, in conjunction with the development of supra-regional centres of specialist cancer care needs to be clearly outlined within the context of a national cancer development and implementation plan. In particular, the consultation process highlighted the lack of understanding in terms of resource allocation under the strategy. For example, the appointment of single-handed practitioners is an approach which will be difficult to sustain in the longer term given that best practice would suggest a requirement for these professionals to work in multi-disciplinary group practices where they can support each other. This needs to be addressed. In turn, the feedback from both the submission process and the consultation process pointed to key resource gaps, especially in the areas of radiotherapy and patient support and care. A human resource plan would assist in identifying how and when such resource issues could be resolved.

- Insufficient information and IT systems (waiting times, etc):

  This hinders considerably the ability to measure performance, identify barriers in service delivery, assess over capacity etc. and ensure service organisation issues are based on timely fact-based information as opposed to individual perception or the lobbying of various stakeholder groups.

- Key terms were not defined in detail, e.g. supra-regional service:

  The variations that exist in terms of how the 1996 National Cancer Strategy has been implemented are also a consequence of the lack of definition of terms and concepts. In particular, while there exists a general level of understanding of what is implied by regional self-sufficiency and supra-regional centres, these have not been sufficiently defined. Nor have the structures or processes been developed that specify how the different elements of the service will interact with each other resulting, for example, in inequities across patient access to tertiary services.

- Provision for public education for strategy buy-in was not given due priority:

  Communication of the strategy and the rationale behind the development of the regional and supra-regional centres of specialist cancer care was not incorporated as part of the first strategy. Communication planning is pivotal in generating acceptance for the next strategy particularly in light of:
  - The consultation process that has been gone through as part of this evaluation process and the expectations that it may have generated
  - Funding constraints
  - Increased public expectations since the 1996 strategy in terms of service quality
  - Public expectation in relation to the provision of local services and in particular the perceived requirement to have all services available locally without a clear understanding of the associated implications for service quality.

- Impossible to cost Strategy and therefore difficult to trace benefits to particular investment streams:

  The initial funding allocated to support the implementation of the 1996 strategy was significantly underestimated, with associated implications for funding budgets at both a Department of Health and Children level and a health board level. In many respects, the strategy was fortunate enough to have benefited from the additional funding allocations made available through the Department and facilitated by the economic boom. However, the next strategy will be implemented in a time of economic constraint with difficult choices to be made in terms of priority etc. In conclusion, a more detailed and accurate level of costs is required in the future.

- Paradox of women in Breastcheck Programme fast tracked potentially causing delay in treatment of women with symptomatic breast disease.

6.4 PRIORITIES & RECOMMENDATIONS

In many ways the Health Strategy, *"Quality & Fairness – A Health System for You"* and the Primary Care Strategy have established the framework and principles to guide the development of the new Cancer Strategy. In conjunction with this, the following section sets out our suggested recommendations and priorities based on the output of the evaluation process. Table 6.4 summarises key priorities for the future, classified under the frameworks for change of the National Health Strategy.

TABLE 6.4: KEY PRIORITIES FOR THE FUTURE CLASSIFIED ACCORDING TO THE FRAMEWORKS FOR CHANGE IN THE IRISH NATIONAL HEALTH STRATEGY 2002

ORGANISATIONAL REFORM	HEALTH INFORMATION
• Significantly improve the availability of radiotherapy services. • Define supra-regional centres. • Clearly define role for National Cancer Forum and Regional Directors of Cancer Services. • Continue the development of a multi-disciplinary team approach. • Co-ordinate health promotion across the system. • Establish effective linkages between the National Cancer Forum and the revised health structures, viz Health Services Executive, the National Hospitals Office and the Health Information and Quality Authority.	• Facilitate availability of information e.g. waiting times. • Establish the Health Information and Quality Authority. • Develop Performance measures/outcomes. • Improve investment in IT. • Develop a strategy for provision of patient information.
STRENGTHENING PRIMARY CARE	**REFORM OF ACUTE HOSPITAL SERVICES**
• Implement the Primary Care Strategy, specifically targeting: - early detection - screening - health promotion and awareness - patient support following discharge - counselling and emotional support - palliative care.	• Introduce the National Hospitals Office and define how the National Cancer Forum will interface with it. • Effectively integrate the symptomatic breast disease and BreastCheck programmes • Improve access to: - radiotherapy - screening programmes - clinical trials

TABLE 6.4: KEY PRIORITIES FOR THE FUTURE CLASSIFIED ACCORDING TO THE FRAMEWORKS FOR CHANGE IN THE IRISH NATIONAL HEALTH STRATEGY 2002 (CONTINUED)

FUNDING HEALTH	DEVELOPING HR
• Increase investment in: - human resources - radiotherapy - developing symptomatic services in tandem with screening services nationally. • Develop system for assessment of benefits of new treatments and drugs under the aegis of the Health Information and Quality Authority. • Optimise existing resources - equipment under utilisation. • Focus on prevention is key to successfully dealing with the issues of cancer in the long-term (new tobacco laws will have a significant positive impact in this area).	• Develop HR plan. • Resourcing: - direct investment at human resources that support the development of specialist cancer centres for the provision of multi-disciplinary care.

It is recognised that some of these fall within the direct remit of cancer services while others will be influenced by developments elsewhere in the health sector. More detailed considerations of these recommendations are structured within the following sections:

- Strategic Focus
- Policy
- Division of Responsibilities and Roles
- Organisations and Structures
- Service Quality and Management, and
- Funding.

Key issues in each section are classified according to the part of the health service that is accountable and responsible for the area relevant to the issue being discussed: Department of Health and Children; Acute Hospitals Service; Health Boards; the National Cancer Forum etc.

6.4.1 STRATEGIC FOCUS

Within the Health Strategy "Quality & Fairness – A Health System for You" it is stated that services should be delivered to meet the needs of the patient rather than the needs of the system. The evaluation of the National Cancer Strategy highlights the lack of provision that exists for patient input into the planning and evaluation of services. The general findings would indicate that the system has some way to go in terms of achieving its objective of delivering patient-centred care. A considerable number of stakeholders expressed the view that the forthcoming strategy needs to place a greater focus on patients' views and preferences. Indeed, the consultation process identified the differences in perceptions that can exist between patient and clinical professionals/health board management in terms of the quality of service being delivered and the importance attached to different elements of patient care.

We would agree with the above viewpoint but would also add that a balance needs to be struck in managing public expectations, particularly in terms of service capacity and the ability of the system to meet expectations and needs. As referenced previously, there is a widely held perception that quality equates to all services being made available locally. This was signalled in the consultation process when patients/families highlighted a preference for local radiotherapy provision across the majority of the health boards.

There is a requirement right across the health system for a public education/communication programme that addresses the issue of public expectations and local service provision with regard to first and foremost setting out how fragmented service delivery is not the most appropriate mechanism for the delivery of quality patient care and then secondly demonstrating that even if patients were prepared to pay for such services it does not provide value for money. The proposed reorganisation of the health system including the proposal to establish a Health Services Executive and a National Hospitals Office will provide a platform for greater public debate and education in this area. However, given the prevalence of cancer at a national level, the National Cancer Forum/Department of Health and Children should assess the merits of undertaking their own public educational campaign on the optimal organisation structures to support the national delivery of cancer services. The publication of the Report on the Development of Radiation Oncology Services will bring this issue to the fore once again.

