

BETTER CANCER CARE

A DISCUSSION

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FOREWORD

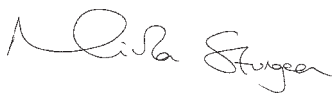


Over the years since the launch of *Cancer in Scotland: Action for Change*, significant improvements have been made in the accessibility and quality of cancer and related services in Scotland.

Evidence of these improvements is readily available through feedback from patients, performance information and annual reports from cancer networks. These are detailed on the *Cancer in Scotland* website (<http://www.cancerinscotland.scot.nhs.uk>).

Although much has been achieved, there is more to be done. More and more people are being diagnosed with cancer and at the same time more and more people are surviving cancer. Against this background and with an ageing population, the various caring services will need to continue to seek out and implement innovative, robust and supportive ways of delivering care. They must focus on the needs of patients and also deliver services in ways that better meet the expectations of all those affected by cancer.

This discussion document sets out a range of broad action areas that we believe will need to be addressed if healthcare services are to keep pace with changes in the level and type of demand across Scotland. It includes questions about specific issues and an open invitation to provide your views and ideas about any aspect of cancer care. We are committed to involving and engaging patients, carers, healthcare professionals and the public in developing our new cancer action plan and your feedback will therefore be invaluable to us. The detailed updated strategy will be published in summer 2008.

A handwritten signature in black ink that reads "Nicola Sturgeon".

Nicola Sturgeon, MSP
Deputy First Minister and Cabinet Secretary for Health and Wellbeing

1. THE CHALLENGE FOR SCOTLAND

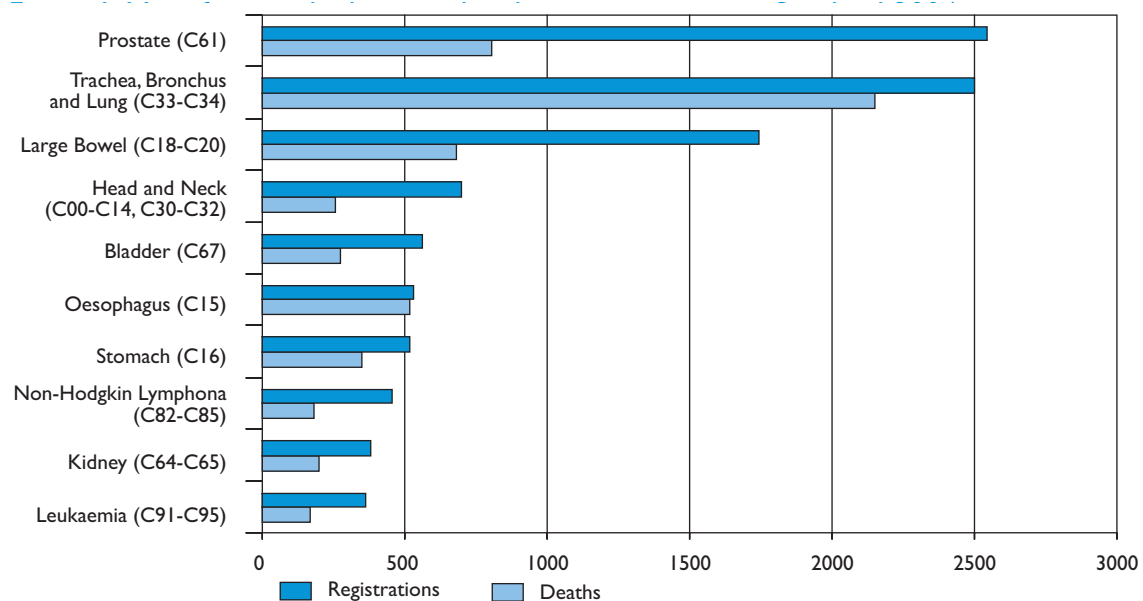
Introduction

Every year, about 27,000 people in Scotland are diagnosed with cancer. This number continues to increase and despite advances in our ability to treat many forms of the disease, cancer remains the leading cause of mortality in Scotland amongst people under the age of 75.

Since the launch of *Cancer in Scotland: Action for Change* in 2001, significant improvements have been made in the quality of care we are able to provide with better access, greater use of new technologies and advances in the training and development of those who work to combat cancer. Our challenge now is to build upon these achievements and ensure that Scotland's approach to tackling cancer continues to reflect the needs of our patients and takes advantage of the opportunities that are open to a modern, efficient system of healthcare.

