

Regional Cancer Framework

A Cancer Control Programme
for Northern Ireland

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Foreword by the Minister for Health
Paul Goggins MP

Cancer represents one of the most significant challenges for our health and social care services and society as a whole. Each of us is likely to be touched by cancer in some way during our lives. Those of us who do not develop the disease will almost certainly have a family member or close friend who will be affected.

It is therefore vital that we do all that we can to control cancer, taking steps to heighten public responsiveness to key health messages about the prevention and early detection of cancer and taking steps to ensure that our health and social care services deliver the best possible outcomes for patients from the resources that are available. Everyone has their part to play in meeting the challenges posed by cancer.

Small changes in lifestyle have the potential to prevent cancers and save lives. Tobacco is responsible for around 1 in 3 cancer deaths. The Draft Smoking (Northern Ireland) Order 2006 is expected to complete its parliamentary process during the autumn and if all goes according to plan, enclosed public spaces will become smoke-free in April 2007. Experience elsewhere has shown that the introduction of smoke-free legislation helps reduce smoking prevalence and I believe it will help to create a climate where children and young people will find it less attractive to smoke. Equally, we must continue to encourage people to eat a healthy, balanced diet and to take regular exercise. These everyday actions have a significant bearing on an individual's general health and wellbeing but also influence their risk of developing cancer. The cross-departmental strategy for improving health in Northern Ireland, Investing for Health, continues to provide the primary vehicle for action in each of these key areas.

This Cancer Control Programme sets out to build upon the progress made in cancer service provision here since the Campbell Report - Investing for the Future¹, was published in 1996. The intervening years have seen significant investments in

¹ Cancer Services – Investing for the Future, DHSS, 1996

cancer services. The new regional cancer centre at Belfast City Hospital is a leading edge facility. The work done there is undertaken within a network of cancer units located across the province, meeting the needs of local communities. It is not only in infrastructure that we have made improvements. We now have more cancer specialists than ever before, new drugs and advances in cancer therapies hold the prospect of improvements in survival rates. We have also established a clinical network for cancer services, the Northern Ireland Cancer Network (NICaN) that has the potential to deliver real and significant benefits for the treatment and care of patients.

The current programme of reform and modernisation of health and social care services in Northern Ireland must also address cancer services, and in doing so ensure that those services are truly patient centred. This Cancer Control Programme sets out recommendations and actions for the further strengthening of cancer services and the setting of standards for the delivery of those services. It is an important step in the development of a comprehensive regional framework for cancer services in Northern Ireland and will, in the future, be supplemented by detailed, transparent standards for the delivery of cancer care.

Cancer services in Northern Ireland have the potential to be amongst the very best in the world. This Cancer Control Programme, building on the work done since the Campbell Report represents further progress in the journey to realise that potential and will help deliver patient centred, high quality and sustainable cancer services for all the population of Northern Ireland.

PAUL GOGGINS MP

Minister for Health, Social Services and Public Safety

1 - INTRODUCTION

- 1.1 Cancer remains a very common condition with some 8,500 new cases diagnosed in Northern Ireland each year (includes non-melanoma skin cancer). By the age of 75, one in three of the population will be affected by cancer and with one in four deaths resulting from cancer; it is the leading cause of death in Northern Ireland.
- 1.2 Many more people are surviving cancer. Some 46,000 people who have had a diagnosis of cancer in the last ten years are living with the disease. The many better treatment options that are now available mean that more people are surviving and for longer. This success presents new challenges for cancer services. The disease increasingly features periods of good health followed by relapse. This pattern requires continued monitoring and access to effective supportive and palliative care services. Significant resources therefore are needed to assist people living with the consequences of cancer to return to a normal life as quickly as possible.

Purpose of the Regional Cancer Framework

- 1.3 This Framework has been developed in the context of a society in which cancer will touch every family, and will for the foreseeable future be a major cause of illness and death. The purpose of the Regional Cancer Framework is to set out a clear and comprehensive plan detailing how we can reduce the burden of cancer in Northern Ireland.
- 1.4 This Framework will exist not as a single document but will comprise a series of composite papers which collectively will address the strategic direction of cancer care, quality standards of care and the monitoring of progress to improve cancer care. This document, A Cancer Control Programme for Northern Ireland is the first in the series of documents that will comprise the Regional Cancer Framework. The aim of this Cancer Control Programme is to set out measures to help to reduce the number of cases of cancer and cancer deaths, and to help improve the quality of life of cancer patients through the systematic and equitable implementation of evidence based strategies for prevention, early detection, diagnosis, treatment and palliative care, making the best use of the available resources.
- 1.5 Over the coming months the Cancer Control Programme will be complemented by a document setting out clear and measurable standards for the delivery of cancer services. Also in due course, following public consultation on the Cancer Control Programme, an action plan will be developed. This will also form part of the Cancer Framework and will include a range of targets by which we can measure progress against the recommendations of the Cancer Control Programme.
- 1.6 In summary, the Cancer Control Programme is the first part of a comprehensive Regional Cancer Framework for Northern Ireland.

How the Framework was developed

- 1.7 The Regional Cancer Framework was commissioned in March 2003 to build on the work of the Campbell Report and to make detailed recommendations for a programme of action for cancer services up to 2008; outline recommendations for the development of cancer services up to 2015; and for the strategic direction of cancer services up to 2024. Appendix 1 contains the Terms of Reference.
- 1.8 A Steering Group, chaired by Dr Henrietta Campbell, the Chief Medical Officer, was established to oversee the Framework Project. Members were chosen for their particular contribution and not as representatives of particular interests. The full membership of the Steering Group is given at Appendix 2.
- 1.9 The Steering Group was supported by a Project Team, led by Dr Bill McConnell, Director of Public Health, Western Health and Social Services Board. The role of the Project Team, whose membership is listed at Appendix 3, was to progress the Framework in accordance with the terms of reference and the directions of the Steering Group.
- 1.10 Members of the Project Team developed a wide range of comprehensive papers, covering all the issues outlined in the terms of reference, to help inform the development of this document. These papers provide substantial detail about developments in Northern Ireland's cancer services and draw conclusions and recommendations for specific aspects of cancer services. Although it has not been possible to include all this very valuable information within the Cancer Control Programme, it was considered important to make the Project Team's papers available on the Department of Health, Social Services and Public Safety (DHSSPS) website www.dhsspsni.gov.uk. The Steering Group considered it essential to seek the views of professionals, users and others with an interest in cancer services. A cancer conference, held in Belfast on 4 November 2004 was helpful in identifying the key issues and challenges which needed to be addressed. The key themes reflected in the Cancer Control Programme were also informed by contributions from healthcare professionals at the NICaN Cancer Services Conference in September 2006.
- 1.11 The Cancer Control Programme mirrors closely the principles and vision set out in the regional strategy A Healthier Future: A Twenty Year Vision for Health and Well-being in Northern Ireland 2005-2025² and takes account of the earlier work to define the best pattern of health care delivery for Northern Ireland, Developing Better Services³. This Control Programme will be subject to review on an ongoing basis. In addition, progress against the final recommendations will be assessed and published within 3 years of publication with a formal review of recommendations by 2011.

² A Healthier Future – A Twenty Year Vision for Health and Wellbeing in Northern Ireland, DHSSPS, 2004

³ Developing Better Services – Modernising Hospitals and Reforming Structures, DHSSPS, 2002

- 1.12 Equality, new Targeting Social Needs and Human Rights issues relevant to the Framework are dealt with in detail at Appendix 4.
- 1.13 A summary of the recommendations made in the Cancer Control Programme is provided at Appendix 5.

2 – A CLEAR PATH FORWARD

This chapter sets out the policy climate in which the cancer framework has been developed and will be implemented. It highlights not only specific strategies on cancer care, but other developments which will affect the provision of cancer care in Northern Ireland.

2.1 The Campbell Report was the first major review of cancer services in Northern Ireland. The Report has been crucial to the significant progress made in cancer services in recent years, providing the foundation from which a host of advances has been made. Most notably amongst those advances is the progress made in establishing modern delivery structures for the treatment and care of people with cancer including:

- The opening of the regional Cancer Centre on the Belfast City Hospital site in the spring of 2006. This state of the art facility provides an environment that fosters excellence in care and treatment.
- The establishment of five cancer units for the management of patients with more common cancers and the provision of local chemotherapy services.
- The creation of specialist multi-professional palliative care teams established at the cancer units and cancer centre.
- The development of the Northern Ireland Cancer Registry, gaining recognition as one of the most comprehensive and high quality cancer registries in Europe.
- The increased investment in consultant oncology staff which by 2005 exceeded the levels anticipated in the Campbell Report.

2.2 Whilst significant progress has been made to achieve most of the Campbell Report's recommendations, some further work is required to achieve full implementation. For example:

- Most people affected by cancer are now managed by appropriately trained medical specialists; this could however be enhanced by enabling consultants and other healthcare professionals to specialise further in their cancer-related work. The development of more clearly defined regional standards of care and service delivery is also essential.
- Most patients are now managed by multi-professional, multidisciplinary specialist cancer teams, however further work is needed to define the membership, processes and standards for multidisciplinary team working and cancer management to ensure consistency across Northern Ireland.

- Whilst some initiatives are in place at cancer units to implement an effective communication strategy with GPs and other providers, some further development is needed.
- A Cancer Forum has been established that incorporates input from the voluntary sector, charitable organisations and self-support groups. Further work will help to harness the collective potential of this sector so that the full benefits of partnership working can be realised for those affected by cancer.

Local policy developments

- 2.3 In addition to the Campbell Report, which specifically focused on cancer services, other major areas of work will have a significant impact on cancer, either in reducing the incidence or improving the quality of care. Most notably, the Department's Investing for Health⁴ (IFH) strategy sets out a far reaching intersectoral approach to improving the health of the population and to reducing inequalities which are often associated with socio-economic status.
- 2.4 A key element of IFH focuses on lifestyle change, specifically diet, exercise and drug and alcohol consumption. The approach contained in IFH has the potential to reduce the incidence of many diseases prevalent in our communities, including many cancers.
- 2.5 A continuing emphasis on health promotion and disease prevention is a common theme throughout Departmental strategies for improving health and care services. This priority is exemplified in IFH; Developing Better Services; A Healthier Future: A Twenty Year Vision for Health and Well-being in Northern Ireland 2005-2025, the Five Year Tobacco Action Plan published in 2003⁵ and the primary care strategy Caring for People Beyond Tomorrow⁶.
- 2.6 The future direction of palliative care services was defined in the report Partnerships in Caring⁷. The role of carers and their needs have been recognised in the strategy document Caring for Carers⁸ published in January 2006. Service reviews, such as the Lymphoedema Services Review⁹ and the Genetics Review¹⁰, have also contained important elements for cancer services. Over the same period, the Regional Advisory Committee on Cancer has produced clinical guidelines on gynaecological cancer, haematological cancer, endocrine cancer, skin cancer and lung cancer services. Similarly the report Assessment of Hospital Pharmacy Aseptic Services in Northern Ireland¹¹, highlights the implications for the preparation and delivery of specialised cancer therapies and a range of other service reviews including

⁴ Investing for Health, DHSSPS, 2000

⁵ Five Year Tobacco Action Plan, DHSSPS, 2003

⁶ Caring for People Beyond Tomorrow, DHSSPS, 2004

⁷ Partnerships in Caring – Standards for Service, DHSSPS, 2000

⁸ Caring for Carers: Recognising, Valuing and Supporting the Caring Role, DHSSPS, 2006

⁹ Lymphoedema Services – Report of the Lymphoedema Services Review Group, DHSSPS, 2004

¹⁰ Review of Clinical Genetics Services, DHSSPS, 2003

¹¹ Assessment of Hospital Pharmacy Aseptic Services in Northern Ireland, DHSSPS, 2005

the Review of Pathology Services¹², the Framework for Respiratory Conditions¹³ and the Oral Health Strategy¹⁴ each have an influence on cancer services provision.

- 2.7 The Wanless Report¹⁵ emphasised the financial benefits of disease prevention for both society and the economy. For Northern Ireland, the Appleby Report¹⁶ highlighted where greater efficiencies can be made within Health and Personal Social Services (HPSS) provision. Reform and modernisation of health and social care services, including the structural changes that will result from the Review of Public Administration in Northern Ireland (RPA)¹⁷ are expected to facilitate the delivery of these efficiencies. Like other aspects of health service provision, cancer services need to be provided in an accessible and responsive way. Service standards for both access and clinical care have an important place in ensuring the effectiveness of arrangements for treatment and care. The Service Delivery Directorate of DHSSPS is currently leading work on the development of access standards for all cancers. This important development will reinforce public confidence in the quality of the service provided and will set a clear context for health professionals working in cancer care.
- 2.8 The Department is strongly committed to the development of managed clinical networks as a key tool in implementing the Developing Better Services agenda. In keeping with this approach, the Northern Ireland Cancer Network (NICaN) was formed in 2004. This important development provides a vehicle through which healthcare professionals can work together across boundaries and with those who use the service, to deliver many real benefits for people affected by cancer. The integration of cancer services across all healthcare sectors, which is enabled by the Cancer Network, will be critical to the delivery of the enhanced and equitable services envisaged in this document. NICaN will have a critical role in establishing and taking forward the development, implementation and monitoring of new standards for access, assessment, diagnosis, treatment and care and will play an important role in the assessment of guidance produced by the National Institute for Health and Clinical Excellence (NICE) for its applicability to the HPSS.
- 2.9 Key themes for cancer control and the future development of cancer services reflect those addressed in the regional strategy.

¹² The Future of Pathology Services in Northern Ireland, DHSSPS, 2006

¹³ A Healthier Future: A Strategic Framework for Respiratory Conditions, DHSSPS, 2005

¹⁴ Oral Health Strategy, DHSSPS, 2004

¹⁵ Securing Good Health for the Whole Population, Derek Wanless, DoH, 2004

¹⁶ Independent Review of Health and Social Care Services in Northern Ireland, Professor John Appleby, DFP, 2005

¹⁷ Review of Public Administration in Northern Ireland, NIO, 2005

Investing in Health and Wellbeing

The Cancer Control Programme provides a renewed focus on cancer prevention, early detection and screening and reflects a determination to remove inequalities in cancer incidence and access to cancer services.

Involving People

The experience of people affected by cancer, both patients and carers, will be central to the development of new models of cancer care. There will be real engagement with patients, carers and representative organisations in the re-modelling and design of services.

Teams Which Deliver

To secure participation of all involved in service delivery, the Cancer Control Programme identifies the managed clinical network model as the most appropriate mechanism to deliver responsive services in an ever-changing healthcare environment. Good clinical leadership at all levels will be critical to the further development of cancer services, supporting teams to deliver in a co-ordinated way across boundaries.

Responsive and Integrated Services

The Cancer Control Programme aims to ensure that accessible assessment, diagnosis, care and treatment are timely and accurate. Cancer is an increasingly complex disease. Care pathways are necessarily complex in order to address the needs of each individual patient. This Programme aims to secure the seamless integration of services across all components of the patient pathway. Pathways must be developed to provide for the ongoing assessment and management of disease progression. To achieve this there needs to be a radical paradigm shift in the current pattern of care through innovation and the development of effective networks across all healthcare disciplines.

The Programme also seeks to ensure evidence-based supportive, palliative and rehabilitation services for those people affected by cancer who need the ongoing support of health and social care services. The valuable contribution that the voluntary sector makes in supporting those affected by cancer is also recognised and the Programme seeks to provide a basis for new, stronger partnerships with the voluntary sector.

Improving Quality

The Cancer Control Programme and subsequent work within the Regional Cancer Framework will ensure clinical and organisational standards will be transparent, workforce development encouraged, quality of patient experience valued, innovation promoted and outcomes subject to on-going audit and both internal and external evaluation.

National policy developments

- 2.10 The NHS Cancer Plan (England, 2000)¹⁸ and Cancer in Scotland – Action for Change (2001)¹⁹ defined the strategic direction for cancer services in these countries. Review of cancer services is well established in both countries through the peer review model in England and the Clinical Standards Board model in Scotland.
- 2.11 NICE provides authoritative, robust and reliable guidance on best practice. Guidance covers both individual health technologies and the clinical management of specific conditions. The DHSSPS has agreed a process for the review and dissemination of NICE guidance to the HPSS. The arrangements announced by the Minister, Paul Goggins, on 26 June 2006 give formal status to NICE guidance considered by the Department to be applicable to Northern Ireland.
- 2.12 Other sources of guidance in the UK include the Scottish Intercollegiate Guidelines Network which issues guidelines on clinical management. The Scottish Medicines Consortium and the London New Cancer Drugs Group also issue guidance on the effectiveness of new drug therapies.
- 2.13 The NHS Cancer Plan was accompanied by a significant investment in clinical leadership in primary care with the creation of a Primary Care Cancer Lead post for each Primary Care Trust in England. These posts are a joint initiative between the Department of Health and Macmillan Cancer Support and provide strategic leadership, helping to support cancer networks and better integration of care across health sectors.
- 2.14 In addition, palliative care standards for primary care are enhanced through the Gold Standards Framework²⁰. Uptake of these standards has been encouraged and the 2006 review of the general medical services contract introduces basic targets for palliative care.
- 2.15 The policy documents Our Health, Our Care, Our Say: A New Direction for Community Services in England²¹ and the NHS Scotland National Framework for Service Change²² have also informed the Department's thinking about future models for cancer services and particularly the need for a radical and sustained shift in the way services are delivered so that high quality, responsive services are better tailored to fit people's lives.

¹⁸ The NHS Cancer Plan – A Plan for Investment, A Plan for Reform, DoH, 2000

¹⁹ Cancer in Scotland: Action for Change, NHS Scotland, 2001

²⁰ The Gold Standards Framework, Dr Keri Thomas/DoH, 2001

²¹ Our Health, Our Care, Our Say: A New Direction for Community Services in England, DoH, 2005

²² National Framework for Service Change, NHS Scotland, 2004

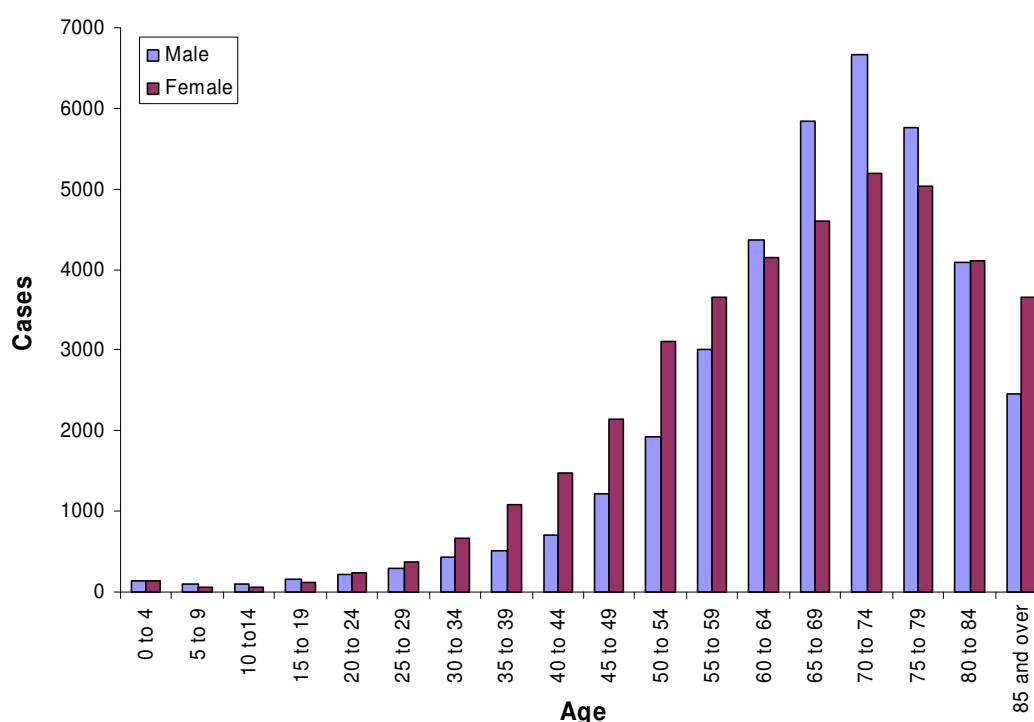
3 - The Challenge We Face

This chapter sets out the current incidence and pattern of cancer in Northern Ireland and future implications in light of changing and anticipated changes in behaviour.