6.4.2 POLICY

The effectiveness of Health Promotion initiatives are difficult to quantify but, by and large, the initiatives that have been implemented to date at a national level are generally regarded as being quite good with the exception of smoking, where historically policy was not considered strong enough. However, recent legislation will bring about stricter controls and indeed result in Ireland being a world leader in terms of anti-smoking legislation. A number of suggestions are proposed for promoting the cancer health agenda and bringing about improvements in efficiency:

- A greater degree of interaction between the Acute Hospitals Division and the Health Promotion Unit in the Department of Health & Children.
- The organisation of regular feedback and input into National Health Promotion campaigns by the National Cancer Forum, as applicable to cancer.
- The sharing of best-practice across the Health Boards facilitated through the quarterly meetings of the National Cancer Forum.
- The development of literature and programmes on a national basis, led by the Department of Health and Children and reproduced regionally to avoid duplication of effort and resources.

There have been significant policy developments since 1996 and in particular since 1999, in relation to cancer services. There needs to be a focus on reducing the level of variation in service provision that exists among different health boards and enhancing equity of access to services across the different geographic regions.

There is evidence of a lack of integration with respect to policies around breast screening, symptomatic breast disease and radiotherapy. This provides opportunities for less than optimal policies to be implemented at a regional level.

Research activity needs to be better integrated across the health sector, rather than individuals/organisations working in isolation. In this context, there may be a role for the Health Research Board to act as the co-ordinator of multi-centred research and minimise the level of duplication of effort that currently exist in the system (cancer and non-cancer research activity).

Most areas/organisations indicated a preference to participate in clinical trials/programmes. This, in our view, should be facilitated as it serves to raise the standards of care through continuous medical education programmes.

6.4.3 ORGANISATION AND STRUCTURES

The division of roles and responsibilities for the planning and management of cancer services needs to more clearly delineated between the Department of Health and Children, the National Cancer Forum, the Health Boards and the Regional Directors of Cancer Services. At it currently stands, there is a lack of clarity in terms of overall decision-making authority and accountability. The key issues to be addressed relate to:

- The focus of the activity of the National Cancer Forum and its role vis-à-vis the Department of Health and Children in relation to the strategic planning of cancer services. There is also a need to more clearly define and specify what the role and activities of the Forum should be in the context of the next strategy.

- The role of the National Cancer Forum as a decision-making authority.
- The nature of the relationship between the National Cancer Forum and the Regional Directors of Cancer Services.
- The nature of the relationship between the National Cancer Forum and whatever new structures emerge in the near future.
- The future role of the Regional Directors of Cancer Services – should the role continue as is or should it be extended to include greater decision-making authority?

The concept of supra-regional centres was identified as part of the 1996 National Cancer Strategy. However, as discussed in Section 5, varied progress has been made in terms of the development of services across each of the three centres in Dublin, Cork and Galway. This has given rise to a perception of inequities in terms of the geographic distribution of tertiary services as well as placing a disproportionate amount of activity through the Dublin hospitals.

The concept of supra-regional centres falls in line with international best practice and has demonstrated the following broad benefits:

- It enables the development of increased specialisation and expertise through critical mass, with adequate throughput and complexity of caseload.
- It supports and facilitates peer review and inter-disciplinary team interaction.
- It supports the on-going learning and education of professional staff thereby enhancing the overall ability and capacity to attract trained and skilled personnel.
- It supports cost-effectiveness and minimisation of duplication of effort.

It is recommended that in terms of the future development of cancer services in Ireland the concept of supra regional centres needs to be clearly defined and supported with robust implementation plans. People must understand that this is the most appropriate structure to be followed. In doing so, a number of areas need to be addressed, namely:

- The development of a shared vision as to the key elements that constitute a supra-regional service and more specifically how these will be applied to each of the centres over the course of the next strategy.
- Clarification as to whether a supra-regional centre is a multi-site service within a single region or whether it constitutes multi-services from within a single hospital. In the case of Dublin it is difficult to say where a supra-regional centre actually exists. Many hospitals regard themselves as the holder of the accolade and indeed many hospitals have developed or are in the process of developing expanded and enhanced cancer services for patients within their region. Those involved in service delivery have called on the National Cancer Forum to have a more dominant role in defining these issues and leading broader multi-disciplinary, co-operative strategies for the planning and the implementation of change. However, it must also be expected that the emerging new office for hospitals nationally would have a primary role in this regard.
- A detailed gap analysis of service provision needs to be completed.
- A definition of the resource requirements (human, physical, financial) to establish and maintain the appropriate levels of service in each centre and how and when such resources are likely to become available. The availability of funding will be a fundamental constraint on development plans and as such key decisions will need to be taken in prioritising resource allocation. Fundamental to this will be the development of an equitable transparent process for funding allocation across the supra-regional centres based on an appropriate needs assessment.
- Issues and challenges have been, and will continue to be, encountered in achieving support for these proposals, particularly among those who share the view that all services need to be located within close geographic proximity to the patient. Furthermore, clear leadership is required in championing the plans

agreed upon for the development of supra-regional centres in light of the barriers that are likely to be encountered. Communication and planning will be pivotal to this.

- A key question arises as to whether it is possible to have a standard definition of regional self-sufficiency given the geographic and demographic differences that exist between health board regions or whether it would be more appropriate to define this on a health board by health board basis? There are strong arguments to support a higher level of self-sufficiency given the distances to be travelled by patients to access some tertiary services. This gives rise to a number of further considerations:
  - Whether the definition of self-sufficiency needs to be determined in line with the timescale to develop and put in place the appropriate level and quality of services across each of the supra-regional centres?
  - In conjunction with the development of supra-regional and regional centres of specialist care, we also see a role for outreach satellite clinics that link into the centres of specialist cancer care through the development and implementation of appropriate structures, processes and systems. Such a system would involve specialists from the centres of specialist care providing clinical sessions in the outreach centres so as to minimise the amount of travel and inconvenience incurred by patients. Successful examples of this model of care already exist in some health boards.

In tandem with the above, the over-riding priority for the development of structures to support cancer services must, in the future, centre on cohesiveness and co-ordination. This implies a re-organisation of existing resources in order to maximise cost-efficiency and service effectiveness through:

- The discontinuation of single-handed medical oncology practices.
- An increased use in multi-disciplinary team working to include pathology, radiotherapy, pharmacy, etc.
- Greater co-operation between clinicians and health board management in planning future developments.
- Improved co-ordination and co-operation between primary care and the acute hospital system (see below).

In our opinion, this approach will also serve to enhance the overall level of skill in the system, support the development of robust clinical risk management practices, in addition to assisting in the recruitment and attraction of key staff.

The focus of delivery for cancer services has to date centred upon the acute hospital system. However, as per the recommendations of the National Health Strategy and also in terms of international best practice, there is a growing recognition and emphasis on primary and community care. In this context, it is recommended that the role of primary and community care in the delivery of cancer services is given priority attention in the next cancer strategy so that efforts are made towards the development of an integrated seamless service spanning both primary care services and the acute services. As part of this:

- The role of primary care, including GPs, needs greater clarity and support, particularly in the areas of:
  - Health promotion and cancer awareness
  - Early detection and screening
  - Palliative care
  - Patient support following discharge from the acute services.
- Initiatives are required to improve the level of communication with GPs from the acute sector in terms of the comprehensiveness and timeliness of the information provided throughout the treatment process. The National Cancer Forum may have a role in this regard in terms of identifying and encouraging the widespread adoption of best practices together with the development of communication guidelines, with professional input.
- The forthcoming cancer strategy must dovetail into the roll-out of the National Primary Care Strategy.