Incidence

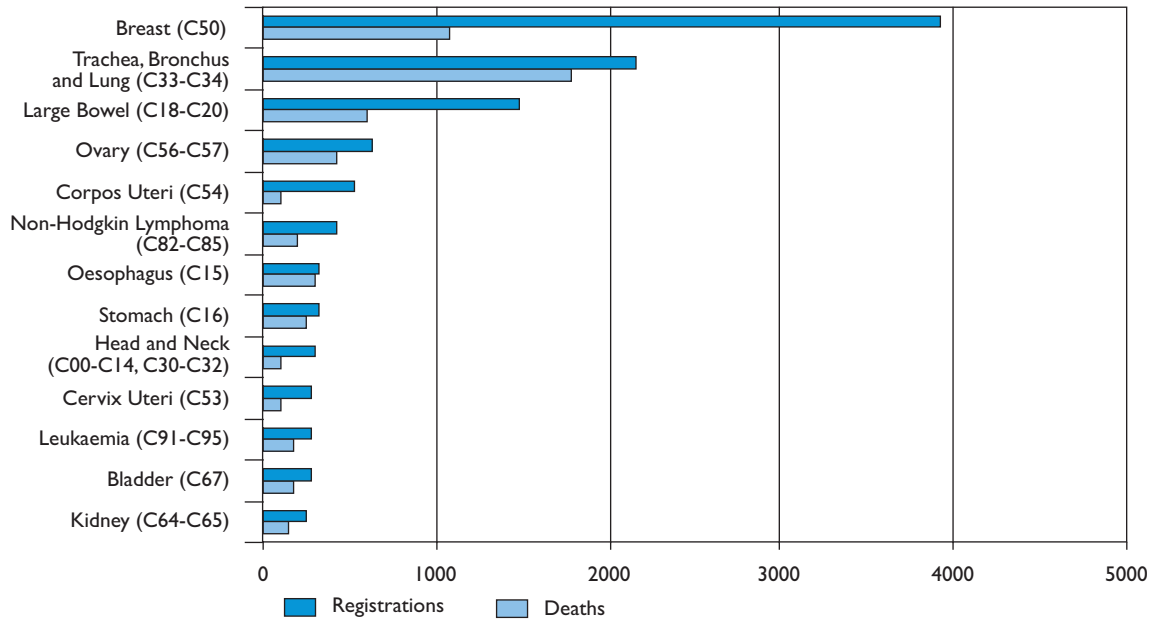
For men, the most common cancers are prostate, lung and colorectal (bowel). These account for 53% of cancers (**Figure 1**).



Source: ISD Scotland

For women, the most common cancers are breast, lung and colorectal (bowel). These account for 55% of cancers (**Figure 2**).