Incidence

3.1 Half of the cancers in our population occur in people aged 70 years and over. As the population lives longer, cancer will become more common (see Figure 1). It is predicted that, by 2025, the population of Northern Ireland will have increased by 8% to 1.8 million, 18% of whom will be over 65 years. This change could result in an overall increase in cancer levels of 54% by 2025. If cancer incidence were to increase by this measure, around 12,500 new cases would be recorded annually.

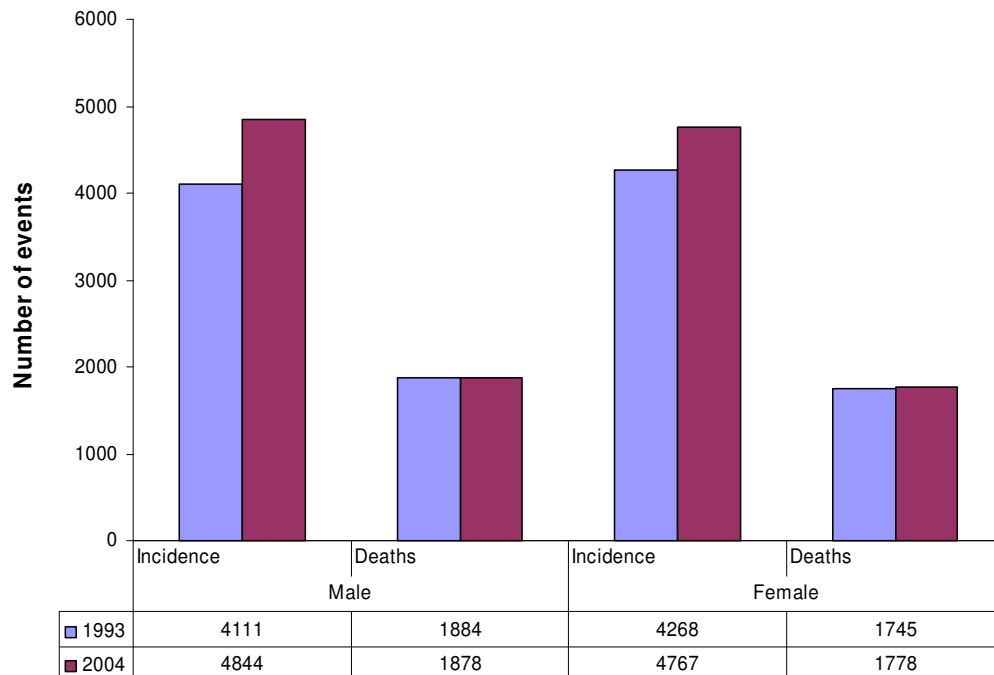
Figure 1: Number of registrations (excluding non-melanoma skin cancer) by sex and age: 1993-2004



3.2 There are however a range of factors that may impact on this projection. The changing trends in cancer include reductions in the incidence of some cancers; falling levels of colorectal cancer and lung cancer in men are predicted to modulate the potential increase in incidence to 30%. If the prevalence of smoking amongst the adult (16+) population is reduced to 5% as targeted in the regional strategy, then this 30% increase would be further reduced so that by 2025 the number of new cases of cancer diagnosed in Northern Ireland each year would be approximately as it stands today (8,500), despite the much older population.

3.3 Between 1993 and 2004 the number of people diagnosed with cancer increased by 1,243 cases to 4,844 new cases in males and 4,767 new cases in females. Deaths from cancer also increased, but less so (38 deaths) with 1,878 deaths in males and 1,778 deaths in females (see Figure 2).

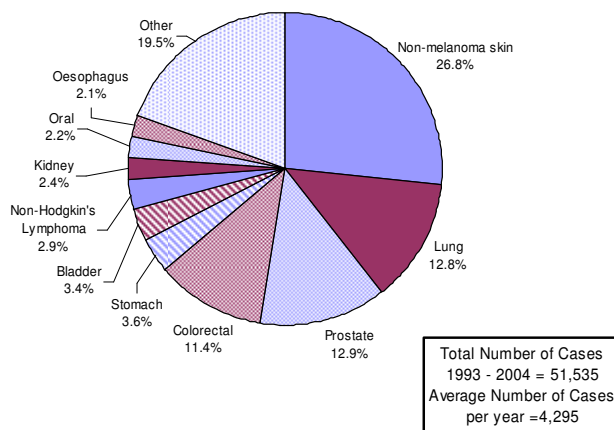
Figure 2: Cancer Incidence and Deaths: 1993 & 2004



3.4 The most commonly diagnosed cancers between 1993 and 2004 in males were skin, lung, prostate and colorectal while in females they were skin, breast, colorectal and lung (Figure 3). Apart from skin these same cancers were the common cause of cancer deaths (Figure 4).

Figure 3: Cancers Diagnosed: 1993-2004

MALE



FEMALE

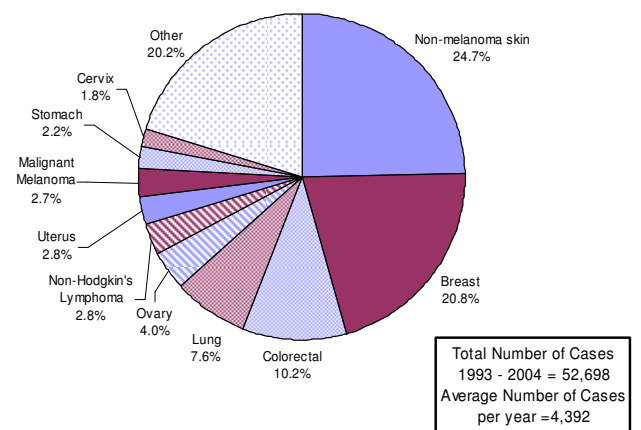
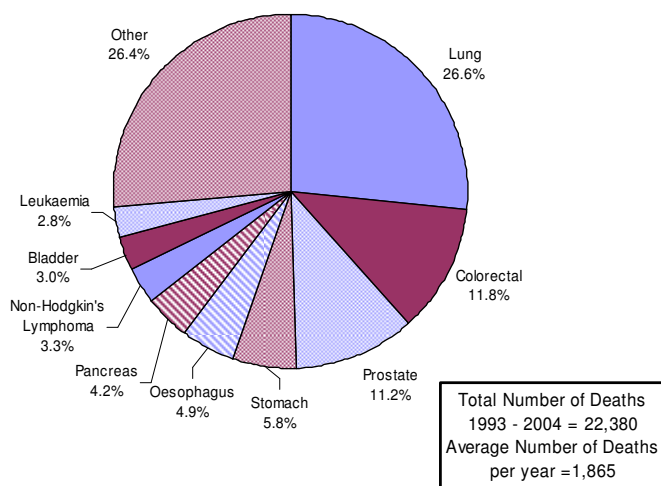
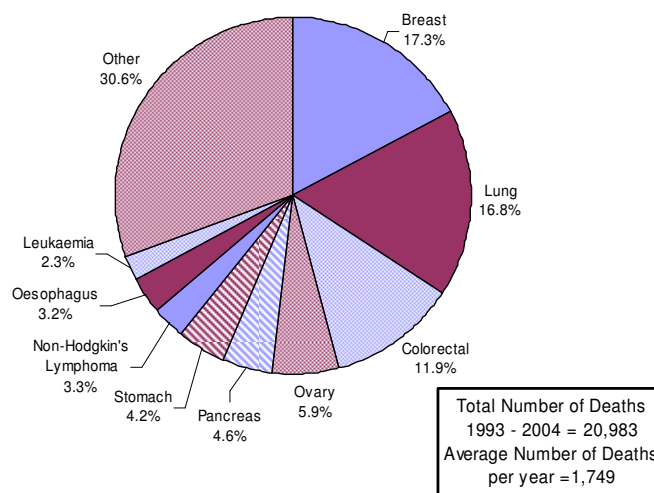


Figure 4: Causes of Cancer Death: 1993-2004

MALE



FEMALE



- 3.5 Rates of total new cancers in males fell significantly during the period 1993 to 2003 by 0.8% each year. This reduction in rate was driven by reductions in tobacco related cancers e.g. lung, stomach, oral. There was no significant change in rates for total new cancers diagnosed in females, whilst death rates from cancer for both sexes decreased during the period by 1.3% per year in males and 0.8% per year in females.
- 3.6 Despite the drop in rates, an increase in the number of newly diagnosed cases and deaths due to cancer was observed. In males cancer cases increased by an average of 20 per year while in females there was an increase of 34 cases per year. These increases in number despite falling or steady rates, reflect the ageing of the population as cancer is more common with increasing age.
- 3.7 These trends will influence levels of cancer over the next 20 years and it is predicted this overall decline will reduce the potential increase due to population change from a 54% increase down to a 30% increase by 2025. Other factors such as the introduction of new population based screening programmes will act with changing population lifestyle and risk factors, such as obesity, to further change cancer rates in our population.
- 3.8 About 7% of the population will have more than one tumour in their lifetime. Many of these are non-melanoma skin cancers, which have excellent

prognosis and are rarely fatal; if these are excluded then about 3.5% of the population will have had more than one serious cancer.

Survival

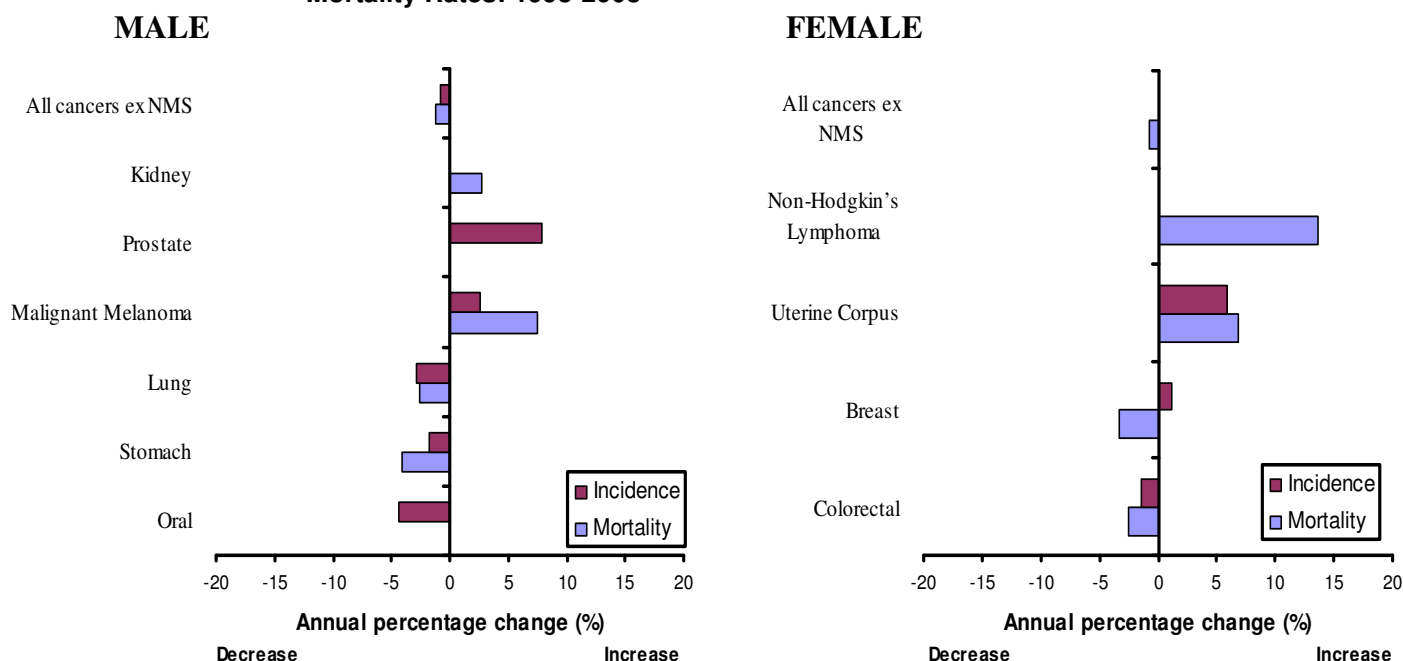
3.9 The number of people living with a diagnosis of cancer depends not only on the number of new cases diagnosed but also the average time of survival from that cancer. Five year survival varies by cancer type and has improved in Northern Ireland over the period 1993/95 – 1996/99 for cancer of the female breast, cancer of the colon and ovarian cancer.

3.10 Survival for melanoma, testicular cancer and breast cancer are good; survival for lung, liver, pancreatic and oesophageal cancer is poor. International variations in survival help us to identify areas for future improvement.

Trends

3.11 Trends in new cases and deaths as a result of cancer vary according to sex and the cancer type. Figure 5 illustrates those cancers for which the trend between 1993 and 2003 was significant. Although the overall rate of cancer incidence decreased the graph shows increases in prostate cancer and melanoma in males and increased cancer of the uterus and lymphomas among females.

Figure 5: Annual Percentage Change in European Age-Standardised Incidence and Mortality Rates: 1993-2003



3.12 The Northern Ireland Cancer Registry has analysed patterns of cancer incidence relating to deprivation and found patterns similar to elsewhere.

Increasing levels of lung, cervical and stomach cancer associated with deprivation have been documented in Northern Ireland (Figures 6, 7 and 8).

Figure 6: European Age-Standardised Incidence and Mortality Rates of Lung Cancer by Deprivation Quintile and by Sex. N. Ireland, 1993-2001

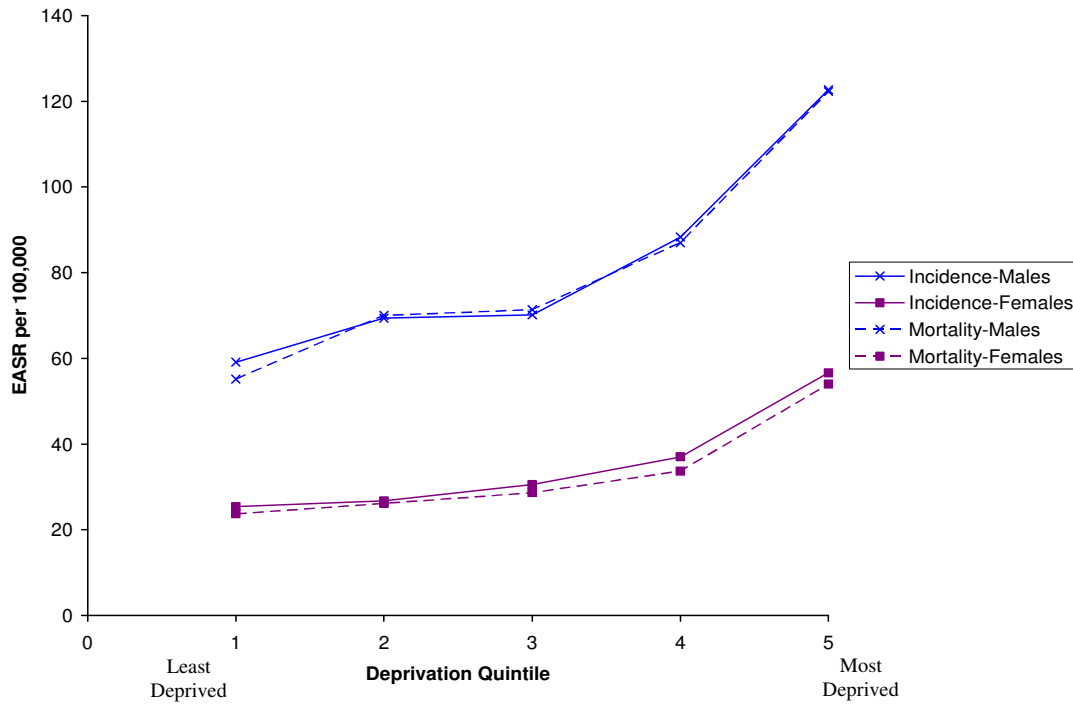


Figure 7: Age-Standardised Incidence and Mortality Rates of Cervical Cancer by Deprivation Quintile. N. Ireland, 1993-2001

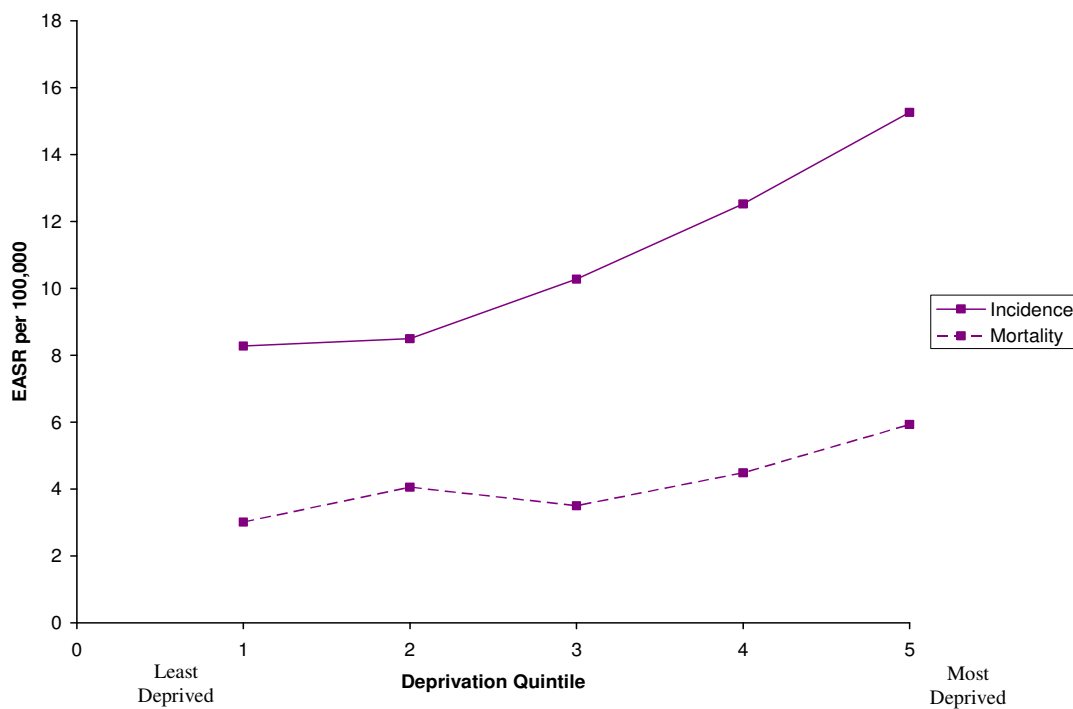
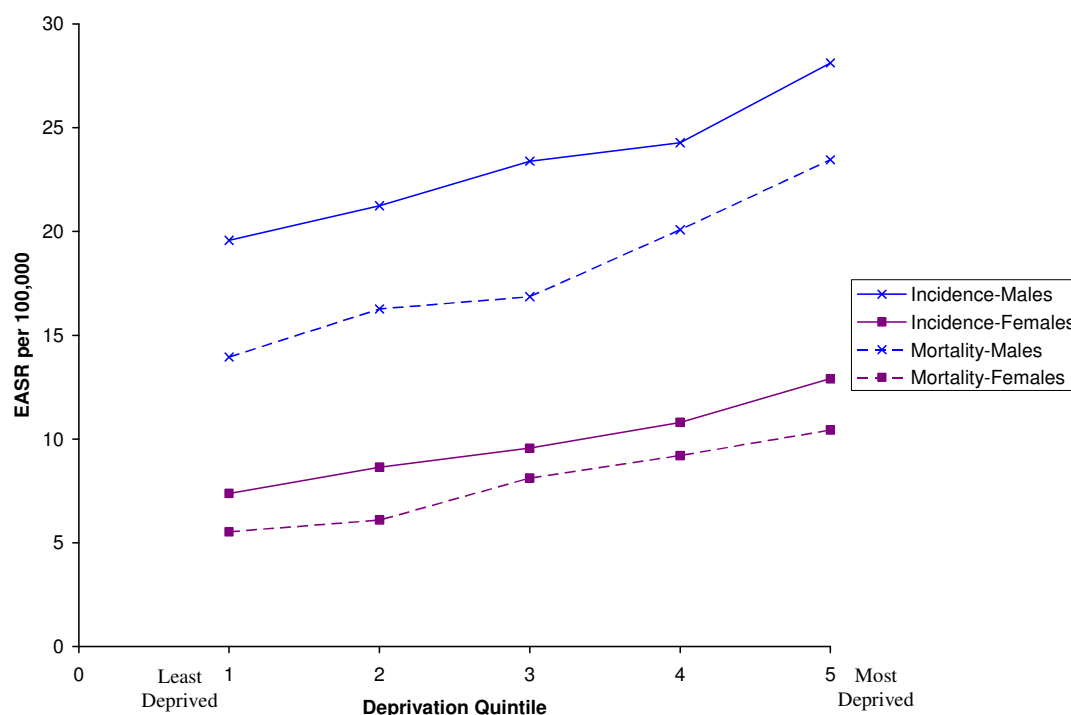


Figure 8: Age-Standardised Incidence and Mortality Rates of Stomach Cancer by Deprivation Quintile and by Sex. N. Ireland, 1993-2001



- 3.13 The higher use of tobacco in deprived populations is associated with the higher levels of lung cancer in those populations.
- 3.14 Unskilled manual workers are more than twice as likely to be smokers as professional people. In 2000, according to the continuous household survey in Northern Ireland, men working in unskilled manual occupations were four and a half times more likely to report that they currently smoke than men employed in professional jobs (42% vs. 9%). Similarly women were three times more likely to smoke (38% vs. 11%). In 1998, in the UK, unskilled and manual workers were more than twice as likely to be smokers than those in professional job roles and were also more likely to have started smoking at an earlier age.
- 3.15 Information collected regarding tobacco use indicates falling levels in males but less so in females since 1984. Still 26% of the adult population, about 400,000 people, continue to smoke.
- 3.16 There is an inverse relationship with deprivation in some cancers e.g. breast cancer, skin cancer and melanoma which show higher levels in more affluent groups (Figures 9, 10 and 11).