6.4.4 SERVICE QUALITY AND MANAGEMENT

An evidence-based approach should underpin the approach to the planning, organisation and delivery of cancer services in the future.

- Disparate efforts have been made across the system to evaluate programme treatments and outcomes and to implement quality guidelines and protocols. Many health boards are implementing nationally developed guidelines but the systems and processes to validate their implementation are quite simply not in place. Mechanisms for risk management, clinical audit and quality assurance are required. Even centres with risk management initiatives will admit that they are only in the early phase of development.

  A consensus exists on the need to develop national clinical protocols, similar to the Royal College of Surgeons in Ireland guidelines for breast, colo-rectal and prostate cancer, for other cancer types. The professional bodies, perhaps as a sub-group to the National Cancer Forum, could take on such a role with any developments in this area taking into account the guidelines of the National Clinical Indemnity Scheme. However, to be most effective, it is recognised that a national system of clinical audit is required.

- In conjunction with the above, new processes are required to establish mechanisms to control the costs of super-expensive treatments and evaluate the cost-effectiveness of different newer treatment and patient management options.

The Health Information and Quality Authority proposed in the National Health Strategy 2001 should provide such a forum whereby clinical leaders could work together to develop guidelines and protocols, evaluate new treatments and assess new technologies in a planned and open process.

National guidelines are required for the appropriate levels of surgical activity across the different cancers and sub-specialities from the professional bodies in conjunction with the National Cancer Forum. In turn, clear lines of responsibility for implementation need to be defined in addition to the allocation of accountability for non-adherence to the guidelines/protocols agreed upon.

The auditing of waiting lists, waiting times, times for investigations, test results, etc is largely absent across cancer services. Right across the system, a common approach is needed to record and analyse this information with the role of data collection and analysis likely to rest with data managers or equivalent.

- Patient access to reliable and timely information is a key component of a quality cancer service. While efforts are made by staff in the system to inform patients about treatment options, etc there is no uniformity in relation to the information given (largely depends on the individual consultant, the availability of a liaison nurse, etc) in the absence of any centrally produced information packs. It is recommended that a role be developed to produce and co-ordinate information on treatment options, side-effects, disease progress, etc and also to direct patients and primary care staff to reliable sources of information on the internet and elsewhere.

The communication skills of medical consultants have improved but further opportunities to enhance these skills should be fully explored through available mechanisms at undergraduate, graduate and consultant level and as part of the continuous medical education processes. Examples of excellence do exist, for example, in the case of the Royal College of Surgeons in Ireland as previously mentioned. However, these need to be rolled out on a more wide-spread basis.

The development of BreastCheck has occurred independently of the programme for the development of services to treat symptomatic breast disease. While the examination of the symptomatic breast disease programme is outside the scope of this study we must point out that its development needs to be co-ordinated with the National Cancer Strategy and the Report of the Expert Review Group on the Development of Radiation Oncology Services in Ireland.

Improved access to services (particularly Out-Patient Clinics and Diagnostic Services) and improvements in overall efficiency can be achieved through the extension of the working day. Options and initiatives to bring about such change need to be further investigated.

6.4.5 FUNDING

Securing funding for the new Cancer Strategy will be a key challenge in itself. However, it is recommended that the funding secured be focused on key priorities and in consolidating, where possible, progress that has been made to date under the 1996 National Cancer Strategy.

6.5 CONCLUSIONS

The key benefit, most commonly attributed by the stakeholders consulted, of the 1996 National Cancer Strategy was that it provided a framework for the development and funding of cancer services in Ireland. It has also been indicated through the consultation process with health boards and other professionals that cancer services have in many parts of the country developed from a low base in 1996 to a level of local self-sufficiency and tertiary service provision, although as we have discussed, progress has been variable.

Also, since 1996, the policy context for cancer services has improved considerably at a general and service specific level. As highlighted by Section 2, an array of policies have been prepared which impact on cancer services in either a direct or indirect manner. Policy development and the evaluation of that policy have also served to focus attention on service gaps and priorities.

At the same time, new structures emerged to support the development of cancer services at a regional level through the appointment of the Regional Directors of Cancer Services and the introduction of the role of the Cancer Nurse Co-ordinator in the Eastern Regional Health Authority. Research and education across cancer services have also been improved.

While there is and always will be a level of complaint about a perceived level of under-funding in the system to implement the vision and objectives of the 1996 National Cancer Strategy, it must be recognised that cancer services have received an additional €400m over the lifetime of this strategy. It must also be accepted that economic constraint is likely to continue into the lifetime of the next strategy. Fundamentally, delivery of a new phase of a National Cancer Strategy and its ultimate implementation relies on an ability to reconfigure present structures, enhance system co-ordination and interaction and redefine accepted working practices and service management.

In summary the strategy has delivered:

- A major reduction in cancer mortalities (per 100,000 of population) ahead of target.
- An ever increasing spend on cancer services.
- Increasing activity in chemotherapy, radiotherapy and surgery.
- A considerable improvement in cancer care through a more co-ordinated and structured approach to its delivery.

Clearly substantial investment has been made in cancer treatment services and the system is considerably better today. That said, it cannot be denied that ongoing developments are required, which will impact on services to further improve and enhance patient care with better treatment and facilities in the future. Much remains to be done. There are still a large number of barriers which need to be overcome.

1

APPENDIX 1

LIST OF ORGANISATIONS AND INDIVIDUALS CONSULTED

List of Individuals / Organisations Consulted

NATIONAL CANCER FORUM
Prof. Paul Redmond (Chairman)
Dr Fin Breathnach, Paediatric Oncology
Prof. Des Carney, Irish Cancer Society
Ms Margaret Codd, Head and Neck Cancer Nurse Co-ordinator
Mr Gerry Coffey, Principal Officer, Department of Health and Children
Dr Harry Comber, National Cancer Registry
Ms Barbara Cosgrave, ARC Cancer Support Centre
Dr Michael Coughlan, Irish College of General Practitioners
Dr Pat Doorley, Directors of Public Health
Prof. James Fennelly, Chair of the First National Cancer Forum
Prof. Donal Hollywood, Faculty of Radiologists, Royal College of Surgeons
Dr Tony Holohan, Deputy Chief Medical Officer, Department of Health and Children
Dr Maccon Keane, Irish Society for Medical Oncology
Ms Joan Kelly, Irish Asscoiation for Nurses in Oncology
Prof. W.O. Kirwan, Irish Society of Surgical Oncology
Ms Emily Logan, Directors of Nursing
Mr Michael Lyons, Chief Executive Officers
Prof. Shaun McCann, Irish Haematology Society
Dr Regina McQuillan, Irish Association for Palliative Care
Ms Marie Moore, Reach to Recovery
Dr Michael Moriarty, Royal College of Physicians
Dr Conor O'Keane, Faculty of Pathology
Dr Risteárd Ó Laoide, Faculty of Radiologists, Royal College of Surgeons

HEALTH BOARD CEOS
Mr Jim Breslin, Director of Service Planning, on behalf of Mr Donal O'Shea – Eastern Regional Health Authority
Mr Michael Lyons – East Coast Area Health Board (now ERHA)
Mr Pat Gaughan – Midland Health Board
Mr Stiofán de Burca – Mid-Western Health Board
Mr Jeoff Day, Assistant CEO Regional Services, on behalf of Mr Paul Robinson – North Eastern Health Board
Mr Pat Harvey – North Western Health Board
Mr Peter Finnegan, Regional Manager, on behalf of Mr Pat McLoughlin – South Eastern Health Board
Ms Wendy Keena, Development Manager, Cancer & Cardiovascular Services, on behalf of Mr Seán Hurley – Southern Health Board

REGIONAL DIRECTORS OF CANCER SERVICES
Prof. Des Carney – Northern Area Health Board
Mr John Hyland – East Coast Area Health Board
Prof. John Reynolds – South Western Area Health Board
Prof. Donal Hollywood – Midland Health Board
Dr Rajnish K. Gupta – Mid-Western Health Board
Dr James Hayes – North Eastern Health Board
Mr Kevin Moran – North Western Health Board
Mr Gordon Watson – South Eastern Health Board (Telephone Interview)
Prof. Paul Redmond – Southern Health Board
Mr Oliver McAnena – Western Health Board

DIRECTORS OF PUBLIC HEALTH

Dr Orlaith O'Reilly - South Eastern Health Board
Dr Patrick Doorley - Midland Health Board
Dr Rosaleen Corcoran - North Eastern Health Board
Dr Kevin Kelleher - Mid-Western Health Board
Dr Maura O'Shea, Specialist in Public Health Medicine - Western Health Board, on behalf of Dr. Declan McKeown, Director of Public Health
Dr Elizabeth Keane - Southern Health Board (Telephone Interview)
Dr Sean Denyer - North Western Health Board (Telephone Interview)
Representative from Eastern Regional Health Authority

DEPARTMENT OF HEALTH AND CHILDREN

Dr Jim Kiely – Chief Medical Officer
Dr Tony Holohan – Deputy Chief Medical Officer
Mr Ger Gavin - Chief Dental Officer
Ms Mary McCarthy – Chief Nursing Officer
Mr Fergal Lynch - National Task Force on Medical Staffing
Mr Claude Grealy - Casemix
Mr Jimmy Duggan - Services for the Elderly (Palliative Care)
Mr David Wolfe - Services for the Elderly (Palliative Care)
Mr Brian Mullen – Community Health (Cervical Screening Programme)
Ms Emer Brady – Community Health (Cervical Screening Programme)
Mr Brian Brogan – Health Promotion Unit
Ms Julie Ling - Nursing Advisor
Mr Fergal Goodman - Primary Care
Mr Eamonn Corcoran – Environmental Health Unit
Mr Gearoid O'Dufaigh – Environmental Health Unit
Mr Kevin Devine – Environmental Health Unit
Mr Joe Cregan – Acute Hospitals Division
Mr Gerry Coffey – Acute Hospitals Division
Ms Tracey Conroy – Acute Hospitals Division
Ms Frances Walsh – Acute Hospitals Division
Mr Hugh Magee – Information Management Unit
Ms Ciara O'Shea – Information Management Unit

OTHERS

Dr Ruth Barrington - Chief Executive Officer, Health Research Board
Mr Tony O'Brien, Director, BreastCheck
Prof. Joe Ennis, Chief Medical Advisor, BreastCheck and Professor of Radiology, UCD
Mr Paul Maguire, Hospital Administrator, North Western Health Board
Mr Tony Cunnivan, General Manager, Mayo General Hospital
Ms Bridget Howley, General Manager, Galway Regional Hospitals
Ms Janet Malone, Senior Administrative Officer, North Eastern Health Board
Mr John Bulfin, Midland Health Board
Ms Eileen O'Donovan, Service Planner, Eastern Regional Health Authority
Ms Louise McMahon, Senior Commissioner, Eastern Regional Health Authority
Mr John McCormack, Chief Executive Officer, Irish Cancer Society
Representative from Portiuncula Hospital, Ballinasloe

PROJECT STEERING GROUP

Prof. Paul Redmond – Chairman, National Cancer Forum
Prof. James Fennelly – National Cancer Forum, Chair of the First National Cancer Forum
Dr Pat Doorley – National Cancer Forum
Dr Tony Holohan – Department of Health and Children and National Cancer Forum
Mr Gerry Coffey – Department of Health and Children and National Cancer Forum
Ms Tracey Conroy – Department of Health and Children
Ms Frances Walsh – Department of Health and Children

2

APPENDIX 2

CONSULTATION TEMPLATE

Stakeholder Questions

OBJECTIVE: PREVENTION & AWARENESS

- What health promotion/preventative measures have been implemented as a result of the 1996 National Cancer Strategy?
  - Qualitative and quantitative information on initiatives/campaigns focusing on cancer risk factors such as smoking, alcohol, nutrition, lifestyle, etc. e.g., production of health education materials, smoking clinics, nutrition programmes, sun exposure information, etc.
  - What initiatives have been undertaken aimed at promoting cancer awareness, for example, breast cancer in women, prostate cancer in men?
- What personnel have been appointed with specific health promotion/prevention responsibilities?
- To what extent are health promotion activities co-ordinated/integrated across different areas and health board regions?
- What progress has been made in relation to the collection of data and the management of information systems on the prevalence of risk factors, e.g. incidence of smoking, alcohol consumption, etc.
- What is the level of investment that has been put into the area of health promotion and awareness?
- Do you think that public policy interventions (e.g. advertising bans, interventions arising from recommendations made by the National Alcohol Task Force) in the areas of alcohol, smoking and nutrition have impacted on cancer awareness and prevention? What have been the most critical interventions?

OBJECTIVE: INFORMATION

- Are patients and their families systematically provided with information regarding their condition and treatment and potential side effects of treatment? Is information clear and easy to understand?
- Have patients/families the opportunity to ask questions at all times?
- Are patients and their families involved in treatment decisions and consultations?
- Are patients and their families informed of the various treatment options available and the benefits and risks associated with each?
- Communication between staff and patients
  - Where would you consider the key points of poor communication to patients to be in the system?
  - Do you see a requirement for communication training to be further addressed as part of graduate and continuous professional education programmes?
- Is the average time between when patients undergo tests and when they actually receive the test results monitored? Are there procedures in place to ensure that this time is minimised for patients?
- Is this information tracked?
  - To what extent has the practice of implementing pre-booked appointments to discuss test results been implemented?
  - Have any initiatives being introduced to reduce patient anxiety during this waiting period?

OBJECTIVE: EARLY DETECTION & SCREENING

- What screening programmes (e.g. BreastCheck, Cervical Screening) have been implemented since 1996? Are they accessible? How does the actual number of programmes compare with the number of programmes that were planned?
- How are the screening programmes regionally distributed?
- Are statistics available on the numbers attending at such screening programmes? How have these statistics changed over time?
- Are statistics available on the incidence of cancer discovered in screening programmes?
- What efforts have been made to highlight awareness and encourage attendance at these screening programmes? Are people aware of the benefits of screening?
- Are written results of screening tests provided to patients?
- Are there statistics available on the incidence and mortality and morbidity rates for cancers targeted by screening, e.g. breast cancer, cervical cancer?

- How many personnel are involved in the area of early detection and screening? How many of these staff have been appointed since 1996?
- What is the level of investment that has been put into the area of early detection and screening?
- What are the key issues associated with the referral of patients from GPs to Specialists/Outpatient clinics?
  - Inappropriate referrals
  - Waiting times
  - Personal relationships between GPs and Specialists
  - Poor communication procedures between GPs and hospitals for example in setting and confirming appointments
  - Public versus private patients
- Have referral guidelines for GPs been developed and to what extent have they been implemented?
  - If guidelines have been developed, are they easy to follow in terms of layout, design, etc?
  - Are guidelines updated on a regular basis in line with new research?
  - Is there a requirement for further training/on-going training to be organised for GPs in this area?
- What role have practice and district nurses played in the early detection and recognition of cancers? What role should they play in the future and what steps need to be taken to facilitate this?