Figure 9: Age-Standardised Incidence and Mortality Rates of Female Breast Cancer by Deprivation Quintile. N. Ireland, 1993-2001

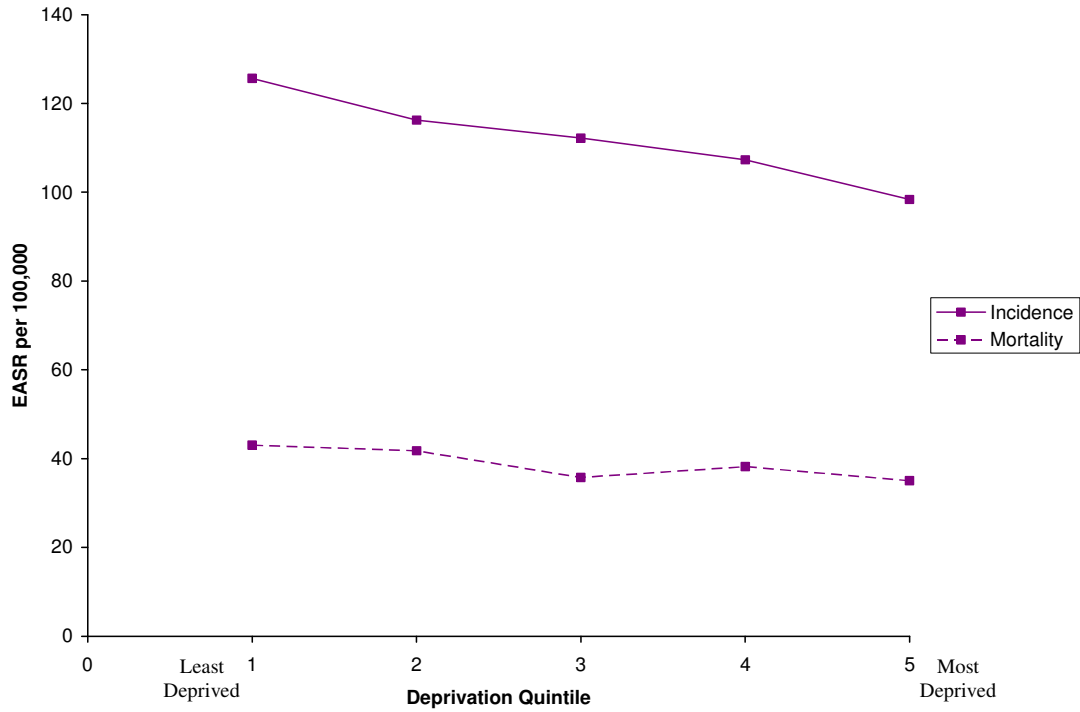


Figure 10: European Age-Standardised Incidence and Mortality Rates of NMS Cancer by Deprivation Quintile and by Sex. N. Ireland, 1993-2001

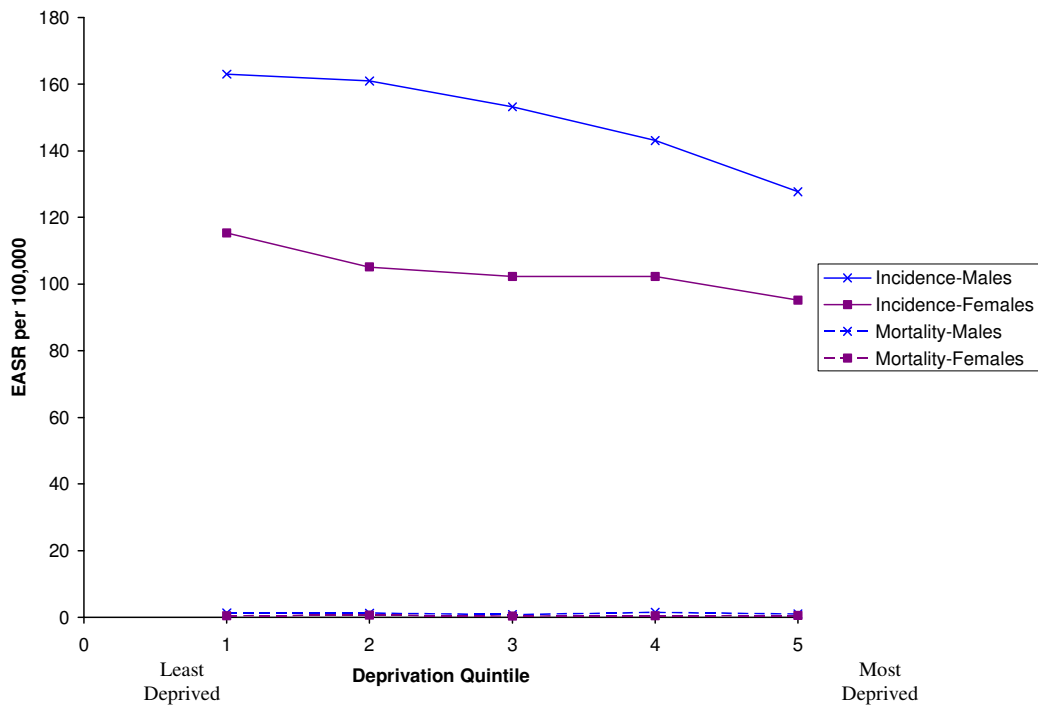
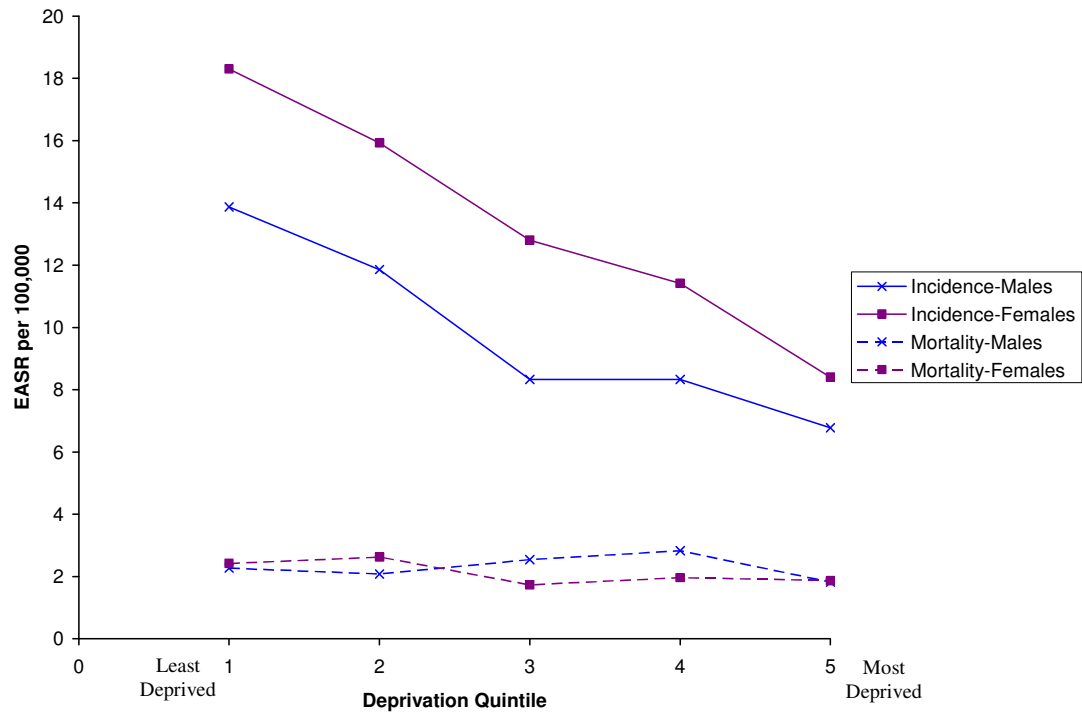


Figure 11: Age-Standardised Incidence and Mortality Rates of Malignant Melanoma by Deprivation Quintile and by Sex. N. Ireland, 1993-2001



4 - PREVENTION, EARLY DETECTION AND SCREENING

Investing in Health and Wellbeing

This chapter addresses the need to encourage changes in lifestyle that will help reduce the incidence of cancer, to highlight the benefits of early detection and to encourage the uptake of screening programmes.

- 4.1 The World Health Organisation estimates that approximately one third of all cancers are completely preventable with a further one third potentially detectable at an earlier stage when treatment would be more effective.
- 4.2 There are 4 main ways through which we can prevent and reduce the impact of cancer:
- Changing those things that have been shown to have a direct causal effect on cancer rates and occurrence.
 - Detecting and treating the causes of pre-cancerous lesions which might lead to cancer.
 - Detecting cancers as early as possible through improved public and professional awareness of symptoms.
 - Detecting cancers through effectively applied cancer screening programmes aimed at either population level or at particularly susceptible people and groups.

Key areas for action on prevention

- 4.3 Factors which are amenable to primary prevention are mainly environmental and lifestyle issues. Key areas for action on prevention are:
- Tobacco
 - Diet/nutrition
 - Obesity
 - Physical Activity
 - Alcohol
 - Exposure to UV light (sunlight)
 - Exposure to radon and other sources of radiation
 - Sexual behaviour
- 4.4 Modifying these factors is the challenge that faces us over the next 20 years. To make significant impacts in terms of cancer prevention we need community based programmes supported by effective intersectoral policies that work across health sectors and the responsibilities of government departments. Investing for Health provides a helpful framework for cancer prevention and a number of relevant action plans are already in place or are under development. There should be formal synchronisation of programmes focusing on cancer prevention with those tackling coronary heart disease,

stroke, diabetes and respiratory disease in view of the overlapping risk factors.

Tobacco control

- 4.5 Tobacco control is the single most important focus of a cancer prevention plan as tobacco use causes approximately 30% of all cancers in developed countries. The Five Year Tobacco Action Plan was launched in 2003. It identifies three key target groups - disadvantaged adults, young people and pregnant women. It addresses issues such as changing public perception of tobacco use, prevention, helping smokers to quit and protecting the public from tobacco smoke. The plan identifies 24 separate action points that are being taken forward by a multi-agency implementation group.
- 4.6 On 21 December 2004, the Government announced a consultation exercise on strengthening existing controls on tobacco use in Northern Ireland. The consultation ended on 25 March 2005 and elicited over 70,000 responses of which 91% were in support of a complete ban. On 17 October 2005 Health Minister, Shaun Woodward, announced his decision to introduce legislation to control smoking in all workplaces and enclosed public spaces. This decision means that from April 2007 smoking will no longer be permitted in enclosed public spaces, including workplaces.

Nutrition, physical activity and obesity prevention

- 4.7 After tobacco use, what people eat is the next biggest contributor to cancer. Increasing fruit and vegetable consumption is considered the second most effective way to reduce the risk of cancer, after reducing smoking. In November 2006, the new Healthy Start Scheme will be launched across the UK. It will replace the Welfare Foods Scheme and is open to pregnant women and families with children under 4 who are on qualifying benefits. The new scheme will provide vouchers that can be exchanged for fresh fruit and vegetables as well as milk and infant formula. The Healthy Start Scheme supports breastfeeding and encourages earlier and closer contact between health professionals and families from disadvantaged groups.
- 4.8 Obesity is also an important risk factor for a number of cancers. Due to concerns about the rising levels of obesity in Northern Ireland the Ministerial Group on Public Health established the Fit Futures taskforce, which published its recommendations in March 2006. The taskforce identified that levels of overweight and obesity among children aged 4.5 to 5.5 living in Northern Ireland had increased from 16.6% to 22.7% in just six years. The taskforce made over seventy cross-departmental recommendations designed to deliver the PSA target to stop the rise in obesity in children by 2010. A response to the Fit Futures report, including a cross-departmental implementation plan is currently under development will be published before the end of 2006.

- 4.9 Progress has already been made in relation to the delivery of a number of the Fit Futures recommendations. In particular, there has been a major investment by the Department of Education in improving the nutritional status of school meals. This will significantly restrict the availability of foods which are high in fat, salt or sugar and will require the provision of at least two portions of fruit and vegetables as part of each school meal.
- 4.10 Efforts to encourage and support people to live more active lives also need to be sustained. A new phase of the Health Promotion Agency's physical activity campaign, Every Small Step is a Forward Step, was launched in 2006. This phase of the campaign was targeted at women, particularly those with young children.

Early detection

- 4.11 Early detection improves survival for many cancers. Early diagnosis through improved public awareness of signs and symptoms is particularly important for cancers such as skin, testicular, breast, colon, lung and rectum. In addition to raising awareness it is also essential to dispel the fear that the public associate with cancer by providing positive messages. People must be encouraged to deal with the symptoms of cancer at the earliest opportunity.
- 4.12 Raising awareness of likely symptoms among the population will, however, increase the number of people presenting with symptoms suggestive of cancer which need urgent investigation but which subsequently turn out not to be cancer. Current ratios for this have been estimated as 3:1 for lung cancer and 15:1 for breast and colorectal cancers. It should be recognised that until their investigations are complete, all of those involved will experience anxiety and require the support of healthcare professionals whether they are found to have cancer or not.
- 4.13 Multi-faceted approaches to raising awareness bring the most benefit. These may include partnership approaches between statutory agencies and the voluntary sector and the many locally based self-support groups and use a variety of media. Public awareness programmes should be underpinned by research as necessary and take into account the conclusions of the report Equality Impact Assessment on the Delivery of Public Information Campaigns, published by the Health Promotion Agency in November 2004.
- 4.14 It is essential that efforts to increase the public's awareness of the early symptoms of cancer are accompanied by measures to ensure that health professionals are also particularly aware of the possibility of cancer with clear referral guidelines and adequate diagnostic capacity in place within the HPSS.

Cervical screening

- 4.15 Cervical smears test for signs of changes which could later lead to cervical cancer. Across Northern Ireland the uptake rate for cervical smear tests is 72%; this is a much poorer rate of uptake than for most parts of the UK. The majority of cervical cancers here occur in women who have either never had a smear test or who have not had regular smears taken. Currently women aged between 20 and 65 years are invited for cervical screening every five years. Based on new research evidence, it is now advised that women receive their first invitation for cervical screening at age 25 and then, up to age 49, should be invited every three years, and, from 50-64 years every five years. These new screening intervals will be introduced in Northern Ireland by 2007. Liquid based cytology, a new technology which can produce a more representative sample and significantly reduce the number of unsatisfactory smears, is currently being implemented in Northern Ireland.
- 4.16 Infection with human papilloma virus (HPV) is one of the primary causes of cervical cancer. Vaccines are now becoming available which have been shown to be highly effective in preventing cervical cancer associated with some HPV types and promise to reduce the rates of this disease. The Department will give consideration to the case for a program of vaccination in Northern Ireland.

Breast screening

- 4.17 In the breast screening programme, all women aged between 50 and 64 years are invited for screening every three years. The UK National Screening Committee has recommended that this be extended to include women aged up to 70 years. The Department has endorsed this policy but the extension of the screening programme to include this older age group cannot be achieved until current staffing challenges are resolved. Northern Ireland has an uptake rate of 75% and this rate compares well with other parts of the UK, however within Northern Ireland there are areas where uptake is considerably less. It is essential that there is a continued effort to raise rates in those areas. The priority is, first, to maintain the quality of the existing programme and then to develop the programme to meet the needs identified above.
- 4.18 Population-based screening programmes for breast and cervical cancer have been in place since the late 1980s. Although uptake is generally good, one in four women invited for screening declines the invitation. Uptake is lower in areas of high deprivation. It is essential that we target these areas raising awareness of the value and importance of screening and utilising approaches which have been shown to influence attendance. The reasons for lower uptake rates in Northern Ireland need to be adequately researched including the psychological components of why women are not taking up the opportunity of a free screening test. Such research might well produce important evidence as to how our messages to different groups within our

population may need to be changed. Improvements in uptake rates in the existing screening programmes would have a beneficial effect on cancer detection and ultimately survival.

Bowel cancer screening

- 4.19 Bowel cancer screening can detect abnormalities at an early stage before symptoms have occurred. There is now clear evidence from research and the pilots in England and Scotland, that population screening for bowel cancer would be effective in decreasing mortality rates by approximately 15-18%.²³ In October 2004, the Secretary of State for Health announced that bowel cancer screening would be rolled out across England from April 2006. In Scotland, screening for bowel cancer will commence in April 2007.
- 4.20 The Department recognises that the introduction of a bowel cancer screening programme in Northern Ireland would be a significant step forward in our ability to detect cancer at an early stage. The effective implementation of such a programme is dependent upon ensuring that the symptomatic service is able to deal with the increased presentation of bowel cancer that a screening programme is likely to identify. The establishment of a bowel cancer screening programme here will have a considerable impact on workload in a number of healthcare settings including diagnostic services, especially for lower bowel endoscopy and will require additional resources. Consequently, the outcome of the 2007 spending review will have a significant bearing on the timescale for introducing bowel screening. The Department is currently working with the HPSS to put in place measures which will help prepare the service for the introduction of a screening programme from 2009.

Prostate specific antigen (PSA) testing

- 4.21 The National Screening Committee has recommended that screening for prostate cancer using the PSA test should not be introduced²⁴. Although PSA testing can identify some men with prostate cancer, it has limited accuracy and has not been shown to reduce the mortality from this disease. Follow-up procedures can cause unnecessary harm to healthy individuals. While the PSA test may be of benefit for men who have particular signs and symptoms, it is not appropriate for those without signs and/or symptoms to have a PSA test. It is very important that men are fully aware of the potential consequences of having a PSA test before they decide whether to have a test or not.