OBJECTIVE: ACCESS

- Are there access statistics available for the different types of treatment, e.g:
  - Waiting times between GP and hospital appointment
  - Waiting times for tests
  - Waiting times for surgery
  - Waiting times for radiotherapy
  - Waiting times for chemotherapy
- What are the key factors impacting on waiting times, e.g. capacity?
- Is there an organised system of patient referral between Health Boards? Are there procedures in place to ensure equity of patient access to service irrespective of geographical location?
- Is an appropriate level of services provided in the community to allow people to spend time at home rather than in a hospital or hospice?
- Are there any issues regarding patient access to hospices and specialist palliative care services?
- What proportion of patients would have to travel significant distances in order to receive treatment?
- Is there access to patient services outside of normal working hours?

OBJECTIVE: TREATMENT

- What proportion of patients are seen by (a) a medical oncologist, (b) a radiation oncologist and (c) a surgical oncologist? Are there Health Board regional variations?
- Are there Health Board regional differences in the types of treatments used for the same cancer types?
- What is the morbidity and mortality rates for different types of treatments and cancers?
- Is there one clinician with overall and continuing responsibility for every individual patient?
- What new equipment has been installed since 1996 (e.g. CT and MRI scanners)? What has the level of investment been? What has been the impact of this new equipment?
- Is the cancer treatment equipment of appropriate quality and modernisation?
- What is the average ratio of hospital patients to CT or MRI scanners across the different regional centres?
- What steps/quality assurance measures are taken to ensure that the treatment delivered represents best practice? Are there systems in place to monitor and evaluate the effectiveness of cancer treatment services? Are the best treatments being used? What are the barriers to implementing a system of clinical audit across cancer services?
- Do you think that the right professional support and care is provided to patients? Would it be described as best practice? Where are the gaps?
- To what extent is continuous professional support available to patients and their families during cancer treatment?

- Is sufficient attention paid to the provision of emotional support and the alleviation of patients' fears?
- Are adequate home care services provided to patients following discharge from in-patient care (e.g. is sufficient consideration given to individual home circumstances)? What has been the level of investment in this area?
- Comment on the provision of hospices and specialist palliative care services. What has been the increase in resourcing and investment in these services since 1996?
- Are patients provided with sufficient support on the management of their recovery following discharge (e.g. written information on medication, activities to do/not to do, etc.)?
- What are the key changes in the structure of cancer treatment services since 1996 – primary care, regional services, supra-regional services and the National Cancer Forum? How effective have the new structures been? What partnership arrangements have been implemented (e.g. within the health sector, between public and private sector, with the voluntary sector)? What is your view on the role of the voluntary sector?
- Questions on Symptomatic Breast Disease Services.

OBJECTIVE: QUALITY

- What are the types of data collection systems and information systems on cancer types and treatments that are maintained? Should national databases be maintained or should national reference centres exist? How do these feed into the development of alternative treatments and the decision to use alternative treatments?
- Are risk management processes a feature of cancer treatment services? What are they?
- What efforts are made to ensure that the quality of life for patients is maximised, e.g. 24 hour access to care, etc?
- What initiatives have been developed to reduce the number of hospital visits for patients?
- What is the proportion of patients who die at home?
- Are there regional variations in the quality of treatments/community services provided?
- Comment on the existence and effectiveness of audit and quality assurance measures in the system.
- To what extent are patients involved in the planning and monitoring of services? Is this an area that needs to be looked at in the future?

OBJECTIVE: CO-ORDINATION

- Are there close links between general practitioners and the cancer treatment services?
- Is there timely communication on the status and progress of patients throughout the system?
- Should the role of primary care teams be strengthened?
- What achievements have been made to improve co-ordination across primary care, hospital care, rehabilitation and palliative care? What are the practical strategies/initiatives that have been undertaken?
- Comment on the quality of co-ordination between the primary care services, regional services, supra-regional services and the National Cancer Forum. Where can improvements be made?
- Are integrated care plans/care pathways with the GP a feature of the acute care cancer treatment services? Are there special features around acute care that focus on primary care?

OBJECTIVE: COST-EFFECTIVENESS

- Are cancer treatment services delivered on the basis of evidence based best practice guidelines?
- What aspects may be considered not to be cost-effective?
- Is the best use being made of available resources? Where is the waste in the system?
- What improvements in the area of cost-effectiveness have been made since 1996?
- Equipment (e.g. CT and MRI scans)
  - Is optimal use made of equipment/machinery?
  - Can it be quantified to what extent machines/equipment are only used between 9 and 5 on weekdays across different regional centres and to what extent extended working hours have been introduced?

  - Are there quantifiable differences between the various hospitals in the use of equipment? Is this information captured and how?
  - What factors impact on the use of equipment e.g. the availability of staff, age of equipment, poor booking systems, etc?
- Have appropriate links been developed between the different strategies pertaining to cancer strategies, e.g. the National Cancer Strategy and the Report of the National Advisory Committee on Palliative Care?

OBJECTIVE: RESEARCH AND EDUCATION

- Is there on-going professional development for the full team of staff involved in cancer treatment services, e.g. cancer treatment specialists, nurses, administrative staff, etc.? Do they have access to up-to-date information on the investigation, treatment and care of patients with cancer?
- Are statistics available on the number of training programmes?
- What research areas have been advanced since 1996? Has actual research matched planned research?
- Identify the key areas where research would yield the most benefits.
- What are the priorities for research? Is current research sufficiently focused?
- To what extent has an evidence based approach to the planning and delivery of services been implemented across the board?
- What role can a country like Ireland play in terms of research and the development of clinical trials – scale, level of funding, etc.
- To what extent is research activity co-ordinated across the various stakeholders? Are there any particular issues that need to be addressed?

OVERVIEW: NATIONAL CANCER STRATEGY

- What do you think are the key achievements of the National Cancer Strategy? Are there statistics available to support these? What improvements can be directly attributed to the National Cancer Strategy?
- Comment on the extent to which practical policies have been implemented on the ground. To what extent has a patient centred approach been adopted?
- Where are the main gaps?
- What do you think should be the direction/focus of future policy? What are the main barriers to changes in future policy?
- Where could additional resources be best channelled?
- What are the key elements of the New National Health Strategy, “Quality and Fairness, A Health System For You” that need to be incorporated into the new Cancer Strategy?

3

APPENDIX 3
CONSULTATION TEMPLATE – CHIEF EXECUTIVE OFFICERS

CEO Questionnaire

- What do you believe have been the key achievements of the National Cancer Strategy 1996?
  - What, if any, have been the key failings of the strategy?
  - Are there lessons to be learnt from other international health care systems?
  - What areas require further prioritisation/resourcing?
  - What policy gaps exist?

- From a regional perspective, what have been the key issues in term of implementing the Strategy?
  - How are these likely to evolve going forward?
  - What actions are required to address these issues at both a regional and/or national level?

- How would you rate the overall level of service provided to cancer patients in your region?
  - What are the key initiatives that you have implemented?
  - What steps have been taken to reduce the amount of time that patients spend in acute hospital care?
  - Where are the key areas where improvements are required?
  - Have you completed any patient satisfaction surveys within your Board that would include cancer patients?
  - How will the development of a national hospital information system assist in the planning and development of services to hospital patients?