²³ UK Colorectal Cancer Screening Pilot Group. Results of the first round of a demonstration pilot of screening for colorectal cancer in the UK. *BMJ*,doi:10.1136/bmj.38153.491887.7C (published 5 July 2004)

²⁴ National Screening Committee's Policy Positions July 2004.

Genetic factors

- 4.22 About one in twenty cases of common cancers of the bowel, breast and ovary are due to genetic susceptibility. Genetic screening of high risk families to identify individuals who are at greater risk of developing cancer than the general population allows advice to be given to these individuals on preventive measures and appropriate screening programmes to modify their risk. As noted above, currently this is particularly relevant in ovarian, breast and colorectal cancer, however, in the future the developing knowledge of genetics may guide us in understanding how our current and future screening programmes may have to be applied differently and selectively to individuals, families and groups.
- 4.23 The Review of Clinical Genetics Services reported that referrals to cancer genetics have increased dramatically since 2000 and account for around 45% of the workload. The number of clinics and cancer genetic staff are currently expanding in an attempt to meet the need for this service.

Cancer Control Programme - Recommendations

1. Action should be taken to reduce smoking levels in younger people as part of an overall programme of lifestyle skills, increase the provision of smoking cessation services and improve the targeting of those services.
2. Public awareness of early symptoms of cancers should be increased through partnership approaches with cancer charities and the community and voluntary sector and self-support groups. Various methods, including the use of media, should be considered to more effectively target different population groupings and those which are seldom heard.
 - A pilot programme to raise public awareness of the symptoms and signs of cancer and the benefits of early detection should be commenced by 2007. The pilot programme should include an assessment of the impact of the programme on symptomatic patients and whether they are presenting earlier for diagnosis and treatment.
 - A revised skin cancer/melanoma prevention programme should be developed.
3. Professional awareness of early signs and symptoms of cancer should also be improved through the development of regional referral guidelines.
4. Cancer Screening Programmes should be enhanced to ensure uptake and effectiveness is maximised.

- The breast screening programme age range should be extended up to 70 years. Service capacity should be developed towards this goal.
 - Northern Ireland should introduce liquid based cytology for all cervical smears by March 2008 at the latest.
 - Commissioners and providers, working with local women and the voluntary sector, should target areas of poor uptake, find out why women are not coming forward, and use an approach likely to best increase the number of women presenting for breast and cervical screening.
 - The Department, in partnership with healthcare professionals, should develop an action plan to take forward introduction of bowel cancer screening in Northern Ireland from 2009.
5. The Department should consider the case for the introduction of a human papilloma virus vaccination programme for young girls, when available, and in line with recommendations of the National Vaccination Committee.
 6. The workload of the regional cancer genetics service should be monitored to ensure that the recommendations in the Review of Clinical Genetics for increased staffing and facilities are appropriate for the future provision of clinical genetics services, including cancer genetics.
 7. The clinical role of all community and primary care professionals should be developed, particularly in relation to health promotion, smoking cessation, screening, symptom recognition and ongoing supportive care by 2010.

5 - IMPROVING THE EXPERIENCE OF PEOPLE AFFECTED BY CANCER

Involving People

In this chapter, we recognise the priority of involving people affected by cancer in all aspects of care. It sets out a range of measures to ensure that services are effectively tailored to the needs of patients and their carers and as such are truly patient centred.

- 5.1 The Regional Strategy, A Healthier Future, set out a vision for health and social services in Northern Ireland that would place a policy of engagement with communities and patients at the centre of service development, design and delivery.
- 5.2 This Cancer Control Programme aims to ensure that people affected by cancer feel cared for as individuals, are involved in decisions throughout their treatment and care and are empowered to help shape the service. As treatments continue to improve, many people are now living longer with cancer. In many cases, the consequences of living with cancer are becoming essentially chronic in nature often involving recurrent periods of relapse. The impact of cancer extends beyond the physical effects of the disease to include psychological, social, economic and spiritual consequences for patients and their carers. Increasingly there is a need for supportive care and rehabilitation as well as palliative care at the end of life.

A patient centred service

- 5.3 Throughout this document the term “people affected by cancer” is used to remind readers that cancer not only affects the patient but also their whole family, carers and their close friends.
- 5.4 Cancer services should be designed around the needs of the patient to ensure that the right professional support and care, and the best available treatments are provided when they are needed. Involving people with cancer, and those with an interest in cancer services, in all aspects of the process, including policy development, service provision and planning, will help to ensure that our cancer services continue to improve.

Living with the consequences of cancer

- 5.5 Living with cancer presents patients and their families with a range of difficult issues; social, practical, financial and emotional. In recent years, there has been a significant expansion in sources of support and information and a growing recognition of the value of that information.

- 5.6 People affected by cancer and their families may need financial, psychological, social and spiritual support as well as support for family carers and in facing bereavement. Much support is currently provided by patient support groups but it is also the responsibility of health care professionals to respond appropriately to these needs. The integration of health and social care services in Northern Ireland provides a strong foundation from which the continuity of these aspects of care can be improved. The Northern Ireland Cancer Network (NICaN) is currently considering standards for such support services and is working to ensure that opportunities are explored for shared learning bringing together the experiences of patients, their families, healthcare professionals and patient support groups.
- 5.7 Work in this area should also consider the need to support people to carry on with life after cancer, recognizing the difficulties many people face in returning to normal day to day life after their treatment has ended. Children and young people will have particular needs as they deal with the consequences of cancer. The disease can have a significant impact on many aspects of day to day life for young people, affecting their education, social interaction, self-image, confidence and future fertility.
- 5.8 In line with the Campbell Report's recommendations, a comprehensive review of palliative care services in Northern Ireland was carried out and completed in May 2000. The review's report, Partnerships in Caring, set the direction for palliative care services and emphasised the need for partnership between patients, families and those commissioning and providing services.
- 5.9 Many positive steps have been taken such as the creation of a network of GP facilitators in palliative care, the adoption of the Gold Standards Programme by a number of general practices and the introduction of new resources such as the Cancer and Palliative Care Online Resource Network (CAPriCORN), a web based information resource for cancer and palliative care across Northern Ireland (www.capricorn-ni.org). In addition, local networks of community pharmacists with advanced training in palliative care are supporting timely access to medicines for palliative care and providing specialist medicines advice. These networks have been funded in partnership with the voluntary sector and provide effective links to specialist palliative care pharmacists in secondary care. These examples illustrate some of the real progress made in palliative care in recent years but further development is necessary to ensure that best practice becomes embedded as the norm regardless of where palliative care is delivered.
- 5.10 The voluntary sector will continue to make a considerable contribution across the range of palliative care provision for people with cancer. The movement of patients between sectors (home, hospital and hospice, for instance), between teams (such as primary care, cancer and palliative care teams), and between statutory and voluntary providers requires effective co-ordination.
- 5.11 UK wide studies confirm that many people would prefer to be cared for at home. Particularly in rural areas of Northern Ireland, there is a strong tradition

of remaining at home at the end of one's life with support from relatives and neighbours as well as primary and palliative care services. Yet, throughout the UK only about 25% of people are able to do this. This Framework recognises the need for patient centred palliative and supportive care services and recommends that measures, including the enhancement of skills in the primary and community sectors, should be taken to ensure that patients will be enabled to remain at home if they choose.

Empowering people

- 5.12 Professionals and carers involved in the delivery of cancer services should be pro-active in helping those who use the service to acquire the confidence, knowledge and skill to manage their condition and make the most of their relationships with health and social care professionals.
- 5.13 The interaction between the healthcare professional and the person affected by cancer is critical and it is important that the privacy and dignity of each individual patient is respected. Equally it is fundamental that in addressing the needs of people with cancer, professionals consider the needs of that person as a whole, caring for the individual rather than merely treating the disease.
- 5.14 Patients and carers need to be offered high quality information, tailored to their individual needs at appropriate points across the care pathway – clinical and patient information pathways should be integrated. A strategy should be developed to ensure there is a co-ordinated approach to the provision of high quality, accessible and accurate information which is in line with regionally agreed quality standards. Such information should be routinely offered to all patients and carers as part of their ongoing care in a variety of formats and in appropriate settings.
- 5.15 Clinicians must be explicit about the nature and intent of treatment, ensuring there is clarity and a shared understanding about its purpose and the steps that will be taken at each stage in the journey. Crucially, this will enable patients to exercise their right to be involved in and central to discussion of their treatment options and to decide on the way forward for them. Clearly this requires healthcare professionals to possess good communication skills and there will need to be appropriate opportunities for professionals to develop the necessary advanced communications skills.
- 5.16 Work currently underway in this area includes the development of the Macmillan Information and Support Centre based at the Cancer Centre in Belfast, the continued development of the CAPriCORN website, the development of patient information services at Cancer Units and the appointment of a NICaN Patient Information Co-ordinator.
- 5.17 Cancer patients can experience fear and loneliness after their diagnosis and during their treatment. For many, support and advice from voluntary organisations can be helpful. Discussions with people affected by cancer have identified the need for information to be readily available on how to

access non-HPSS support. For example, many face financial pressures because they may have to take prolonged time off work and need advice on what statutory financial benefits are available and how to apply for them. Also some cancer patients report that they were not told about the supporting role provided by voluntary sector groups or how to contact them. There are also benefits to be delivered from enabling patients to contact other people who have been on a similar cancer journey and who can share their experience.

Complementary therapies

- 5.18 Many people affected by cancer choose to receive complementary therapies alongside their conventional cancer treatment. Many report that they are helped by complementary therapy and that it provides a sense of enhanced wellbeing. Whilst it is acknowledged that there is a lack of research evidence of the benefits of complementary therapies in improving physical or psychological symptoms, patients should be able to make their own decisions about complementary therapies and therapists through the provision of high quality information.

Cancer Control Programme – Recommendations

8. Advanced communication skills training, delivered through a phased implementation programme. will be mandatory for health and social care professionals working with people affected by cancer.
9. The Cancer Network, working particularly through the NICaN Supportive and Palliative Care Network, should develop action plans for implementation of recommendations for best practice contained in NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) to include:
 - a. an audit of the implementation of the Breaking Bad News guidelines,
 - b. a coordinated approach to user involvement,
 - c. the development of an information strategy to align the information pathway with the care pathway and to include the development of appropriate patient information material,
 - d. the adoption of NICE guidance on the use of complementary therapies,
 - e. the assessment of supportive and palliative care needs at each stage of the cancer journey,
 - f. the provision of appropriate care for people with conditions associated with cancer such as lymphoedema
10. The education and training recommendations outlined in Partnerships in Caring should be fully implemented.
11. CAPriCORN should be further developed to better support staff, patients carers and those affected by cancer.

12. Commissioners/service planners should draw up local development plans by 2007 to ensure that as soon as possible, but no later than 2010, there should be an enhancement of service provision in the community which extends into the evening and the weekends. The particular needs of patients who are dying should be identified and addressed.
13. As soon as possible, but no later than 2010, there should be an enhancement of service capacity to provide intensive coordinated home support (including any necessary equipment) to patients (both adults and children) with complex needs who are at home.

6 - IMPROVING ACCESS TO DIAGNOSIS AND TREATMENT

Responsive integrated services / Teams which deliver

This chapter discusses the benefits that can be gained for patients and their carers from more effective integration of cancer services across professional and institutional boundaries and makes recommendations to deliver real improvements in the quality of cancer services

- 6.1 The implementation of the Campbell Report has secured significant developments in the delivery of cancer services; in particular, it has provided a springboard for greater integration of services. The last decade has been marked by a move from a pattern of service where individuals were responsible for the delivery of specific components of care to one where increasingly those individuals work together in teams to provide a more responsive service and better outcomes for patients. The next step in this development will be to ensure that the necessary enablers are in place to enable cancer teams to work more effectively across professional and organisational boundaries.
- 6.2 This Cancer Control Programme aims to achieve the seamless operation of cancer services reflecting care pathways for patients; for the integration of cancer care to become a reality and for the barriers that often arise between services provided in different sectors of care to be addressed. Clinical networks differ from other service developments in that they provide configurations of healthcare professionals much more closely aligned to the patient's pathway and experience of care. Consequently, they have the potential to overcome service boundaries which have existed between primary, secondary and tertiary care. It is recognised that a number of enablers is required to allow networks to effectively optimise patient care including information and communications technology, systems for performance assessment and case management and effective communication systems.

Information and communication technology

- 6.3 Timely, accurate communication between health professionals is vital so that those caring for patients can access the most up-to-date information about their condition and treatment.
- 6.4 Modern Information Communication Technologies promise greater ease of access to expert opinion and benefits in education and training. ICT can also help to reduce the constraints of geography in providing a service and improve communication between distant sites. This is particularly relevant in the effective treatment of cancer, which is seen to depend critically on, often difficult, early diagnosis. Developments such as telemedicine have the potential to facilitate multidisciplinary cancer meetings locally, regionally, nationally and internationally. As well as promoting effective communication

between health professionals, effective ICT solutions must provide a common and secure platform for handling images and other patient specific data.

- 6.5 ICT is also an important enabler for performance management of cancer services, providing accurate and timely information about service delivery. As the Cancer Network develops, it will be important to support its work with the necessary ICT systems to enable the efficient and collaborative management of cancer data. This should be done in conjunction with the Northern Ireland Cancer Registry (NICR) so that one common spine of information can be used for individual patient management, performance assessment of service delivery and the measurement of long term improvement in outcomes.

Teams which deliver

- 6.6 The planning for, and delivery of, cancer services will be progressed across the Cancer Network by supporting clinical networks of healthcare professionals, patients and voluntary sector representatives to work together in a co-ordinated way across geographical, organisational and professional boundaries.
- 6.7 These clinical networks are responsible for the development of regional standards. These will include protocols, audit, patient pathways, service redesign, quality assurance and the identification of funding priorities. Working collaboratively, they provide leadership and carry regional authority to take forward a programme of work to ensure a high quality, equitable cancer service across the region for patients, carers and their families.
- 6.8 Local multidisciplinary teams (MDTs), and, where appropriate regional MDTs, for all cancer types should be further developed in line with regionally agreed standards. To be fully effective, MDTs must be appropriately supported with both facilities and administrative / secretarial support. Administrative support is a key component of the clinical service and should be recognised for the contribution it brings to the effectiveness of the clinical team. The facilities required may include suitable videoconferencing support to enable optimum discussion to take place with the minimum disruption to clinical time and the engagement of regional experts in specialties with small numbers of staff centrally located. Effective coordination of MDT meetings across Northern Ireland will also be needed to use such expert input optimally.
- 6.9 Effective, responsive team working is itself a skill which will need support through learning, training or other development activities.

Integrated services

- 6.10 The average GP will see several hundred patients each year with symptoms which could possibly be cancer. Some estimates suggest that as many as 1 GP consultation in 20 will be related to cancer or related continuing care. A GP may, however, only see patients with rare cancers once or twice in their

working lives. There is a need, therefore, for referral guidance to help GPs identify those patients who require urgent referral to a specialist for assessment and investigation.

- 6.11 NICA will facilitate the development of regional evidence-based guidance for GP referral, investigation, diagnostics (including imaging), treatment, and follow-up. Key stakeholders, including GPs, service commissioners and providers, cancer professionals and cancer patients should be involved in their development. The guidance will reflect related developments in service modernisation such as the introduction of Integrated Clinical Assessment and Treatment Services in the HPSS.
- 6.12 Primary care teams should have a central role in the ongoing management and support of cancer patients and their families. With perspectives from primary and community care now being weaved across all levels within the Cancer Network, the potential for greater integration across care sectors and standardisation of care is beginning to be realised.
- 6.13 Many patients wish to be cared for at home. The development of new models of service delivery and practitioners, at primary and community levels, with enhanced clinical skills will enable specialist advice and support to be provided to cancer patients, families and professionals. This, plus timely advice from specialists in other settings, will improve continuity of care and prevent unnecessary admission to hospital.
- 6.14 Changes in clinical practice such as outreach chemotherapy and innovative review arrangements will be better facilitated with a fully integrated HPSS. The development of posts for GPs or nurses with special interests (GPwSI / Advanced Practitioner) and nurse specialists in primary care oncology will facilitate the provision of integrated oncology services responsive to the needs of patients and families.
- 6.15 Primary Care leadership is required to provide strategic direction in developing cancer services. While much good work has been undertaken by the Macmillan GP Facilitators, the appointment of dedicated primary care leads across the Cancer Network will help progress the raising of standards of cancer care.

Integrated workforce planning

- 6.16 There have been difficulties in meeting workforce needs in different parts of Northern Ireland. Cancer workforce planning should be developed to meet the needs of the local population and circumstances, including the geography and epidemiology of a 'locality'. An overall regional workforce plan should be built up through the Cancer Network to reflect these local needs. Cancer Units and the Cancer Centre based MDTs have an important role in this through the identification of the priority workforce gaps and training needs. The aggregated plans will support the DHSS and professional bodies in the

development of strategies to ensure the correct numbers of professionals are trained, in place and working effectively to offer the maximum benefit to patients.

- 6.17 Cancer workforce capacity needs to draw from the full range of providers across the Health and Social Services, independent and voluntary sectors. A mechanism needs to be developed to support cancer services workforce planning and development across these sectors.
- 6.18 Capacity also needs to be further increased through new ways of working, including skill mix changes, service redesign and modernisation, education and training. Anticipated developments in many aspects of cancer treatment will require on-going provision of highly qualified health care professionals and the continued development of undergraduate and postgraduate training programmes.
- 6.19 It will be important in taking forward the many developments in cancer services envisaged in this framework document, that a priority is given to the effective implementation of workforce plans and that education and training needs are appropriately resourced.

Services for children and young people

- 6.20 The needs of children and young people with cancer differ from those of adults. Services for the investigation, diagnosis, treatment, support and care for children and young people affected by cancer are highly specialised and are centralised in Belfast, mostly at the Royal Belfast Hospital for Sick Children. Children with cancer, however, may also be affected by other healthcare problems and need the support and input of their GP, primary care team and their local hospital.
- 6.21 The social, educational, sexual health needs and wider impacts of cancer need to be recognised for children, adolescents and young adults. The cure rates for many cancers in younger people are now very good and continually improving. Consequently there are particular needs for continued support and monitoring during their lives.
- 6.22 Care pathways for the different types of cancer which affect children and young people should be developed and used as a basis for relevant clinical audit so that the most important service changes and developments can be identified.

Standards for access to cancer services

- 6.23 Specific standards for access to and progress through cancer services should be introduced. In order to achieve this, every part of the patient care pathway, from referral, through investigation, diagnosis and treatment, needs to be carefully examined with a view to ensuring timely access is consistently available to people across Northern Ireland. From the patient's perspective, the timeliness of treatment and the accuracy of the information they receive from the service about when each stage of their treatment will commence is extremely important. New ways of working should be explored to improve access to diagnostics and treatment, building on the current programme of modernisation and reform in the HPSS to secure real and lasting improvements for patients.
- 6.24 In England, the 1995 Calman/Hine Report and subsequent evidence-based Improving Outcomes Guidance began the process of setting out an evidence-based framework for the configuration of services, high quality care and effective drugs and technologies. Building on the Improving Outcomes series of cancer guidance reports, the National Institute for Health and Clinical Excellence (NICE) has commissioned a comprehensive package of clinical guidance on cancer services covering all cancers. Clinical guidance published by NICE for specific tumour groups (including haematology) should be adopted as the minimum standard for clinical practice in Northern Ireland and should inform the development of access standards.

Improving services, treatment and facilities

- 6.25 Since the Campbell Report there have been significant changes in radiotherapy equipment and treatment planning technology in conjunction with developments in chemotherapy regimes and advances in cancer surgery. At one time patients received treatments sequentially for cancer, including surgery, radiotherapy and chemotherapy. Now the approach to cancer treatment is likely to be a complex combination of these with input from more than one discipline and one provider.
- 6.26 As recognised in the Campbell Report, multidisciplinary management leads to more appropriate treatment and has been shown to produce better outcomes. It is vital that surgery and post-operative care take place under the care of skilled and experienced practitioners and multidisciplinary teams (MDTs) in hospitals equipped to deal with them. The Cancer Centre and Cancer Units will continue to be the main focus for the delivery of specialist cancer treatment.

Cancer surgery

- 6.27 For many patients with cancer, surgery will remain the central treatment option. There is increasing evidence that the best results are obtained when surgery is carried out by specialists. For breast and gynaecological cancers, surgical specialisation is becoming the norm in Northern Ireland. However, this is less commonly the case for other cancers. There needs to be continued development, from a regional perspective, of specialisation in cancer surgery and additional development of necessary support facilities such as intensive care and high dependency unit capacity. Increased specialisation will need to be accompanied by increased capacity for surgery of upper gastrointestinal cancers, bowel cancer, lung cancer and prostate cancer. Further specialisation within surgical oncology is necessary with the aim that all elective cancer surgery should take place within accredited services in designated sites.
- 6.28 New surgical techniques are being developed. These include high intensity focused ultrasound (HIFU); microwaves or radio waves (radiofrequency ablation, or RFA); or even magnets in an attempt to maximise cancer tissue destruction. While promising, these techniques are still largely experimental. Intraoperative radiotherapy administration and chemotherapy use are being tested and, if proven to be clinically-effective, will further influence the number of sites where modern surgery can be performed.

Chemotherapy

- 6.29 An optimal chemotherapy service will increasingly adopt new practices and treatments, innovation and new models of care. This may mean chemotherapy treatment being delivered to patients in a variety of clinical settings - hospital, facilities near to the patient's home and for a number of patients, in their own home. Such advances need to be taken forward in consultation with all the affected stakeholders, including the patients themselves. This work is being progressed by the NICaN Chemotherapy Group.
- 6.30 There needs to be an ongoing and systematic process for evaluating and introducing new drug treatments and technologies when evidence emerges to support their use. From July 2006, NICE guidance will be reviewed for its applicability to Northern Ireland and, where deemed applicable, will be endorsed by the DHSSPS for implementation in the HPSS.
- 6.31 The Regional Oncology and Haematology Drugs and Therapeutics Committee has a pivotal role in identifying priorities for the service in Northern Ireland. In addition NICaN has established a Regional Chemotherapy Group which is working towards the development of standards for the delivery of chemotherapy across Northern Ireland. Action in each of these areas will promote equity of access to chemotherapy drugs for all cancer patients.

Radiotherapy

- 6.32 A regional radiotherapy service is provided at the Cancer Centre. The Centre currently operates eight Linear Accelerators and was built with the capacity to meet planned growth in radiotherapy services until 2015. It will be important in the intervening years to monitor capacity and demand including the ability of the radiotherapy service to sustain equitable access.
- 6.33 Approximately 50%-60% of cancer patients require radiotherapy, either as a curative therapy or for symptom management and palliation. There have been significant improvements in the numbers and types of radiotherapy treatments available in Northern Ireland, including the introduction of brachytherapy and intensity modulated radiation therapy (IMRT). Future advances in chemotherapy and radionuclide combinations must be kept in focus to ensure the Northern Ireland population benefits from therapy advances.
- 6.34 In planning for the decade from 2015-2025, consideration needs to be given as to how future capacity should be planned for including the need to address the issue of equitable access for the population in the western parts of Northern Ireland and concerns about travelling times (see Appendix 4 Equality Impact Assessment). Any review should also take account of further specialisation and advances in technology.

Diagnostic services

- 6.35 Diagnostic services play a critical role supporting evidence based care pathways. There is an increasingly sophisticated range of diagnostics in use of which imaging is a key component. More sophisticated imaging equipment has meant better outcomes for patients. Medical imaging services, which are pivotal to cancer care delivery, from diagnosis through staging and monitoring of the effectiveness of treatment, have been improved through the provision of ten MRI scanners by the end of 2006. In addition, a PET/CT scanner was installed at the Royal Group of Hospitals in 2003 through charitable donation.
- 6.36 A business case for the development of a cyclotron and radiopharmaceutical production unit within the Royal Victoria Hospital has been approved by the Department. It is planned that the cyclotron should be operational from April 2007 and this will enable a wider range of applications for cancer patients to be carried out. It is likely that over the next decade, PET/CT will have an increasing role to play in treatment planning and delivery.
- 6.37 New ways of working, including the introduction of Integrated Clinical Assessment and Treatment Services, place an emphasis on the streamlining of diagnostics in support of improved access to treatment. It will be important that Northern Ireland sustains current levels of investment in state of the art

diagnostic technologies to keep pace with advances that have the potential to bring real improvements in the care and treatment of cancer patients.

Cancer Control Programme - Recommendations

14. Modern information and communication technology should be exploited to facilitate links across clinical networks within the Cancer Network to improve information exchange and decision making in relation to patient care.
15. There should be proactive management and co-ordination of care for patients across the care pathway ensuring access to the highest quality of services through the effective use of MDT trackers and ICT systems.
16. Working through the NI Cancer Network, DHSSPS, commissioners and service providers must ensure that clinical networks are established for all cancer types and that these are appropriately resourced.
17. NICaN will develop standards for the effective working of local and regional multidisciplinary teams. Clinical leadership will be developed and enhanced at all levels.
18. Specialist posts in primary care settings such as GPs with a Special Interest (GPwSIs), nurse specialists and special interests within community pharmacy should be developed in cancer care as well as in palliative and supportive care. Some initial pilot schemes should be in place by 2010.
19. By December 2007 each Local Commissioning Group should have established a professional Cancer Lead post to provide local strategic leadership in developing cancer services.
20. A regional clinical network within the Cancer Network should be developed to address cancers in children and young people. Formal links should be established by the new Children's and Young People's Cancer group with a specific partner cancer network elsewhere in the U.K. or Ireland.
21. By 2007, NICaN should develop regional evidence based referral guidance, to help GPs identify those patients who require urgent referral to a specialist. Referral protocols/care pathways will address the care pathways between GPs and integrated clinical assessment and treatment services (ICATS) and hospital based cancer services and will be subject to ongoing review and monitoring.
22. All cancer patients will have agreed evidence based follow-up and re-referral criteria.
23. By March 2007 standards for access to first definitive treatment will be published for all patients urgently referred from primary care with suspected cancer.

24. By 2010, Northern Ireland will have adopted all departmentally endorsed NICE clinical guidance for all cancers as the minimum standard for clinical practice. Effective implementation strategies for such regional guidance need to be developed and resourced but should be in place as soon as possible and no later than 2010.
25. A regional mechanism should be set up for a comprehensive and co-ordinated approach to competency based cancer workforce planning and development.
26. A regional mechanism should be developed to take forward the 'modernisation' of cancer services that will adopt a competency-based approach to include workforce redesign, and skill mix solutions.
27. By 2007 all cancer patients will have their treatment plan agreed at appropriately constituted and resourced multidisciplinary team meetings.
28. By 2010 all complex cancers (gastric, lung, rectal, oesophageal, gynaecological, melanoma, and ENT) will have their surgical treatments delivered within accredited sites.
29. There will be ongoing identification and implementation of recognised accreditation frameworks for diagnostic services (e.g. Global Rating Scale for endoscopy).
30. NICaN should lead in developing the strategic direction, and future models of practice for chemotherapy services in Northern Ireland.
31. The Regional Oncology and Haematology Drugs and Therapeutic Committee, working with the NICaN chemotherapy group, should develop a multidisciplinary chemotherapy capacity planning model which is regularly reviewed.
32. Given the critical role of diagnostics in many of these developments, DHSSPS, commissioners and service providers should give due consideration to the case for additional investment in this area.

7 - RESEARCH, INFORMATION AND AUDIT

Improving Quality

Previous chapters have focused on the need to improve the quality of the patient experience and the quality of our services and the structures which underpin them. This chapter considers the role of research in improving quality, the need for better information about the outcomes cancer services deliver for people affected by cancer and the role of internal and external validation in ensuring that the standards of service employed in Northern Ireland are of the highest order and are consistently delivered.

The contribution of research

- 7.1 Research will continue to be a key component of the development, implementation and evaluation of cancer services. National and international research findings provide an important source of new knowledge while much vital information can also be obtained through Northern Ireland based research.
- 7.2 Northern Ireland has established a high profile in biomedical/laboratory and clinical cancer research. Genetic science is progressing rapidly and ultimately may lead to ways of preventing some cancers. Northern Ireland has a number of unique social and demographic features which facilitate genetic research. Well established cancer research groups, the clinical genetics service and the Northern Ireland Cancer Registry (NICR) have made significant contributions to cancer research particularly in the area of common genes which predispose to the development of cancer.
- 7.3 Over the last five years there have been many significant developments in cancer research in Northern Ireland.
 - The Ireland-Northern Ireland-National Cancer Institute (USA) Cancer Consortium was established by a Memorandum of Understanding in 1999. The signatories were representatives of the three respective governments. The Memorandum provides support and training for research in cancer. It has facilitated the development of many links between medical and scientific staff both within Ireland and the USA. NCI Cancer Prevention Fellowships were recently opened to Irish applicants. These fellowships provide a unique opportunity for training researchers in cancer prevention research and building up a cadre of researchers with expertise in this field.
 - In 2000 the R&D Office sponsored the formation of a recognised research group (RRG) in cancer. Fifteen projects covering a range of topics such as investigation into the causes of cancer, improvements in

cancer diagnosis and cancer therapies have been approved and funded.

- The All-Ireland Co-operative Group for Cancer Clinical Trials was launched in 2003 under the auspices of the Cancer Consortium. The group has strong links with NCI and may take part in multi-centre trials organised in the USA. It is also building links with the UK National Cancer Research Institute and National Cancer Research Network in Great Britain and with Europe.
- In 2003, Queen's University was successful in attracting £35 million under the Support Programme for University Research (SPUR), £15.8 million of which will go toward a new Centre for Cancer Research and Cell Biology, costing £22 million in total. This state-of-the-art centre will complement the new Cancer Centre at the Belfast City Hospital complex. It will focus on rapid transfer of laboratory developments to patient care. It will bring together researchers from the Schools of Medicine, Chemistry, Biology & Biochemistry and Pharmacy to develop multidisciplinary teams and will provide a foundation model for future research in life sciences with an emphasis on basic science and its translation into clinical application.
- Also in 2003, the Cancer Centre was successful in achieving accredited centre status with NTRAC (National Translational Cancer Research Network).
- At the University of Ulster (UU) at Coleraine a new Centre for Molecular Biosciences opened in February 2004, funded by a £30 million grant from SPUR. This will provide researchers with a purpose built facility in which to undertake cancer research.
- The Northern Ireland Cancer Clinical Trials Unit, located on the Belfast City Hospital site, has provided greatly increased opportunities for Northern Ireland cancer patients to be entered into the latest clinical trials. Currently there are over 50 clinical trials in progress and the number of local patients recruited annually is about 250. This is set to rise significantly in the next few years.

7.4 A number of key themes need to be addressed as we look to the future.

- The planning of a cancer research strategy and the setting of research priorities should be a continuous activity within an integrated programme of cancer services.
- There is a need to enhance research skills and build research capacity within a wide range of groups.

- Cancer research should be developed beyond biomedical/laboratory and clinical cancer research opportunities to explore other areas such as evaluative research into the effectiveness of psychotherapeutic interventions at different stages of disease, longitudinal studies of patient and carer experience or research to explore the impact of policies for service user involvement.
- There is a need to enhance research into preventive work including methods of improving the uptake of cervical and breast screening programmes, the implementation of smoking cessation services and effective public education programmes.
- Patients and carers should have opportunities to influence research programmes. Exploratory research to determine the effects, consequences and practice, of policies and specific strategies for service user involvement and the experience of users should be considered.
- The collaboration with the Republic of Ireland and the National Cancer Institute should be maintained and enhanced through the Consortium to promote excellence in cancer services and research throughout the island of Ireland.
- Steps should be taken to ensure equity of access for all patients into appropriate clinical trials.
- Generally, research into palliative care has not attracted a high priority. Northern Ireland will be able to learn from recommendations forthcoming from the National Cancer Research Institute's work on actions to enhance research in supportive and palliative care.
- Northern Ireland, in common with the rest of the United Kingdom, has many patients who present 'late' with their cancer-related symptoms. This 'late-stage' presentation has an adverse effect on treatment options and outcomes. Qualitative research into this pattern of patient behaviour may have rich rewards for the population as a whole.

Northern Ireland Cancer Registry (NICR)

7.5 The Registry has played an important role in the development of cancer services here and has made a vital contribution in monitoring the impact of the changes since the 1996 Campbell Report. The Registry collects details on all cancers diagnosed in Northern Ireland. It also provides information on cancer deaths, incidence and survival that can be used for research, education, planning and evaluating health services. Through the collaboration

established by the Cancer Consortium, the Cancer Registries in Northern Ireland and the Irish Republic use common data collection and information systems, and hence all-Ireland cancer statistics can be produced.

- 7.6 The Registry's cancer services audit reports mark a significant step forward in the local evaluation of cancer care and confirms the value of the Registry as a vital public health tool.
- 7.7 The development of regionally agreed minimum data sets and the efficient and collaborative management of cancer data would greatly enhance our ability to monitor improvements in cancer services over the next 20 years. The Registry has the potential to play a major role in supporting outcome measurement, in providing analysis and support to clinical audit and in providing performance and management information to support the service improvement work of both service commissioners and service providers. There is a need, however, for the Department and commissioners to consider how this work can best be supported and this consideration must address the funding arrangements that will support the work of the Registry in the future.

Quality standards and monitoring progress

- 7.8 It is important that common quality standards and working processes are agreed across Northern Ireland. Effective clinical governance depends upon effective audit and quality assurance. Processes to monitor new developments in cancer services need to be established. The development of regionally agreed cancer information datasets will also allow the analysis of ongoing performance in investigation and treatment, in addition to the longer term analyses of overall outcomes. Consideration should also be given to the development of a core set of person-centred outcome measures, robust enough to capture changes over time and outcome measures for supportive and palliative care.
- 7.9 Clinical audit will play an increasingly important role in measuring the pace of improvements in patient care and clinical outcomes. It will provide a fundamental tool for multiprofessional and multidisciplinary teams in evaluating the impact of regionally agreed care pathways for cancer patients. The future development of existing and new services should take place within a rigorous audit and evaluation framework.
- 7.10 The Regulation and Quality Improvement Authority (RQIA) is the independent body with responsibility for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland and encouraging the improvement in the quality of those services. The RQIA will provide independent assessment of cancer services against national standards and against the Quality Standards for Health and Social Care.
- 7.11 The Department of Health (England) and the National Institute for Health and Clinical Excellence (NICE) have developed a comprehensive package of

guidance (Improving Outcomes Guidance (IOG)) on services which are most likely to improve outcomes for different types of cancers. This Framework recommends the adoption of NICE clinical guidance on cancer services and that NICA^N takes a lead role in taking forward their implementation in Northern Ireland.

- 7.12 Experience in England has shown that regular peer review is a valuable way of improving the quality of cancer services. It is recommended that cancer services in Northern Ireland should be assessed against national and international standards through a very clear performance management and assessment process which should include peer review.

Ensuring quality in screening programmes

- 7.13 Screening programmes must be of high quality if their potential benefits are to be realised. Each screening programme should have effective quality assurance and performance management arrangements in place and should meet nationally agreed standards. Performance against these standards should be monitored on an ongoing basis to ensure the quality of the service is maintained and improved.

Cancer Control Programme - Recommendations

33. DHSSPS, with the R&D Office, should establish a strategic process for overseeing and facilitating cancer research. That process should reflect a 'from research to policy and practice' perspective.
34. The NICR 5-yearly reviews of patterns and outcomes of care for cancer patients should be repeated to build on existing 1996 and 2001 data.
35. NICA^N and NICR should put in place a prioritised programme of development of regionally agreed minimum data sets for each cancer type.
36. NICA^N and NICR should work with RMAG/NIAAC to ensure that a regionally agreed programme of cancer audit is developed and the methods and results of all audits are shared throughout Northern Ireland.
37. DHSSPS and commissioners should examine the capability of NICR to support outcome measurement and other information needs and the resources necessary to support this work.
38. DHSSPS, commissioners and service providers should ensure, through NICA^N, that action plans, containing costs and milestones, are developed for the implementation of NICE clinical guidance relating to cancer with consideration given as to the likely impact upon other aspects of the HPSS.

39. DHSSPS, commissioners and service providers should ensure, through NICaN, the establishment and development of a rigorous programme of service improvement for cancer services.
40. By 2010, a clear and transparent performance management and assessment process should be developed to enable cancer services to be measured against national and international service standards. This may include a Peer Review process to support quality assurance and enable quality improvement for cancer services.
41. Mechanisms to measure the quality of care and patient experience should be developed and the performance of the service in this regard reviewed regularly.
42. The RQIA should provide independent assessment of cancer services against UK-wide standards.
43. There should be robust quality assurance systems in place for each screening programme.
44. Steps should be taken to ensure equity of access for all patients into appropriate clinical trials.

8 - MAKING IT HAPPEN

This chapter addresses how the recommendations for change and improvement contained in this Cancer Control Programme should be taken forward.

- 8.1 The Regional Cancer Framework aims to ensure excellence in the provision of cancer services for all people affected by cancer. This Cancer Control Programme sets a challenging agenda for the HPSS. Challenging both in the scale of the vision it creates and challenging in terms of the co-ordination of effort that will be required to see the recommendations fulfilled.
- 8.2 Substantial additional resources will be required over the next 20 years to implement the Programme recommendations. The Programme does not, however, provide a financial envelope. Whilst the rate of progress will depend on the availability of finite resources, the DHSSPS will make every effort to argue a substantive case for additional cancer services funding through the Spending Review process. In line with the policy of devolving responsibility to the front line, HPSS organisations will have the maximum flexibility to use allocated resources to meet local needs and priorities within the context of the Cancer Control Programme.
- 8.3 Following public consultation, the next phase will be the development of a detailed action plan to implement the Programme's recommendations. This plan will identify responsibility for delivering action and indicate the steps that can be undertaken within existing resources and those areas where additional resources will be needed. The implementation plan will define the processes that will manage, monitor and review implementation of the Programme recommendations.

The role of HPSS organisations

- 8.4 The publication of the Cancer Control Programme comes at a time of significant change in the organisational structure of the HPSS. The Department, the new Health and Social Services Authority and Health and Social Services Trusts will each have an important role in making the vision of integrated, flexible and responsive cancer services become a reality. Also vital to that success will be the commitment of these organisations to the Cancer Network, recognising it as the agreed mechanism for inclusive service planning and coordination across institutional and professional boundaries. As indicated in the introductory chapter, NICaN is charged with a leading role in taking many of the recommendations forward. That responsibility recognises the crucial part played by healthcare professionals working in all aspects of cancer care. No less crucial, however, is the continued commitment of those involved in policy development, service commissioning and delivery to ensure excellence in the provision of cancer services in Northern Ireland.