- What are your views on the development of Regional/Supra-Regional centres of excellence?
  - To what extent has this concept been developed within your board area and what issues and challenges were encountered and remain?
  - To what extent is the concept being applied nationally?

- What impact has the appointment of the Regional Director of Cancer Services had on service delivery and service quality?
  - To what extent has the relationship between the Regional Directors and the National Cancer Forum developed?

- What impact has the appointment of the Cancer Nurse Co-ordinators had on service delivery and service quality (as far as I am aware this only applies to the ERHA region)?

- What progress has been made within your board area in developing and implementing multi-disciplinary primary care teams?
  - To what degree, if any, will the implementation of these teams support the provision of cancer services in the community?

- What are your views on the regional variation in services between Health Boards?
  - What factors have contributed to these differences?
  - Where are the variations most pronounced?
  - What initiatives can be implemented to provide a more consistent approach to service delivery?

- To what degree has the implementation of the National Cancer Strategy been linked with other key strategies such as the National Cardiovascular Strategy, the National Health Promotion Strategy, etc in terms of resourcing, activities, etc?

- In your view to what extent does a structured system of patient referrals exist between Health Boards?
  - What are the issues that exist and what steps can be taken to resolve these?

- What do you think should be the direction / focus of the new Cancer Strategy?
  - Are there initiatives / approaches that have been implemented internationally that could be considered for Ireland?

4

APPENDIX 4

SYMPTOMATIC BREAST DISEASE SERVICES – QUESTIONNAIRE AND FINDINGS

QUESTIONNAIRE ON SYMPTOMATIC BREAST DISEASE SERVICES

1. **Staffing**

- What staffing is in place? (Surgeons, Radiologists (trained and with continuing interest in breast disease), Pathologists, Occupational Therapists, Physiotherapists, Nurses)
- Is there a designated medical oncologist and radiotherapist within the breast care team?
- How many breast diagnostic radiographers with the necessary training and expertise are available in mammography?
- Does the unit have access to a clinical psychologist or a psychiatrist?
- Does the unit have access to a plastic surgeon?
- Is there a designated social worker for the breast unit?
- Does the unit have links with a clinical geneticist?
- Does the unit have a data manager?

2. **Technology**

- What technology is available to the breast unit in relation to Mammography?
  a. ultrasound
  b. Sentinel lymph node mapping
  c. Scinti-mammography
  d. Stereotactic facilities
  e. Needle localisation facilities.

3. **Facilities**

- Does the breast unit provide designated breast clinics i.e. independent clinics that are not run in conjunction with the general surgery clinics?
- Is the clinic staffed by a breast team i.e. surgeon, breast care nurse, pathologist and radiologist?
- Does the breast clinic have the necessary accommodation including reception area, waiting room, close proximity to the x-ray department and nurse counselling area?
- Does the breast unit have designated in-patient beds and designated operating time?

4. **Organisation**

- Does the breast unit have a dedicated multi-disciplinary meeting for breast patients?
- Do the breast clinics provide a range of clinics including new patient clinics, result clinics, follow-up clinics, family history clinics?
- Are there procedures in place to ensure adequate and clear communication between all those involved in patient care?
- Does the breast unit have agreed guidelines and protocols in place?
- Do clinical trials take place within the unit?

5. **Standards and Audit**

- Can the unit provide results of its audit on at least an annual basis in the following areas:
  a. Data on the number of patients treated and the type of treatment received.
  b. Long term outcome measures including data on local and regional recurrence.
  c. Long term morbidity of primary treatment such as lymphadoema control, local recurrence, distant metastases and death.

RESPONSE TO QUESTIONNAIRE ON SYMPTOMATIC BREAST DISEASE SERVICES

1. Staffing

	HEALTH BOARD									
	ECAHB	**SWAHB**	**NAHB**	**MHB**	**MWHB**	**NEHB**	**NWHB**	**SEHB**	**SHB**	**WHB**
1. Staffing in place:										
Surgeons	3 (not f/t)	Yes		Full team not in place	4	1		4	1	Yes
Radiologists	2 (not f/t)	Yes			1 (p/t)	2(vacant)	2	2	1 (due)	Access
Pathologists	3 (not f/t)	Yes			1 (p/t)		2	1	Interview	Access
Occupational Therapists	Access	Yes					0	No	1	No
Physiotherapists	Access	Yes					Access	1	1	Access
Cancer Nurse Co-ordinator	1									
Breast Care Nurses		Yes			5	1		5	2	
2. Dedicated medical oncologist?	2	Yes		Yes	1	No	Yes	No	Yes	
Dedicated radiotherapist?	1	2			No	No	No	No	Yes	
3. Number of breast diagnostic radiographers with necessary training.	2	2			2	None	4	2	3	
4. Access to clinical psychologist?	No	Yes		No	Yes	No	No	No	Yes	
Access to psychiatrist?	Yes	Yes		No	Yes	No	Yes	Yes	No	Yes
5. Access to a plastic surgeon?	Yes	Yes	Yes	No	Yes (limited)	No	No	No	Yes	Access
6. Designated social worker?	Yes	No		No	Access	No	No	No	Yes (share)	No
7. Links with a clinical geneticist?	Yes	Yes	Yes	Nothing formal	No	Yes	No	No	Yes	No
8. Data Manager?	No	Yes	Yes	No	Yes	No	No	Yes	No	No

2. Technology

	HEALTH BOARD									
	ECAHB	SWAHB	NAHB	MHB	MWHB	NEHB	NWHB	SEHB	SHB	WHB
TECHNOLOGY AVAILABLE IN RELATION TO MAMMOGRAPHY?										
a. Ultrasound	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes
b. Sentinel lymph node mapping	Yes	Yes	Yes		Yes	Yes	Yes	Yes	Yes	Yes
c. Scinti-mammography	Yes	Yes		No	No	No		Yes	Yes	Yes
d. Stereotactic facilities	Yes	Yes	Yes		Yes	Yes	No	Yes	Yes	Yes
e. Needle localisation facilities	Yes	Yes	Yes	No	Yes	Yes		Yes	Yes	Yes

3. Facilities

	HEALTH BOARD									
	ECAHB	SWAHB	NAHB	MHB	MWHB	NEHB	NWHB	SEHB	SHB	WHB
1. Designated breast clinics that are not run in conjunction with general surgery clinics?	One all day clinic per week	Yes		Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Staffed by a breast team, i.e.	Yes – team in place	Yes – team in place					Fully staffed			No
• surgeon			Yes	Yes	Yes	Yes		Yes	Yes	
• breast care nurse			Yes	Yes	Yes	Yes		Yes	Yes	
• pathologist			Yes	No		Not yet		Yes	No	
• radiologist			Yes	No	Yes	Not yet		Yes	Yes	
3. Necessary accommodation?										
• reception area	Yes	No – accommodation is unsatisfactory		Unsatisfactory accommodation	Yes	Yes	Yes	No	Yes	
• waiting room	Yes				Yes	Yes	Yes	No	Yes	
• proximity to x-ray department	Across the road					No	Yes	No	Yes	
• nurse counselling area	Yes (on-site)					No	Yes	No	Yes	
4. Designated in-patient beds?	No	No but not creating a problem	No	No	Yes	Not yet		No	No	No
Designated operating time?	2/3 sessions per week		No	No	Yes			No	No	No