Cancer services funding

- 8.5 The continued development of cancer services in Northern Ireland is one of the highest priorities for the DHSSPS. Since the publication of the Campbell Report, the DHSSPS has allocated considerable capital funding for cancer services, with a total of approximately £73 million allocated for the period 1996/97 to 2004/05. Much of this spend was allocated to the construction of the Northern Ireland Cancer Centre, which opened on schedule in March 2006.
- 8.6 In addition, the DHSSPS has provided significant additional revenue funding to Health and Social Services Boards for cancer services in the last number of years, allocating approximately £28 million recurrent and £1.3 million non-recurrent additional funding for cancer services between 1996/97 and 2004/05.
- 8.7 The DHSSPS estimates that the total acute hospital expenditure on cancer services was some £83 million in the financial year 2004/05 and this figure is expected to increase in future years.
- 8.8 There are a number of areas where information about expenditure on cancer services could be improved. For example, although substantial palliative care and other community services are also provided in support of people with cancer, the DHSSPS does not currently collect details of community expenditure by type of condition. Instead, community spend information is collated centrally on the basis of programme of care and by service area such as residential care or domiciliary care. There is also limited information on workforce demographics creating difficulty in accounting for those staff not devoted exclusively to the provision of cancer services.
- 8.9 In recent years, financial monitoring of cancer services has focused on new cancer monies mainly allocated to implement developments arising from the Campbell and Partnership in Caring Reports. Consequently, the DHSSPS is unable to identify the total spend on cancer services across all levels of care.
- 8.10 Better cost and performance information is needed to manage services and identify spending on prevention, detection and treatment. This information would help the DHSSPS to benchmark cancer services in terms of their cost and their outcomes. The development of a more sophisticated understanding of current spend across all aspects of cancer provision (tumour types, prevention, detection, treatment, palliative and supportive care and community cancer care) would better inform future decisions on the allocation of resources.

Securing value for money

- 8.11 The World Health Organisation (WHO) guidelines on national cancer control programmes require cancer strategies to take account of the balance of resources committed to preventing, detecting and treating cancer. The

guidelines state that as an initial step, an analysis of the cancer burden, risk factors and capacity should be undertaken. They also require cancer strategies to detail how to achieve value for money in future policies and investments. These requirements were taken into account during the development of this document, together with government policy in relation to public sector efficiency which in both the Wanless Report and specifically in relation to the HPSS, the Appleby Report, anticipates a shift of resources from treatment to prevention as a central strand of improving NHS performance over the coming decades.

- 8.12 Clear and specific measures against which progress in improving cancer services can be assessed and reported have been set. The implementation of this Cancer Control Programme is expected to deliver improved, quality services which provide value for money.

Targets

Cancer incidence and mortality - targets

- (i) To achieve a 25% reduction in age-adjusted cancer incidence by the year 2025.
- (ii) Increase the 5 year cancer survival rates to the levels of the best European countries²⁵

Specific primary prevention targets - to contribute to the reduction in the incidence of cancer:

- (i) **smoking levels:**

Increase the proportion of 11-16 year old children who do not smoke from 86.9% in 2003 to 95% in 2025.²⁶

Increase the proportion of adults who do not smoke from 74% in 2002/03 to 95% in 2025²⁷.
- (ii) **obesity in children and adults:**

Reverse the current increase in the level of obesity in men and women so that by 2025, the proportion of men who are obese is less than 15%

²⁵ For those diagnosed in 1993-1996 in Northern Ireland the 5-year survival for all cancers (excluding NMS) were 38% for males and 51% for females. For males diagnosed in 90-94 in Austria (the best in Europe at that time) the 5-year survival rate was 55% and for females diagnosed in 90-94 in France (the best in Europe at that time) the 5-year survival rate was 59%.

Source the Regional Strategy Healthier Future

²⁶ Source the Regional Strategy Healthier Future

²⁷ Source the Regional Strategy Healthier Future

and the proportion of women who are obese is less than 17%. (In 1997 17% of men and 20% of women were obese).²⁸

Stop the increase in levels of obesity in children by 2010 and reduce it by 50% by 2025.²⁹

(iii) **levels of alcohol consumption**

Reduce the number of men and women drinking above the recommended limits from 33% and 11% in 2002/03 to 10% and 5%, respectively, by 2025.³⁰

Cancer Control Programme - recommendations

45. The Cancer Control Programme will be subject to review on an ongoing basis. Progress against the recommendations will be published within 3 years of publication with a formal review of the recommendations in 2011.
46. Following public consultation, a detailed action plan for implementation should be developed.
47. The Department should ensure that robust arrangements are put in place to monitor how the regional action plan is being delivered. Progress towards implementation should be reported in HPSS annual reports.
48. Systems should be established to provide better cost and performance information.

²⁸ Source the Regional Strategy Healthier Future

²⁹ Source the Regional Strategy Healthier Future

³⁰ Source the Regional Strategy Healthier Future

REGIONAL CANCER FRAMEWORK – TERMS OF REFERENCE

The Regional Cancer Framework aims to develop recommendations which will set in place a cohesive service for the provision of a uniformly high standard of care for people of all ages with cancer. In particular, the terms of reference are to:

- Review the current services and achievements since the publication of the Campbell Report Cancer Services – Investing for the Future and the palliative care report Partnerships in Caring;
- Assess the level of future need, taking account of changing patterns of cancer and demographic and social trends;
- Identify key issues in service modernisation, workforce development and skill-mix and the associated education and training implications.
- Review the potential for prevention and early detection and develop recommendations for cancer screening programmes and other prevention initiatives;
- Develop recommendations for improving the quality and accessibility of cancer services in primary, secondary, tertiary and community care, in the light of emerging research, new treatments and technologies, the impact of policy changes, and best practice elsewhere;
- Undertake the work in accordance with the principles in the Campbell Report Cancer Services – Investing for the Future, the palliative care report Partnerships in Caring and Developing Better Services – Modernising Hospitals and Reforming Structures; and
- Make detailed recommendations for a programme of action for cancer services up to 2008; outline recommendations for the development of cancer services up to 2015; and for the strategic direction of cancer services up to 2024.

REGIONAL CANCER FRAMEWORK STEERING GROUP

Chairperson

Henrietta Campbell Chief Medical Officer

Members

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REGIONAL CANCER FRAMEWORK PROJECT TEAM

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Gillian Seeds	Principal, Regional Information, DHSSPS
Claire Willis	Senior Medical Officer, DHSSPS

EQUALITY IMPACT ASSESSMENT

Introduction

Section 75 of the Northern Ireland Act 1998 requires the Department of Health, Social Services and Public Safety (DHSSPS) in carrying out its functions relating to Northern Ireland, to have due regard to the need to promote equality of opportunity -

- between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- between men and women generally;
- between persons with a disability and persons without; and
- between persons with dependants and persons without.

In addition, without prejudice to the above obligation, DHSSPS must also, in carrying out its functions relating to Northern Ireland, have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group.

Consequently, each public authority is required to:

- Review its policies and procedures to determine whether there is any adverse or differential impact as regards equality of opportunity in relation to any of the Section 75 groups;
- Make changes to address any identified adverse or differential inequalities;
- Consider new ways of working to promote equality of opportunity among the Section 75 groups.

An Equality Impact Assessment (EQIA) is a thorough and systematic analysis of a policy to determine the extent of differential impact upon the relevant groups and, in turn whether that impact is adverse. Adverse impact is where it has a negative impact on groups or individuals in relation to one or more of the Section 75 groups. The DHSSPS has identified the development of the Regional Cancer Framework as a policy requiring EQIA.

Aim of the Regional Cancer Framework

The proposals in the Regional Cancer Framework, Cancer Control Programme, aim to provide high quality, equitable and cost-effective cancer prevention, screening, early detection, diagnostic, treatment, rehabilitation and palliative care services for

people in Northern Ireland. The aim is to ensure that cancer services are provided to everyone who has need of them on an equitable basis.

Method of working

In the course of our work to develop recommendations, we considered it important to include the views and opinions of people with cancer. To this end, two people with cancer participated as active members of the Framework Group. User views were further gathered at the Framework conference on 4 November 2004 which was attended by representatives of local voluntary cancer groups and health professionals. In addition, representatives from the Framework Group met key interests in the voluntary and professional sectors to discuss various aspects of the Framework's development.

During the development of the Framework, the impact of the proposals on Section 75 equality groups, as well as new TSN requirements, such as inequalities between affluent and deprived communities and people living in rural and urban areas, were considered. As the Framework spans a wide range of aspects of cancer care and prevention, equality issues have been considered separately for cancer incidence, cancer prevention, cancer screening, primary care, palliative care and secondary care cancer services. Before considering these issues in more detail, a general overview of equalities and inequalities in cancer care is discussed below.

EQUALITIES AND INEQUALITIES IN CANCER CARE: GENERAL OVERVIEW

We considered that the 2004 DHSSPS publication Equalities and Inequalities in Health and Social Care in Northern Ireland - A Statistical Overview (www.dhsspsni.gov.uk/stats&research/index.asp) provided a useful introduction to the discussion on equality issues for people with cancer and that the key findings in relation to cancer care should be included in this section of the EQIA. The publication's findings are also relevant to new TSN requirements, for example in relation to socio-economic groups, and these are also discussed in this section.

Age

The incidence of cancer increases with age. Half of all male cancers in Northern Ireland occurred in those aged over 70 years and half of those in females occurred in the 69 and over group. The equality implications in relation to age are discussed more fully in the following sections on registered cancer incidences.

Gender

In 2000, 49% of people diagnosed with cancer were male and 51% were female. These percentages are the same as the overall percentage of males and females in the Northern Ireland population so it is concluded that there is no adverse impact in relation to cancer incidence for the gender equality category.

Death rates were higher for males than for females with males having a one in seven chance of dying from cancer before the age of 75 compared with a one in eight chance for females. Survival rates (between 1993 and 1996) were significantly better in females than in males. This gender difference may be explained by the higher levels of smoking and alcohol related cancers in men, with these cancers generally showing poor survival rates. On the other hand, the more common female cancers have higher survival rates (breast cancer has a five-year survival rate of 78% compared with 8% for lung cancer).

Socio-economic groups

In general, people in lower socio-economic groups tend to have higher incidence of cancer and poorer cancer survival rates, when compared with those in higher socio-economic groups. There are higher rates of lung cancer incidence in the deprived areas of Belfast and in Derry City Councils. People from Newry and Mourne Council area also experienced higher levels of stomach cancer among males than was expected. Across Health Board areas, the Eastern Board area experienced a high rate of cervical cancers, possibly due to lower screening uptake rates. The Southern Board area reported more cases of prostate cancers than expected which may have been attributable to the increased use of prostate specific antigen (PSA) testing in that area. There were no significant differences between the survival rates for each individual cancer site (cancer type) across the four Health and Social Services Board areas (1993-1996).

The differences in cancer incidence and mortality rates across the socio-economic groups can be partly explained by known risk factors such as tobacco smoking, diet and exposure to the sun. There is no data available for Northern Ireland or the UK on the actual contribution of risk factors to cancer deaths but a study in America by Doll and Peto estimates that 30% of cancer deaths are attributed to tobacco smoking which, given the high prevalence of smoking among individuals in lower socio-economic groups, explains the observed differences in lung and other smoking related cancers. A further risk factor for cancer is diet. A higher daily intake of fruit and vegetables is known to offer protection against most cancers. People from lower socio-economic groups, adolescents and males are more likely to have a poor diet and are least likely to change dietary habits.

Sexual orientation

Variations in the incidence of cancer among people of different sexual orientations are difficult to identify due to the lack of available data.

Rural and non rural areas

In relation to all types of cancer, the risk of someone living in a rural area developing cancer is lower than for someone in non-rural areas (7% lower for males and 9% lower for females). In relation to lung cancer, the risk of someone living in rural areas developing lung cancer is markedly lower than someone in non-rural areas (35% lower for males and 43% lower for females).

REGISTERED CANCER INCIDENCES (1995-2001)

In addition to the 2004 DHSSPS publication Equalities and Inequalities in Health and Social Care in Northern Ireland - A Statistical Overview, we have considered data on registered cancer incidences, which has been provided by the Northern Ireland Cancer Registry and the DHSSPS Project Support Analysis Branch (PSAB).

An analysis of 60,252 incidences of all cancers registered from 1995-2001 showed that cancer affects the elderly disproportionately with 63% of all cancer incidences occurring in the 65+ age groups although they only constitute 13% of the total population.

Table 1: All cancer incidences broken down by age group 1995-2001

	0-14	15-39	40-64	65-79	80+	Total
% of all incidences	0.6%	5%	32%	43%	20%	100%
% of all popn	22%	36%	29%	10%	3%	100%

Source: Northern Ireland Cancer Registry / DHSSPS

Breaking the same data down by gender shows that cancer affects both sexes equally.

Table 2: All cancer incidences broken down by gender 1995-2001

	Male	Female	Total
% of all incidences	49%	51%	100%
% of all popn	49%	51%	100%

Source: Northern Ireland Cancer Registry / DHSSPS

Cancer incidence data does not contain any other Section 75 equality group information. However, we can use postcode details as a proxy. All cancer incidences were allocated to electoral ward and incidence rates were standardized across wards to remove the effects of variations in age-gender population structure. The equality profile of the fifth of wards with the worst incidence rates was then compared to the equality profile of Northern Ireland.

The results are presented below and show that those areas with the highest incidence rates have higher percentages of protestants (8% higher) than in Northern Ireland overall. There is a higher proportion of people who are separated/widowed/divorced (5% higher) and a higher proportion of households without dependent children (8% higher) than average in these areas. By both measures of disability, i.e. proportion of people on disability benefits (Disability Living Allowance (DLA) and Attendance Allowance (AA)) and persons with limiting long-term illness (LTI), there is a higher proportion of disabled people in these areas than in Northern Ireland generally (4% higher for DLA & AA and 5% higher for limiting LTI).

In summary, this analysis indicates that the elderly have higher cancer incidence rates and that the protestant community, people separated / widowed / divorced, those without dependent children and disabled people generally live in areas with higher cancer rates.

Table 3: Comparison of equality profile of wards with highest cancer incidence rates with Northern Ireland profile (age-sex standardised)

	Marital Status				Ethnic Group			Persons with Community Background			
	Single	Married	Separated /Widowed /Divorced	All persons	White	Other	All persons	Catholic	Protestant	Other/None	All persons
20% worst wards	33%	45%	21%	100%	99%	1%	100%	35%	61%	4%	100%
NI	33%	51%	16%	100%	99%	1%	100%	44%	53%	3%	100%
Difference	0%	6%	5%	0%	0%	0%	0%	9%	8%	1%	0%

	Disability		Long Term Illness			Unpaid carers		Dependants		
	DLA+AA	All persons	Persons with limiting LTI	Persons without limiting LTI	All persons	All persons who provide	All persons	With Dependent Children	Without Dependent Children	All households
20% worst wards	17%	100%	25%	75%	100%	12%	100%	28%	72%	100%
NI	13%	100%	20%	80%	100%	11%	100%	36%	64%	100%
Difference	4%	0%	5%	5%	0%	1%	0%	8%	8%	0%

	Political Opinion- 2001 Local Council Elections				
	Nationalist	Unionist	Other	No Vote	Electorate
20% worst wards	20%	31%	12%	38%	100%
NI	26%	31%	8%	34%	100%
Difference	6%	1%	4%	4%	0%

Source: Northern Ireland Cancer Registry / DHSSPS (PSAB)

CANCER PREVENTION

In relation to promoting health, which includes cancer prevention initiatives, the Health Promotion Agency (HPA) provides leadership, strategic direction and support where possible to all those involved in promoting health in Northern Ireland, including the Health and Social Services Boards and HSS Trusts. The HPA, Boards and Trusts as public authorities are charged with ensuring that their plans and activities for people in Northern Ireland meet the requirements of all the Section 75 equality groups.

Health Promotion Agency - Equality Impact Assessment (HPA EQIA)

A final equality impact assessment report Equality Impact Assessment on the Delivery of Public Information Campaigns was published by the Health Promotion Agency in November 2004. The Framework concluded that the findings of this report were highly relevant to equality issues regarding cancer prevention campaigns and that it was important to discuss these findings in this section.

The EQIA covered five case studies, including two anti-smoking campaigns, which were screened for equality implications as required by Section 75 and Schedule 9 of the Northern Ireland Act 1998. Equality Commissioners guidance states that the purpose of screening is to identify those policies which are likely to have significant impact on equality of opportunity so that the greatest resources can be devoted to these. A series of screening consultation meetings identified the potential for differential impact arising from the operation of the policy, in particular with regard to disability and ethnic minority groups.

Key findings

The assessment suggests differential impact on two Section 75 groups - disability and ethnicity. There is some evidence to suggest that the opportunities for people with a disability or from black and minority ethnic background may find it more difficult to access campaigns. While differential outcomes were noted on the basis of gender, it is reasonable to assume that they are less due to the impact of the campaigns but rather on the wider factors beyond their scope. No evidence emerged regarding adverse impact differential on sexual orientation, age, religious affiliation, political opinion, marital status and dependents.

Gender

In many cases, men appear to take less note of public information campaigns than women. The evaluation research does not produce any evidence of this being due to adverse impacts in the way the campaigns are delivered. Male and female participants of the research do not differ substantially in their assessment of the content and design of the campaign. The observed differences may equally be ascribed to wider factors, such as the priority attached to health issues by men and women respectively.

Disability

There are indications that public information campaigns may continue to have some differential impacts on people with a disability. On the one hand, the production of material in alternative formats for some of the campaigns (e.g. audiotapes for people with visual disability or subtitles for TV advertisements for people with hearing difficulties) has been an important way of mitigating impacts on people from these groups. But there are some concerns for people with learning disabilities or mental illness that written health promotion material may not reach them due to barriers posed by their format.

Ethnicity

Public information campaigns may have differential impacts on some black and minority ethnic groups. Barriers were identified in relation to language, literacy, a lack of familiarity with some of the concepts promoted, the chosen media of

communication, the distribution of written material and cultural sensitivities. Not all barriers apply to the same extent to all black and minority ethnic groups. Experiences and views also differ within groups.

HPA's key recommendations

- People with a disability or people from black and minority ethnic groups should be portrayed in HPA campaigns.
- Information should be disseminated to people with a disability and to black and minority ethnic groups through more interactive methods (e.g. via roadshows, through outpatient clinics, or through peers and lay workers).
- There should be systematic efforts to determine the health promotion needs of all section 75 groups. (The HPA is raising this with all organisations involved in health promotion in Northern Ireland through the Regional Planning Forum, which brings together all key stakeholders in order to establish more comprehensive joint review of equality of opportunity in relation to health promotion).
- The HPA should review its engagement with organisations representing the interests of people from Section 75 groups. (To begin the process, it is seeking to organise an informal seminar, in conjunction with the DHSSPS, aimed at sharing information. This will include, amongst other things, identifying further opportunities for promoting equality of opportunity in HPA campaigns for the most marginalised groups and consultation on how campaign leaflets and posters can best be disseminated to people from all the Section 75 groups).

Assessment of equality issues in cancer prevention

We noted the HPA's findings about the potential adverse impact of public information campaigns on disability and minority ethnic groups and considered it appropriate to reflect briefly on cancer prevention campaigns, particularly regarding disability and ethnicity.

In relation to the needs of persons with a disability, some literature on cancer prevention is available in other formats, such as audio tapes for people with a visual disability. In relation to cancer prevention literature, it is acknowledged that Boards and Trusts have made efforts to provide this in alternative formats for some ethnic minority groups. However, cancer prevention literature is probably not available in the format required to meet the requirements of all Section 75 groups across the whole of Northern Ireland and we conclude that there is a need for a more consistent and inclusive approach to mitigate the impact on people with a disability or from a minority ethnic group.

Regarding gender, cancer prevention literature and campaigns target men and women. This necessitates some gender specific literature or initiatives according to cancer type (such as testicular cancer and cervical cancer). We have concluded that there was no indication of potential negative impact in relation to gender.

We also considered cancer prevention initiatives for persons of different ages. As previously mentioned, cancer is predominantly a condition affecting older people but all ages are included within cancer prevention activities. For example, care in the sun campaigns specify that preventative action must be taken by adults and children. Although the elderly have higher cancer incidence rates, there are good examples of smoking cessation services which target young people, both boys and girls. The implementation of the Regional Tobacco Action Plan also takes fully into account the need to meet in full the requirements of all the Section 75 equality groups, including people of all ages.

CANCER SCREENING AND EARLY DETECTION

DHSSPS is already tasked with undertaking a detailed equality screening exercise in relation to each screening programme, including cancer screening. For this reason, it was not considered necessary to carry out a detailed equality cancer screening analysis. Instead, it was decided to consider the equality implications of cancer screening programmes for the nine equality groups.

Gender

In Northern Ireland breast and cervical cancer screening services are provided for women by the HPSS because these services are universally regarded as effective. There are no HPSS screening services specifically recommended for men. Regarding PSA testing for prostate cancer, the National Screening Committee has advised that the research evidence does not support the introduction of a prostate cancer screening programme at present. The available evidence for the effectiveness of screening programmes helps to explain the gender inequalities in the provision of screening services.

In the future, the introduction of bowel cancer screening services for both men and women in Northern Ireland will meet Section 75 gender requirements. Currently colon and rectal cancer account for 10% of cancers in women and 11% in men.

Age

Mammography services are available for women aged 50-64. In light of recent evidence about the benefits of screening older women there are plans to extend the service to women up to 70 when current workforce difficulties are resolved. Accessible mammography screening services are provided to all women of relevant age through static services or mobile screening services throughout all Board areas. Currently there is no evidence that population screening is beneficial to women under 50 years of age.

Local cervical cancer screening services are currently offered to all women between the ages of 20 and 65 every five years in primary care and secondary care settings. The age category is set on grounds of evidence of effectiveness.

Socio economic groups/areas of deprivation

Although socio-economic group is a new TSN requirement, rather than a Section 75 one, we recognised that, although screening uptake is generally good, there are pockets of poor uptake, particularly in areas of high deprivation. It is essential to target these areas to raise awareness of the importance of screening and to use approaches that have been shown to influence attendance. These include encouragement by GPs and the removal of barriers to participation.

Ethnicity

Cancer screening services include targeted campaigns for minority communities to ensure that there is no inequality of access to services for any racial group. There is also no evidence that breast and cervical screening services are not equally available to persons with a disability and those without or to any other Section 75 group.

Conclusions and recommendation for cancer screening

Having considered the provision of cancer screening services for each of the nine equality groups, we have concluded that the existing potential adverse impact on gender in relation to female only screening programmes at present is defensible because breast and cervical cancer screening programmes have evidence of efficacy which is lacking for PSA testing for men. Colorectal cancer screening, when introduced, will be available to both men and women. We have, therefore, concluded that the current provision and recommendations for the development of cancer screening services have no potential adverse impact on any of the Section 75 equality groups.

However, we recognise that the more detailed screening exercise on all screening programmes, including cancer, may have implications for the nine equality groups.

PRIMARY CARE

The first point of access to cancer diagnostic services is usually through the patient's local general practitioner. Access to primary care services for the new TSN categories of deprived areas and rural/non rural areas is considered in the 2004 DHSSPS publication Equalities and Inequalities in Health and Social Care in Northern Ireland - A Statistical Overview. The Framework considered it appropriate to include the findings from this document in this section.

Deprived areas

The document advises that the DHSSPS has calculated access times to GP practices (including branch surgeries) for each 2001 Census Output Area. Accessibility is defined as how far people are from services and not how easily they can access the service they require within the health and social care system. Accessibility times reflect travel for vehicles, not pedestrians.

A very small proportion of the population (0.1% or 1,830 people) live more than 15 minutes away from a GP practice and none live more than 30 minutes away. 22% of people and one third of GP practices are located in deprived areas. The average travel time to the nearest GP practice in deprived areas is 3.2 minutes and is slightly less than the Northern Ireland average of 4.1 minutes. When weighted for need, there is virtually no difference in travel times.

Rural/non-rural areas

13% of GP practices are located in the most rural areas. This is similar to the proportion of the Northern Ireland population who live in these areas (15%). The average time it takes to travel to the nearest GP practice from rural areas is 7 minutes. This is double the average in non-rural areas. The difference is slightly less when the travel time is weighted for need.

Conclusion on the accessibility of primary care cancer services

The first point of access to cancer diagnostic services is usually through the patient's local general practitioner. Primary care services for people with cancer are accessible to everyone who has need of them and there is no evidence of any potential negative impact on any of the Section 75 equality groups.

PALLIATIVE CARE

Accessibility of palliative care services

Adult palliative care services are provided in four hospices - Foyle Hospice in Derry, the Southern Area Hospice in Newry, Marie Curie in Belfast and the Northern Ireland Hospice in Belfast. Patients in the Southern, Western and Eastern Boards have access to a local hospice in their Board area. However, there is no hospice in the Northern Board area, which currently uses inpatient services at the Northern Ireland Hospice in Belfast. The Framework noted that accessibility to inpatient palliative care will be improved for the Northern Board's population when the 10 bedded specialist palliative care unit opens at Antrim Hospital in 2006.

There is only one children's hospice - in Belfast - but the DHSSPS policy is that palliative care services for children should be provided at home by a multi-professional team including medical, nursing, allied health, social work and psychology staff. Health and Social Services Boards all provide specialist paediatric nursing services for children in their own home. In light of Departmental policy, the

Framework did not consider that accessibility of access to a children's hospice service was an equality issue.

Out of hours palliative care services

There are some specific problems related to the delivery of general palliative care in the community. Mechanisms need to be implemented to ensure that medical and nursing services are available to patients with advanced cancer on a 24 hour, seven days a week basis regardless of the patient's location and that equipment can be provided without undue delay.

In relation to accessibility to out of hours services, including palliative care, patients in rural areas are at greater disadvantage than those in urban areas. Although there is no detailed analysis of the areas where out of hours services are not so accessible, we have anticipated that it is reasonable to assume that patients in the rural west and south of the province would be particularly affected by the lack of out of hours provision. As these areas contain a higher proportion of nationalists and catholics, there could be a potential adverse impact for these equality groups.

SECONDARY CARE SERVICES

In line with the 1996 Campbell Report, the regional provision of cancer services (all radiotherapy and diagnosis, treatment and management of less common cancers) is undertaken at the regional cancer centre at Belfast City Hospital Trust, which also works closely with the Royal Group of Hospitals (Model 1). The diagnosis, treatment and management of more common cancers is undertaken at the five cancer units at Belfast City, Altnagelvin, Antrim, Craigavon and the Ulster Hospitals (Model 2).

Although the Framework does not propose any change to this pattern of care, the impact of the location of these secondary care services for Section 75 equality groups was nevertheless considered because these services existed before the Northern Ireland Equality Act came into force and had never been subject to an equality assessment.

Statistical data on the nine equality groups was requested from the DHSSPS Information and Analysis Unit. An analysis of the quantitative data available focused on the accessibility of the nine different equality groups to the two models of care outlined above.

Methodology

Access times from the centre of each Census Output Area (COA) by road to the various models of services were calculated using the NMG package based on work using the Microsoft MapPoint software. This has been developed by Dr Tony Hindle to update the SMOSS model which was used to inform a rurality adjustment in the Board capitation formula and was subsequently adapted for the Northern Ireland Ambulance Service (NIAS) Strategic Review.

Numerical data was obtained at COA level in respect of the majority of the nine equality categories (or suitable proxies for the groups) from the 2001 Census of Population. For the “persons with dependants” category, two sources were used: people who provide unpaid care and households with dependent children. Unpaid care in this context is defined as looking after, giving help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability or problems relating to old age. For “political opinion”, first preference votes for 2001 Local Government elections are available on the ARK Northern Ireland Social and Political Archive maintained by the Queen’s University of Belfast and the University of Ulster. This information is broken down by 101 district electoral areas and can be mapped to electoral ward level by assuming that all wards in each electoral area follow the same voting patterns. Although this assumption may be open to question particularly in mixed areas, results using this approach are consistent with other indicators of voting preference.

Table 0-1: Data sources for each equality category

Equality Category	Data Source
Gender	Usually Resident Population (Table KS01)
Age	Age Structure (Table KS02)
Marital Status	Marital Status – all persons aged 16 and over (Table KS04)
Community Background	Community Background: Religion or Religion brought up in. (Table KS07b)
Persons with a disability	Persons with limiting long-term illness (Table KS08)
Persons with dependants	Households With Dependent Children (Table KS21) Persons who provide unpaid care (Table KS08)
Ethnic Group	Ethnic Group (Table KS06)
Political Opinion	2001 Local Government elections
Sexual Orientation	N/A

Once the datasets were assembled at COA (in the case of political opinion – electoral ward level), it was then possible to find the equality group composition of areas which are furthest away from a particular model of services and compare this composition to that of Northern Ireland as a whole.

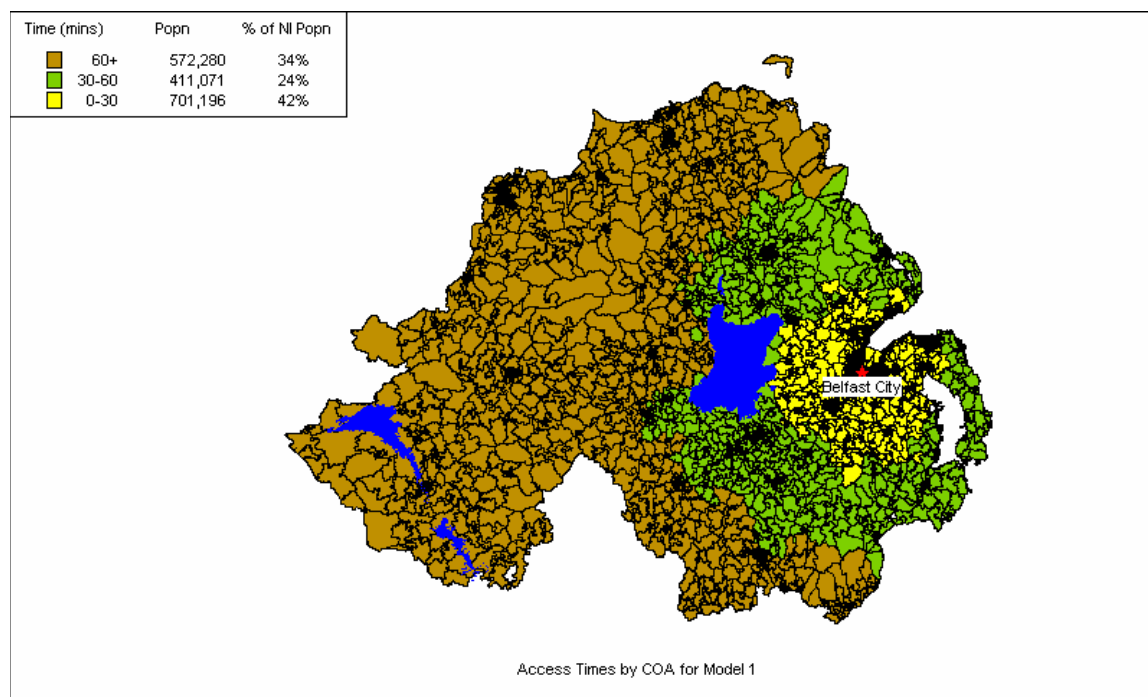
Model 1 (regional cancer services)

Regional cancer services (radiotherapy and diagnosis, treatment and management of rarer cancers) are provided in Belfast at the Belfast City Hospital Trust, which works closely with the Royal Group of Hospitals.

This location has been mapped below and COAs have been shaded according to their access time to this configuration. It can be seen that all of Fermanagh, Tyrone, Derry as well as parts of North Antrim, South Armagh and South Down would be over 60 minutes from services under this configuration. This area contains over

572,000 people representing 34% of the Northern Ireland population. However, 42% of the Northern Irish population would be less than 30 minutes from services.

Figure 0-1: Access times by Census Output Area for Model 1



Using the small-area level data described above, the equality group composition of each of these access time ranges was then determined. The tables below give the equality group breakdowns (with ethnic group analysed at Para 9.68 below).

Table 0-1: Equality group composition of each time range

Access time (mins)	Gender			Age				Marital Status			
	All persons	Males	Females	All persons	Persons under 18	Persons aged 18-64	Persons aged 65+	All persons aged 16 and over	Single (never married)	Married / Remarried	Divorced / Widowed / Separated
Under 30	100%	48%	52%	100%	25%	61%	14%	100%	34%	49%	18%
30 to 60	100%	49%	51%	100%	27%	60%	13%	100%	30%	55%	15%
Over 60	100%	50%	50%	100%	29%	59%	12%	100%	35%	51%	14%
NI	100%	49%	51%	100%	27%	60%	13%	100%	33%	51%	16%

Access time (mins)	Persons with Community Background					Political Opinion - 2001 Local Council Elections				
	All persons	Catholic1	Protestant	Other	None	Electorate	Nationalist	Unionist	Other	NoVote
Under 30	100%	31%	64%	1%	4%	100%	16%	33%	12%	39%
30 to 60	100%	39%	58%	0%	2%	100%	22%	36%	7%	34%
Over 60	100%	62%	36%	0%	1%	100%	42%	26%	5%	28%
NI	100%	44%	53%	0%	3%	100%	26%	31%	8%	34%

Access time (mins)	Disability			Dependants - children			Dependants-unpaid care	
	All persons	Persons with limiting LTI	Persons without limiting LTI	All households	With Dependent Children	Without Dependent Children	All persons	All persons who provide unpaid care
Under 30	100%	21%	79%	100%	33%	67%	100%	12%
30 to 60	100%	19%	81%	100%	37%	63%	100%	11%
Over 60	100%	20%	80%	100%	41%	59%	100%	10%
NI	100%	20%	80%	100%	36%	64%	100%	11%

There is little variation in composition for gender, age, marital status, disability and dependants. For example, 50% of those over 60 minutes away from services are female compared to 51% of the Northern Ireland population. Therefore, for these equality categories there would not appear to be any particular equality group that is especially affected by these locations of services.

In the case of the “community background” category it can be seen that catholics appear to be over-represented in those ranges farther from services. For example, 62% of those living in the ‘over 60 min’ range are catholic yet only 44% of the Northern Ireland population are catholic. In contrast, 36% of those living in the ‘over 60 min’ range are protestant while this community accounts for 53% of the total population.

It can be seen in the case of “political opinion” that 42% of the electorate in the ‘over 60 minutes range’ are nationalist yet this group represent only 26% of the Northern Ireland electorate. In contrast 26% of the electorate in the ‘over 60 minute’ range are unionist while this group accounts for 31% of the total electorate. In the ‘under 30 minute’ range nationalists (16%) are under represented compared to their Northern Ireland average (26%).

An analysis of ethnic group composition of each time range is not very informative as it is generally 99% ‘white’. Instead, Table 0-2 below shows the proportions of each ethnic group in each range of access times. It can be seen, in the ‘over 60 minutes’ time range, only “Irish traveller” (51%) and “other black” (39%) are significantly greater than that of the “white” group. The 2001 Census recorded a total of 1,715 “Irish travellers” and 357 “other black” in Northern Ireland making the numbers in each ethnic group over 60 minutes from services relatively small (875 and 139 respectively).

Table 0-2: Proportions of each ethnic group in each time range

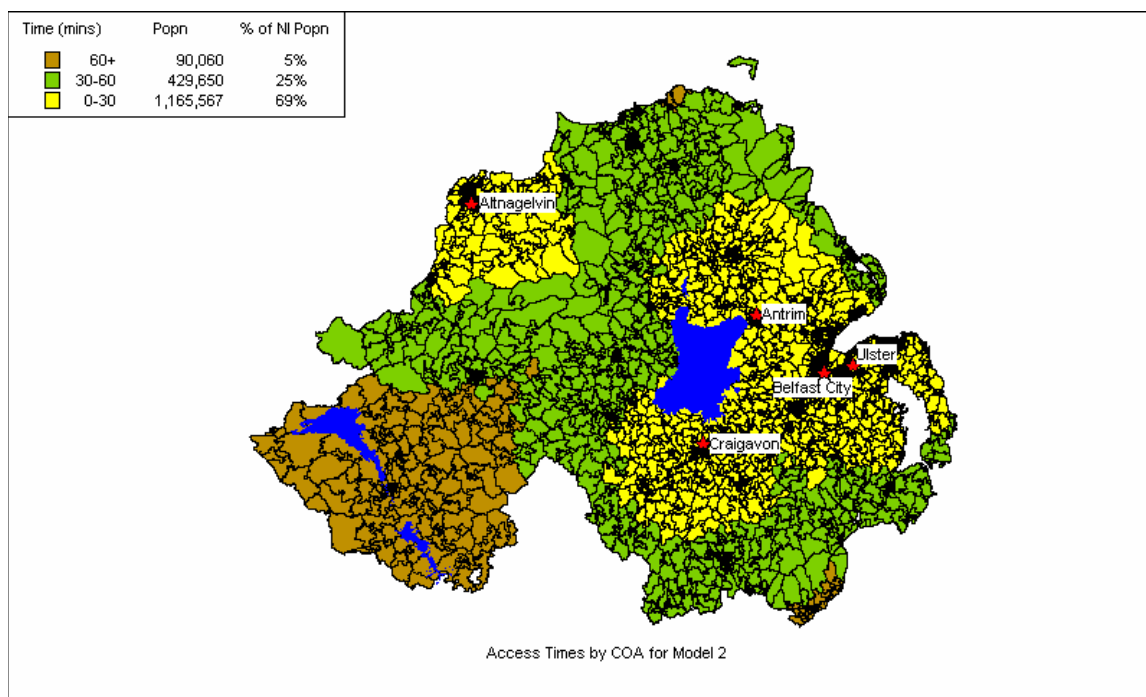
Access time (mins)	Ethnic Group												
	All persons	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla- deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
Under 30	42%	42%	24%	50%	52%	56%	76%	76%	46%	62%	37%	66%	62%
30 to 60	24%	24%	26%	23%	19%	33%	13%	9%	18%	14%	24%	16%	19%
Over 60	34%	34%	51%	28%	30%	11%	11%	15%	35%	24%	39%	18%	19%
NI	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Model 2 (diagnosis, treatment and management of more common cancers)

Diagnosis, treatment and management of more common cancers are provided at the following hospitals: Belfast City, Ulster, Antrim, Craigavon, Altnagelvin.

These locations have been mapped below (Figure 0-1) and COAs have been shaded according to their access time to this configuration. It can be seen that all of Fermanagh, and parts of South Tyrone, South Down and North Antrim would be over 60 minutes from services under this configuration. This area contains over 90,000 people representing 5% of the Northern Ireland population. However 69% of the Northern Irish population would be less than 30 minutes from services.

Figure 0-1: Access times by Census Output Area for Model 2



Using the small-area level data, the equality group composition of each of these access time ranges was then determined. The tables below give the equality group breakdowns (with ethnic group analysed at Para 9.75 below).

Table 0-1: Equality group composition of each time range

Access time (mins)	Gender			Age				Marital Status			
	All persons	Males	Females	All persons	Persons under 18	Persons aged 18-64	Persons aged 65+	All persons aged 16 and over	Single (never married)	Married / Remarried	Divorced / Widowed / Separated
Under 30	100%	48%	52%	100%	26%	60%	13%	100%	33%	50%	17%
30 to 60	100%	49%	51%	100%	28%	59%	13%	100%	33%	53%	14%
Over 60	100%	50%	50%	100%	28%	58%	14%	100%	34%	53%	13%
NI	100%	49%	51%	100%	27%	60%	13%	100%	33%	51%	16%

Access time (mins)	Persons with Community Background				Political Opinion - 2001 Local Council Elections					
	All persons	Catholic	Protestant	Other	None	Electorate	Nationalist	Unionist	Other	NoVote
Under 30	100%	38%	59%	0%	3%	100%	21%	33%	9%	37%
30 to 60	100%	58%	40%	0%	2%	100%	37%	26%	7%	29%
Over 60	100%	56%	43%	0%	1%	100%	39%	34%	3%	24%
NI	100%	44%	53%	0%	3%	100%	26%	31%	8%	34%

Access time (mins)	Disability			Dependants - children			Dependants-unpaid care	
	All persons	Persons with limiting LTI	Persons without limiting LTI	All households	With Dependent Children	Without Dependent Children	All persons	All persons who provide unpaid care
Under 30	100%	20%	80%	100%	35%	65%	100%	11%
30 to 60	100%	20%	80%	100%	39%	61%	100%	10%
Over 60	100%	19%	81%	100%	39%	61%	100%	10%
NI	100%	20%	80%	100%	36%	64%	100%	11%

Except for “community background” and “political opinion” there is little variation in composition for any of these equality groups compared to the Northern Irish average. It can be seen in the case of community background that catholics are over-represented in those ranges farther from services. For example, 56% of those living in the ‘over 60 minute’ range are catholic yet only 44% of the Northern Ireland population are catholic. In contrast, 43% of those living in the ‘over 60 minute’ range are protestant while this community accounts for 53% of the total population.