4. Organisation

	HEALTH BOARD									
	ECAHB	**SWAHB**	**NAHB**	**MHB**	**MWHB**	**NEHB**	**NWHB**	**SEHB**	**SHB**	**WHB**
1. Dedicated multi-disciplinary meeting for breast patients?	Weekly Meetings	Yes		In development	Yes	Yes		Yes	Weekly meetings	Yes
2. Range of clinics provided?										
• New patient clinics	Yes	Yes	Yes		Yes	No			3 Breast clinics covering all these areas	Yes
• Result clinics	Yes	Yes	Yes		Yes	No				Yes
• Follow-up clinics	Yes	No	Yes		Yes	No		Yes		Yes
• Family history clinics	Yes	Yes	Yes		No	No				No
3. Procedures in place to ensure adequate and clear communication between all those involved in patient care?	Yes	Yes	Yes		Yes	Yes		In development	Yes	Some in place
4. Agreed guidelines and protocols in place?	Yes	Yes	Some	No	Yes	Yes	Yes		Yes	Developing
5. Do clinical trials take place within the unit?	Yes	Yes	Yes	No	No	Yes	No		Yes	Yes

5. Standards and Audit

	HEALTH BOARD									
	ECAHB	SWAHB	NAHB	MHB	MWHB	NEHB	NWHB	SEHB	SHB	WHB
Ability to provide result of audit on an annual basis in the following areas:	On-going data collection relating to patient treated and type of treatment received		Some data exists – shortage of personnel to collect it							
a. Number of patients treated?		Yes		Yes	Yes	Not yet	Yes	Yes	Yes	Yes
b. Treatment received		Yes		No	Yes	Not yet	Yes	Yes	Yes	Yes
c. Long term outcome measures including data on local and regional recurrence		Yes		No	No	Not yet	No	No	Yes	No
d. Long term morbidity of primary treatment such as lymphadoema control local recurrence, distant metastases and death		Yes		No	No	Not yet	No	No	Yes	No

5

APPENDIX 5

CONSULTATION PACK FOR SUBMISSIONS

HAVE YOU SOMETHING TO SAY ABOUT CANCER SERVICES IN IRELAND?

The National Cancer Forum, at the request of the Minister for Health & Children Micheál Martin, T.D. is developing a new National Cancer Strategy. The purpose of this strategy is to plan for the development of cancer services over the next seven years.

We want to hear from members of the public, from organisations involved directly with health services, and from any individual group or organisation with a view about how cancer services have been developed over the past number of years. We would also welcome your views on how we can best promote and develop cancer services, including prevention strategies in the future.

You have a real opportunity to help shape the future and decide priorities.

If you wish to make a contribution, please send your name and address to the following:

Frances Walsh
National Cancer Forum
Department of Health & Children
Hawkins House
Hawkins Street
FREEPOST
Dublin 2
(No postage stamp is needed)

Or Locall: 1890-635302
Or e-mail to: **frances_walsh@health.irlgov.ie**

You will be sent a consultation pack and some relevant documentation that you are invited to read before you forward your submission.

Submissions must be received not later than **Friday 22 November 2002.**

(Please note that submissions may be released under the Freedom of Information Act 1997)

The National Cancer Forum, the advisory body on cancer services to the Minister for Health & Children Micheál Martin, T.D. is developing a new National Cancer Strategy 2003.

DEPARTMENT
OF HEALTH
AND CHILDREN
AN ROINN
SLÁINTE
AGUS LEANAÍ

The National Cancer Strategy 2003 will set out a programme of investment and reform to tackle both current and future problems and ensure the delivery of high quality cancer services. The new Cancer Strategy will build on our first National Cancer Strategy which was published in 1996 and be based on the principles and goals set out in the National Health Strategy 'Quality and Fairness – A Health System for You'.

Your views will form an integral part of the preparation of the new National Cancer Strategy.

We would like you to tell us how you think cancer services have been developed over the past number of years and how you think these cancer services can best be developed in the future, so as to ensure best treatment for cancer patients.

Please use the consultation form included to give us your views. You are not required to answer every question – just those that are important to you. In the consultation form, we ask for some personal information. The purpose is to check if we are getting a good spread of views from different parts of the country and different age groups. While this information will be helpful, you are not obliged to give it.

What issues will the new Cancer Strategy address?

In considering your response, you may wish to bear in mind that the new Cancer Strategy will address a broad range of issues, including prevention, screening and early detection, treatment (including surgery, radiotherapy, chemotherapy, hormonal treatment, psychological support and counselling) and palliative care. The Strategy will also focus on care provision not only in hospitals but also in the community, people's homes and other health care settings.

CONSULTATION FORM

YOUR VIEWS ABOUT CANCER SERVICES

TELL US WHAT YOU THINK IS IMPORTANT

1. Is this submission from:

(a) An individual ☐
(b) A family ☐
(c) A health service worker ☐
(d) An organisation directly connected with health/health services ☐

Name of organisation:

____

(e) An organisation not directly connected with health services ☐

Name of organisation:

____

Individual submissions (It would be very useful if you could give us some information about yourself)

2. Gender (Please tick box)

Male ☐
Female ☐

3. Age (Please tick box)

18 and Under	☐	45 – 54	☐
19 – 24	☐	55 – 64	☐
25 – 34	☐	65 – 74	☐
35 – 44	☐	75 and Over	☐

4. Where you live (Please tick box)

Urban Area ☐
Rural Area ☐

The County you live in:

____

5. Have you or your family used cancer services in recent years?

Yes ☐ No ☐

If yes, what was the year?

6. Please rate your satisfaction with cancer services by putting an X along this line of satisfaction indicating your level of satisfaction on a scale from zero to ten

Example

					✗					
0	1	2	3	4	5	6	7	8	9	10

Very dissatisfied Very satisfied

e.g. this person rates their satisfaction as five on a scale from zero to ten

0	1	2	3	4	5	6	7	8	9	10

Very dissatisfied Very satisfied

7. What do you regard as the 3 most important strengths of cancer services?

Strength 1:

Strength 2:

Strength 3:

8. What do you regard as the 3 greatest weaknesses of cancer services?

Weakness 1:

Weakness 2:

Weakness 3:

9. List your 3 key priorities for the development of cancer services in the future.

Priority 1:

Priority 2:

Priority 3:

If you would like us to send you an acknowledgement of your submission you may wish to give us your name and address:

Name:

Address:

6

APPENDIX 6
PATIENT SURVEY

SURVEY TEMPLATE

Your views about Cancer Services

The National Cancer Forum, the advisory body on cancer services to the Minister for Health and Children, is developing a new National Cancer Strategy 2003. The National Cancer Strategy 2003 will set out a programme of investment and reform to tackle both current and future problems and ensure the delivery of high quality cancer services. The Strategy will build on the first National Cancer Strategy which was published in 1996 and will be based on the principles and goals set out in the National Health Strategy "Quality and Fairness – A Health System for You".

Deloitte & Touche Management Consultants have been commissioned by the Department of Health and Children on behalf of the National Cancer Forum to carry out an evaluation of the first National Cancer Strategy 1996. This will involve assessing the main areas of progress that have been made since 1996 and identifying the areas where further progress is required. The output of this evaluation will be a key input into the National Cancer Strategy 2003. We believe that input from patients is critical in order to carry out a successful and thorough evaluation study. Your views will form an integral part of the findings of our evaluation. We appreciate you taking the time to consider the issues raised in this survey.