It can be seen from fig 6.1 that only 5% of the population would be in the ‘over 60 minute’ range and therefore differences in equality group composition in this range should be taken in context. To account for different numbers of people in each access time range, it is helpful to look at the proportion of each community in each range. Table 6-2 below confirms the picture above of less favourable access to services for catholics. It can be seen that 60% of catholics live in the ‘under 30 minute’ range compared to the Northern Ireland average of 69% whilst 76% of protestants live in the same range. It can also be seen that a greater percentage of catholics (7%) than protestants (4%) are over 60 minutes away from services.

Table 6-2: Proportions of each community in each time range

Access time (mins)	Persons with Community Background				
	All persons	Catholic	Protestant	Other	None
Under 30	69%	60%	76%	85%	83%
30 to 60	25%	34%	19%	12%	15%
Over 60	5%	7%	4%	3%	2%
NI	100%	100%	100%	100%	100%

For “political opinion” Table 6-1 shows that 39% of the electorate living in the ‘over 60 minute’ range are nationalist, yet only 26% of the Northern Ireland electorate are nationalist, and 34% of the electorate living in the ‘over 60 minute’ range are unionists while this group accounts for 31% of the Northern Ireland electorate. Therefore, Table 6-1 does not show that any one political opinion group is disadvantaged. However, for further clarification, it is beneficial to repeat the analysis of Table 6-2. The results in Table 6-3 below show that fewer nationalists (55%) than unionists (77%) are within 30 minutes of services and a higher proportion of nationalists (8%) than unionists (6%) are over 60 minutes from services.

Table 6-3: Proportions of each political group in each time range

Access time (mins)	Political Opinion - 2001 Local Council Elections				
	Electorate	Nationalist	Unionist	Other	No vote
Under 30	69%	55%	73%	76%	74%
30 to 60	26%	37%	21%	22%	22%
Over 60	6%	8%	6%	2%	4%
NI	100%	100%	100%	100%	100%

An analysis of ethnic group composition of each time range is not very informative as it is generally 99% 'white'. Instead, Table 6-4 below shows the proportions of each ethnic group in each range of access times. It can be seen that the proportions of all ethnic groups except "Irish traveller" less than 30 minutes from services are larger than that of the "white" majority. However, the vast majority of this group (93%) are less than 60 minutes from services.

Table 0-4: Proportions of each ethnic group in each time range

Access time (mins)	Ethnic Group												
	All persons	White	Irish Traveller	Mixed	Indian	Pakistani	Bangla- deshi	Other Asian	Black Caribbean	Black African	Other Black	Chinese	Other ethnic group
Under 30	69%	69%	56%	77%	83%	90%	91%	86%	74%	80%	75%	84%	83%
30 to 60	25%	26%	37%	19%	16%	9%	7%	12%	25%	16%	22%	14%	14%
Over 60	5%	5%	7%	4%	1%	1%	3%	2%	1%	4%	3%	2%	3%
NI	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Summary results

The likelihood of impact on equality categories for both regional secondary care cancer services in Belfast (Model 1) and for cancer unit diagnostic, treatment and management services for more common cancers (Model 2) is summarised below.

Table 0-2: Likelihood of impact on equality categories for each proposed model

Equality Group	Model 1	Model 2
Gender	N	N
Age	N	N
Marital Status	N	N
Community Background	P	P
Persons with a disability	N	N
Persons with dependants	N	N
Ethnic Group	N	N
Political Opinion	P	P

N = No differential Impact

P = Potential Impact

Action to lessen potential negative impact

Whilst the cancer incidence rate is higher for the elderly and persons from the protestant community, people separated/widowed/divorced, people without dependent children and disabled people generally live in areas with higher cancer rates (see paragraphs 9.18 – 9.24), we have noted the potential differential impact in relation to access to secondary care cancer services for the categories of “community background/religion” and “political opinion” for both Models 1 and 2.

Model 1(regional cancer services)

In order to achieve the best possible cancer care, it is essential that the people of Northern Ireland should have a regional cancer centre service, which is currently met through the regional cancer centre on the Belfast City Hospital site, working closely with the Royal Group of Hospitals (Model 1). Substantial capital investment (over £58m) has been already allocated for the development of the first purpose built cancer centre in Europe on the Belfast City Hospital site the new centre opened in March 2006. The cancer centre already has prestigious research and professional links with the United States National Cancer Institute through the all-Ireland Memorandum of Understanding and the centre is well on the way to becoming a world recognised centre. This can only benefit all people with cancer in Northern Ireland.

However, we recognise that the provision of regional radiotherapy services in Belfast, where they have always been provided, does provide accessibility difficulties for people from Derry, Fermanagh, Tyrone and parts of north Antrim, south Down and Armagh, in particular. The opening of the patient hotel, where overnight accommodation on the Belfast City Hospital site will be available free of charge for any cancer patient who is attending for treatment such as radiotherapy or chemotherapy, is expected to alleviate accessibility difficulties for many people from these areas. We have concluded that the opening of the patient hotel will be a very positive measure and should help mitigate the potential negative impact on the equality categories of “community background/religion” and “political opinion”.

We also considered whether it would be feasible to develop a second cancer centre to promote equality between all Section 75 groups. In line with other cancer centres nationally and elsewhere, the cancer centre in Belfast provides highly specialised cancer services which require to be concentrated in a specific area to provide high quality and viable services. Guidance in England and Wales, published in the 1995 Calman Hine Report A Policy Framework for Commissioning Cancer Services, specifies that a cancer centre should provide regional cancer services for a population of at least 1,000,000 people. On grounds of population size, the Framework concluded that it was not feasible to develop proposals for a second cancer centre in Northern Ireland.

We also considered whether a second cancer centre could be justified on capacity grounds. At present, there are sufficient linear accelerators for the treatment of radiotherapy to meet the needs of the population until at least 2015. In the period 2015-2025, there may be a need to develop proposals for a satellite radiotherapy

unit, which would work closely with the cancer centre at Belfast City Hospital and perhaps provide 2 linear accelerators for the treatment of palliative care patients and patients with less complex cancers. Should the need for a satellite radiotherapy unit be identified, we considered that it should be sited in the area best placed to meet the needs of all Section 75 groups. Currently, it would appear that locating a satellite radiotherapy unit at Altnagelvin Hospital would be the best site in relation to improving accessibility for people from the west of Northern Ireland and would be the means of mitigating against potential adverse impact in relation to the equality categories of “community background/religion” and “political opinion”.

Model 2 (cancer unit services)

In line with recommendations in the 1996 Campbell Report, cancer unit services are provided in each Board area at Altnagelvin, Antrim, Craigavon, Belfast City and the Ulster Hospitals. Prior to the establishment of the cancer units, all chemotherapy services were provided at Belvoir Park Hospital in Belfast. Currently over half of all chemotherapy services are now provided in cancer units which has improved accessibility for many people in Northern Ireland. The de-centralisation of oncology services also means that review clinics now take place at cancer units, as well as the management and treatment of more common cancers.

Access times to the five cancer units shows that all of Fermanagh, parts of South Tyrone, South Down and North Antrim are farthest from services, with a potential adverse impact on catholics and nationalists. In relation to Fermanagh and parts of South Tyrone, we have noted that the Western Board’s establishment of an oncology outreach nursing post covering the Erne and Tyrone County Hospitals means that review patients can now be seen nearer to their own homes rather than having to travel to Altnagelvin Hospital. An evaluation of this post has been very positive and there are recommendations to develop the concept from the current post into a wider service. These are being taken forward by the Western Board, Altnagelvin Cancer Unit and the Belfast City Hospital Cancer Centre.

Equality, Targeting Social Need and Human Rights

Section 75 of the Northern Ireland Act 1998 requires public authorities in carrying out their functions to promote equality of opportunity between persons of different religious belief, political opinion, racial group, marital status, sexual orientation, gender, disability and persons with dependents or without. The DHSSPS has identified the development of cancer services as a policy requiring an Equality Impact Assessment (EQIA).

The new Targeting Social Need (New TSN) policy aims to tackle poverty and exclusion by targeting the efforts and available resources of public agencies towards the people, groups and areas objectively defined as being in greatest social need. The DHSSPS aims to ensure that the implementation of the Regional Cancer Services Framework is compatible with New TSN requirements. Specific areas of concern within the DHSSPS business area include:

- The inequalities which exist in health, many of which are associated with differences between affluent and deprived communities;
- The difficulties in accessing services faced by people in rural areas; and
- That people in some of the Section 75 equality groups may not, for various reasons, use health and social services to the same extent as people from other population groups with similar levels of morbidity.

Another important consideration is the Human Rights Act 1998 which came into force in October 2000. It provides additional focus and emphasis to the rights and freedoms guaranteed under the European Convention of Human Rights. The Framework Steering Group is satisfied that the recommendations in this Report are compatible with the Human Rights Act.

Recommendations

49. Having considered the data in the 2004 DHSSPS publication Equalities and Inequalities in Health and Social Care in Northern Ireland - A Statistical Overview, it is recommended that commissioners, service planners and relevant agencies should take full account of these findings regarding cancer inequalities in planning and developing regional and local cancer prevention strategies. This should help to target cancer prevention campaigns and initiatives on the socio-economic groups and areas where most preventative action is needed.
50. It is recommended that commissioners and service planners should note the EQIA analysis, prepared by the Northern Ireland Cancer Registry and the DHSSPS, in relation to cancer incidence and take effective action to target cancer prevention campaigns and screening programmes to mitigate against any potential adverse impact, particularly in relation to the protestant community, people separated/widowed/divorced, those without dependent children and disabled people.
51. It is recommended that the conclusions and recommendations arising from the more detailed screening exercise of all screening activities, being undertaken by the DHSSPS, should be disseminated to the HPSS and that appropriate action should be taken to mitigate against any potential adverse impact on any of the nine equality groups.
52. It is recommended that commissioners and service planners should expand provision of out of hours services, including palliative care services, to promote equality of access to these services for the whole population.
53. It is recommended that the future needs for radiotherapy services should continue to be kept under review and that, following detailed analysis, future services development should be located at the optimal location to meet the requirements of all Section 75 equality groups.

54. The findings of the HPA EQIA are extremely relevant to cancer prevention campaigns. It is therefore recommended that the DHSSPS, commissioners and service planners should ensure that the conclusions and recommendations arising from the HPA's EQIA are fully taken on board in planning and implementing cancer prevention campaigns.
55. It is recommended that commissioners, working with the cancer units and the cancer centre, should consider developing and implementing oncology outreach posts to mitigate against any potential adverse impact to the catholic and nationalist community in relation to accessibility to cancer unit services. It is also recommended that commissioners should monitor the impact of cancer unit developments to ensure that Section 75 requirements are met for all equality groups.

SUMMARY OF RECOMMENDATIONS

Prevention, Early Detection and Screening

1. Action should be taken to reduce smoking levels in younger people as part of an overall programme of lifestyle skills, increase the provision of smoking cessation services and improve the targeting of those services.
2. Public awareness of early symptoms of cancers should be increased through partnership approaches with cancer charities and the community and voluntary sector and self-support groups. Various methods, including the use of media, should be considered to more effectively target different population groupings and those which are seldom heard.
 - a. A pilot programme to raise public awareness of the symptoms and signs of cancer and the benefits of early detection should be commenced by 2007. The pilot programme should include an assessment of the impact of the programme on symptomatic patients and whether they are presenting earlier for diagnosis and treatment.
 - b. A revised skin cancer/melanoma prevention programme should be developed.
3. Professional awareness of early signs and symptoms of cancer should also be improved through the development of regional referral guidelines.
4. Cancer screening programmes should be enhanced to ensure uptake and effectiveness is maximised.
 - a. The breast screening programme age range should be extended up to 70 years. Service capacity should be developed towards this goal.
 - b. Northern Ireland should introduce liquid based cytology for all cervical smears by March 2008 at the latest.
 - c. Commissioners and providers, working with local women and the voluntary sector, should target areas of poor uptake, find out why women are not coming forward, and use an approach likely to best increase the number of women presenting for breast and cervical screening.
 - d. The Department, in partnership with healthcare professionals, should develop an action plan to take forward introduction of bowel cancer screening in Northern Ireland from 2009.

5. The Department should consider the case for the introduction of a human papilloma virus vaccination programme for young girls, when available, and in line with recommendations of the National Vaccination Committee.
6. The workload of the regional cancer genetics service should be monitored to ensure that the recommendations in the Review of Clinical Genetics for increased staffing and facilities are appropriate for the future provision of clinical genetics services, including cancer genetics.
7. The clinical role of all community and primary care professionals should be developed, particularly in relation to health promotion, smoking cessation, screening, symptom recognition and ongoing supportive care by 2010.

Improving the Experience of People Affected by Cancer

8. Advanced communication skills training, delivered through a phased implementation programme, will be mandatory for health and social care professionals working with people affected by cancer.
9. The Cancer Network, working particularly through the NICaN Supportive and Palliative Care Network, should develop action plans for implementation of recommendations for best practice contained in NICE Guidance on Improving Supportive and Palliative Care for Adults with Cancer (2004) to include:
 - a. an audit of the implementation of the Breaking Bad News guidelines,
 - b. a coordinated approach to user involvement,
 - c. the development of an information strategy to align the information pathway with the care pathway and to include the development of appropriate patient information material,
 - d. the adoption of NICE guidance on the use of complementary therapies,
 - e. the assessment of supportive and palliative care needs at each stage of the cancer journey,
 - f. the provision of appropriate care for people with conditions associated with cancer such as lymphoedema.
10. The education and training recommendations outlined in Partnerships in Caring should be fully implemented.
11. CAPriCORN should be further developed to better support staff, patients carers and those affected by cancer.
12. Commissioners/service planners should draw up local development plans by 2007 to ensure that as soon as possible, but no later than 2010, there should be an enhancement of service provision in the community which extends into the evening and the weekends. The particular needs of patients whose illness is at a terminal stage should be identified and addressed.
13. As soon as possible, but no later than 2010, there should be an enhancement of service capacity to provide intensive coordinated home support (including

any necessary equipment) to patients (both adults and children) with complex needs who are at home.

Improving Access to Diagnosis and Treatment

14. Modern information and communication technology should be exploited to facilitate links across clinical networks within the Cancer Network to improve information exchange and decision making in relation to patient care.
15. There should be proactive management and co-ordination of care for patients across the care pathway ensuring access to the highest quality of services through the effective use of MDT trackers and ICT systems.
16. Working through the NI Cancer Network, DHSSPS, commissioners and service providers must ensure that clinical networks are established for all cancer types and that these are appropriately resourced.
17. NICaN will develop standards for the effective working of local and regional multidisciplinary teams. Clinical leadership will be developed and enhanced at all levels.
18. Specialist posts in primary care settings such GPs with a Special Interest (GPwSIs), nurse specialists and special interests within community pharmacy should be developed in cancer care as well as in palliative and supportive care. Some initial pilot schemes should be in place by 2010.
19. By December 2007 each Local Commissioning Group should have established a professional Cancer Lead post to provide local strategic leadership in developing cancer services.
20. A regional clinical network within the Cancer Network should be developed to address cancers in children and young people. Formal links should be established by the new Children's and Young People's Cancer group with a specific partner cancer network elsewhere in the U.K. or Ireland.
21. By 2007, NICaN should develop regional evidence based referral guidance, to help GPs identify those patients who require urgent referral to a specialist. Referral protocols/care pathways will address the care pathways between GPs and integrated clinical assessment and treatment services (ICATS) and hospital based cancer services and will be subject to ongoing review and monitoring.
22. All cancer patients will have agreed evidence based follow-up and re-referral criteria.
23. By March 2007 standards for access to first definitive treatment will be published for all patients urgently referred from primary care with suspected cancer.

24. By 2010, Northern Ireland will have adopted all departmentally endorsed NICE clinical guidance for all cancers as the minimum standard for clinical practice. Effective implementation strategies for such regional guidance need to be developed and resourced but should be in place as soon as possible and no later than 2010.
25. A regional mechanism should be set up for a comprehensive and co-ordinated approach to competency based cancer workforce planning and development.
26. A regional mechanism should be developed to take forward the 'modernisation' of cancer services that will adopt a competency-based approach to include workforce redesign, and skill mix solutions.
27. By 2007 all cancer patients will have their treatment plan agreed at appropriately constituted and resourced multidisciplinary team meetings.
28. By 2010 all complex cancers (gastric, lung, rectal, oesophageal, gynaecological, melanoma, and ENT) will have their surgical treatments delivered within accredited sites.
29. There will be ongoing identification and implementation of recognised accreditation frameworks for diagnostic services (e.g. global rating scale for endoscopy).
30. NICaN should lead in developing the strategic direction, and future models of practice for chemotherapy services in Northern Ireland.
31. The Regional Oncology and Haematology Drugs and Therapeutic Committee, working with the NICaN chemotherapy group, should develop a multidisciplinary chemotherapy capacity planning model which is regularly reviewed.
32. Given the critical role of diagnostics in many of these developments, DHSSPS, commissioners and service providers should give due consideration to the case for additional investment in this area.

Research, Information and Audit

33. DHSSPS, with the R & D Office, should establish a strategic process for overseeing and facilitating cancer research. That process should reflect a 'from research to policy and practice' perspective.
34. The NICR 5-yearly reviews of patterns and outcomes of care for cancer patients should be repeated to build on existing 1996 and 2001 data.
35. NICaN and NICR should put in place a prioritised programme of development of regionally agreed minimum data sets for each cancer type.

36. NICA and NICR should work with RMAG/NIAAC to ensure that a regionally agreed programme of cancer audit is developed and the methods and results of all audits are shared throughout Northern Ireland.
37. DHSSPS and commissioners should examine the capability of NICR to support outcome measurement and other information needs and the resources necessary to support this work.
38. DHSSPS, commissioners and service providers should ensure, through NICA, that action plans, containing costings and milestones, are developed for the implementation of NICE clinical guidance relating to cancer with consideration given as to the likely impact upon other aspects of the HPSS.
39. DHSSPS, commissioners and service providers should ensure, through NICA, the establishment and development of a rigorous programme of service improvement for cancer services.
40. By 2010, a clear and transparent performance management and assessment process should be developed to enable cancer services to be measured against national and international service standards. This may include a peer review process to support quality assurance and enable quality improvement for cancer services.
41. Mechanisms to measure the quality of care and patient experience should be developed and the performance of the service in this regard reviewed regularly.
42. The RQIA should provide independent assessment of cancer services against UK-wide standards.
43. There should be robust quality assurance systems in place for each screening programme.
44. Steps should be taken to ensure equity of access to all patients into appropriate clinical trials.

Making it Happen

45. The Cancer Control Programme will be subject to review on an ongoing basis. Progress against the recommendations will be published within 3 years of publication with a formal review of the recommendations in 2011.
46. Following public consultation, a detailed action plan for implementation should be developed.
47. The Department should ensure that robust arrangements are put in place to monitor how the regional action plan is being delivered. Progress towards implementation should be reported in HPSS annual reports.

48. Systems should be established to provide better cost and performance information.

Equality Impact Assessment - Recommendations

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