1. DIAGNOSIS

Q. Were you satisfied with the way that you received news of your diagnosis?

Q. Were you provided with sufficient information regarding your condition at the time of diagnosis?

Q. Was the information communicated clearly and in an understandable fashion?

Q. Did you feel that you had the opportunity to ask questions?

Q. Were your questions answered to your satisfaction?

2. TREATMENT

Q. What types of treatment were provided, for example, acute hospital (in-patient care), day care, out-patient care, chemotherapy, radiotherapy?

Q. Were you given sufficient information concerning your treatment, its purpose and potential side effects?

Q. Were you involved in making decisions regarding your treatment?

Q. Were you kept up-to-date regarding how your treatment was progressing?

Q. How would you describe the accessibility of cancer treatment services, for example, did you experience any issues regarding waiting times, did you have to wait to have radiotherapy treatment, did you have to travel to receive your treatment, what issues did you experience regarding transport, the postponement of appointments, were there financial issues, how long did it take to get an appointment with your radiologist etc.

Q. Did you have confidence in the professionals who were in charge of your care?

Q. Did you feel that you were treated with dignity and respect at all times?

Q. Was every effort made to alleviate your fears and anxieties?

3. AFTER CARE

Q. How satisfied were you with the after care services provided to you following your treatment / discharge from hospital?

Q. Were you given sufficient information regarding your care, for example, care instructions, clear instructions regarding medication, etc.?

Q. How satisfied were you with your follow-up care appointments (e.g. were any postponed, was sufficient time allocated to them, were you given a time for your appointment, was this appointment time kept, etc.)?

4. Overview of Cancer Services

Q. Do the cancer treatment services provide sufficient consideration and support to family and friends?

Q. What do you regard as the most important strengths of the cancer services?

Q. What would you identify as the key priorities for the further development of cancer services?

5. ANY OTHER COMMENTS

Please use this space to provide any additional information.

6. PERSONAL DETAILS (IT WOULD BE USEFUL IF YOU COULD GIVE US SOME INFORMATION ABOUT YOURSELF)

Q. Gender (please tick): Male ☐ Female ☐

Q. Age (for example, 20s, 30s, etc.) ____________________

Q. Where you live (please tick): Urban Area ☐ Rural Area ☐

Q. Type of Cancer ____________________

GLOSSARY OF TERMS

GLOSSARY OF TERMS

Biochemistry: The scientific study of the chemistry of living cells, tissues, organs and organisms.

Bowel Cancer: Cancer affecting the lower gut.

Breast Cancer: The uncontrolled growth of malignant breast tissue.

Bronchosopy: Investigation to assess a patient's airway and upper lungs.

Bronchitis: Inflammation of one or more bronchi (the smaller airways in the lung).

Cardiology: The medical study of the diagnosis and treatment of diseases affecting the heart and blood vessels.

Cardiovascular: Pertaining to the heart and blood vessels.

Chemotherapy: The treatment of disease by means of chemicals that have a specific toxic effect upon the disease-producing micro-organisms (antibiotics) or that selectively destroy cancerous tissue (anticancer therapy).

Clinician: A health professional directly engaged in the care of patients, as distinguished from one working in support areas such as finance, administration etc.

Colorectal cancer: A malignancy that arises from the lining of either the colon or the rectum. Cancers of the large intestine are the second most common form of cancer found in males and females.

Colonoscopy: An endoscopic (fibreoptic) examination of the large intestine (colon).

Colposcopy: Examination of the cervix through a magnifying device to detect abnormal cells.

Colposcopist: Professional who carries out colposcopy.

Cytology: The study of cells. Implies the use of light or electron microscopic methods for the study of morphology.

Dermatologist: A specialist expert in the treatment of disorders of the skin.

E.N.T.: Ear, nose and throat.

Endoscopy: Investigation to look into internal body orifices e.g. gut, airways.

Gene Therapy: Insertion of normal DNA directly into cells to correct a genetic defect. The treatment of disease by replacing, altering, or supplementing a gene that is absent or abnormal and whose absence or abnormality is responsible for a disease.

Gastroenterologist: Doctor specialised in diseases of the gut.

Gynaecology: A branch of medicine dealing with the diagnosis and treatment of disorders affecting the female reproductive organs.

Gynaecological Oncologist: A gynaecologist who treats cancer is a gynaecological oncologist - and this involves special training.

Haematologist: A doctor who specialises in the treatment of blood diseases.

Histopathologist: This is the science concerned with the study of microscopic changes in diseased tissues.

Lung Cancer: A cancerous growth in lung tissue. Lung cancer may be metastatic from another source (e.g. colon) or may be primary (tumour is of lung cell origin). Classification is based on the type of cell the lung cancer originates from (adenocarcinoma, alveolar cell carcinoma, squamous cell carcinoma, large cell and small cell carcinomas).

Mammogram: A special imaging examination of the breast using X-rays. The purpose of this test is to detect breast cancer early when lumps are less than 2 cm or smaller in size (most lumps are not felt by the hand when they are 1 cm or less in diameter). Currently, it is believed that routine mammography is life saving in women over the age of 50 yrs, useful between 40 and 50 yrs and not normally recommended as a routine test for women under 40 yrs.

Mammography: The practice of taking diagnostic X-ray pictures of breasts to produce a mammogram.

Microbiology: The study of organisms too small to be seen with the naked eye, such as bacteria, viruses and yeasts.

Magnetic Resonance Imaging (MRI): Specialist scan, which gives detailed images of body organs, etc.

Neoplasm: New abnormal growth of tissue, which may be benign or cancerous.

Obesity: An increase in body weight beyond the limitation of skeletal and physical requirement, as the result of an excessive accumulation of fat in the body.

Ovarian Cancer: A malignant tumour of the ovary is the leading cause of death from gynaecological malignancies. Often diagnosed in later stages, symptoms include abdominal pain, increasing abdominal girth and abnormal uterine bleeding.

Obstetrician/Gynaecologist: A physician specialist expert in the delivery of total obstetrical care and the diagnosis and treatment of gynaecological disease.

Ocular cancer: Cancer of, pertaining to or affecting the eye.

Oncologist: A doctor who specialises in the diagnosis, treatment and rehabilitation of individuals suffering with cancer.

Orthopaedics: The medical specialty concerned with the preservation, restoration, and development of form and function of the musculoskeletal system, extremities, spine, and associated structures by medical, surgical, and physical methods.

Palliative Care: Treatment aimed at relieving symptoms and pain rather than effecting a cure.

Pathologist: A doctor who specialises in identifying diseases by studying cells and tissues under a microscope.

Primary Care: Care within the community, which provides the patient with a broad spectrum of care, both preventive and curative.

Radiotherapy: The treatment of disease by ionising radiation.

Solid Tumour: Well-defined mass of cancer as opposed to cancer of blood etc.

Secondary Care: Care in general hospital.

Stereotactile Mammography: Specialist investigative scan of the breast.

Symptomatic Breast Unit: Directed at the delivery of comprehensive multi-disciplinary care required by patients diagnosed with symptomatic breast disease, i.e. breast cancer that has advanced to a stage where patients develop a palpable breast mass, which leads them to present for diagnosis and treatment.

Tertiary Care: Care in hospital with specialist services, which may include national referral centres.

Urology: A branch of medicine concerned with the diagnosis and treatment of diseases of the urinary tract and urogenital system.

Uterine Cancer: Cancer of the uterus.