Figure 2: Most frequently diagnosed malignancies in women in Scotland 2004



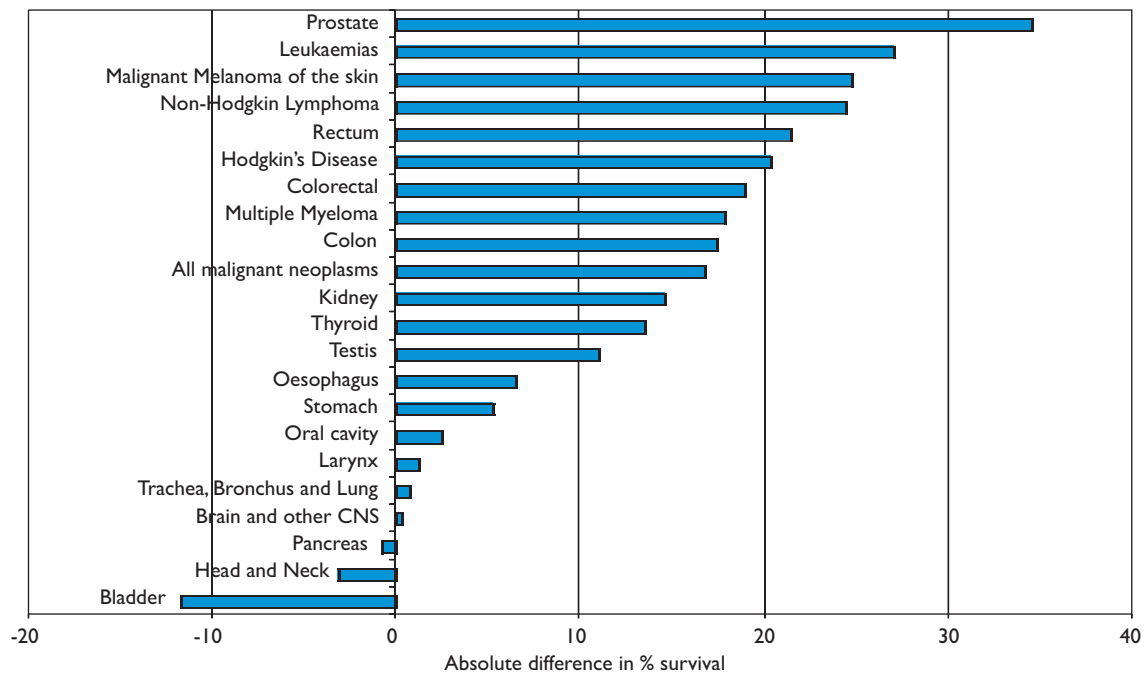
Source: ISD Scotland

Beating Cancer

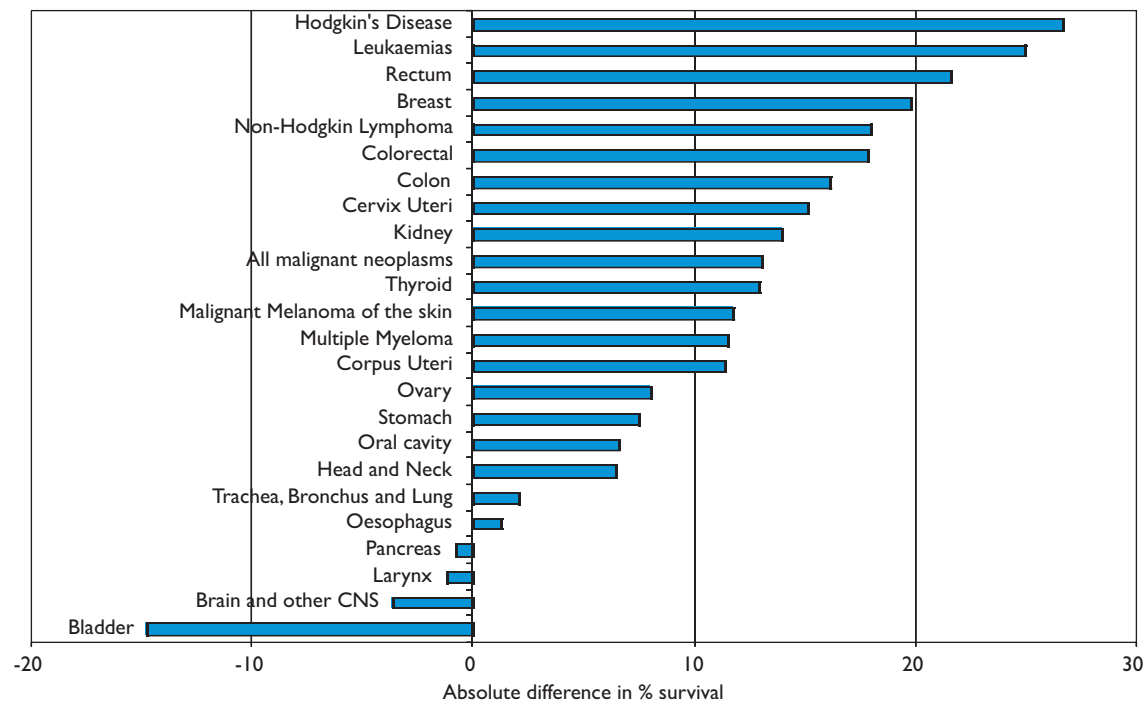
Since the 1980s, almost all cancers showed improvement in survival five years after diagnosis (**Figure 3**) and, for some cancers, this improvement was marked. For example, for malignant melanoma of the skin, male survival increased from 61% in the period 1980-1984 to 86% in the period 2000-2004, an absolute increase of 25%. Over the same period the increase for females was 12%.

Figure 3: Absolute difference¹ in relative survival at five years by cancer and sex: patients diagnosed in 2000-2004 compared to those diagnosed in 1980-1984 (patients aged 15-99)²

Males



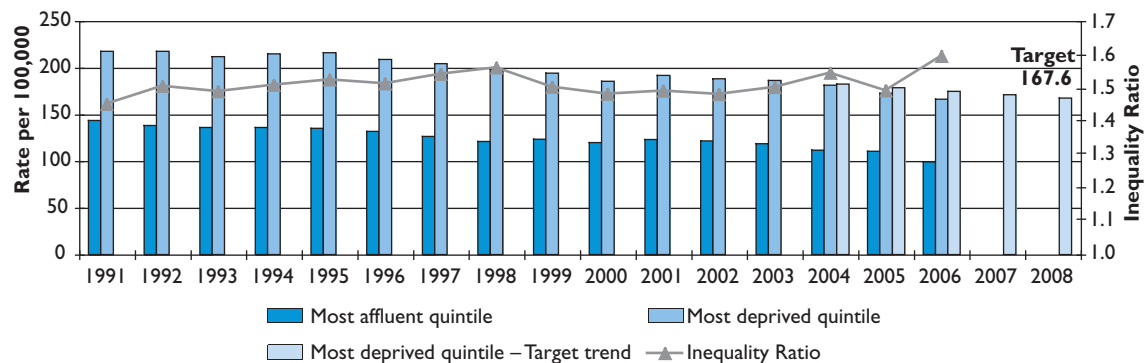
Females



1 The change over the whole period is calculated as the difference between relative survival at 5 years in 1980-1984 and 2000-2004
 2 The recent decrease in survival from bladder cancer is an artefact of classification. Over the period 1996-1999 there were fewer registrations of invasive bladder carcinoma, reflecting a change in coding practice recommended by the European Network of Cancer Registries (ENCR) and subsequently by the United Kingdom Association of Cancer Registries (UKACR).

We are on track to meet the national target of reducing the mortality rate from cancer by 20% in the under 75s between 1995 and 2010, with the overall reduction standing at 18.1% by 2006. In addition, we are also on track to achieve a further 10% reduction in mortality rates in the most deprived sectors of our population. With a 7.5% decrease in the period 2003 to 2006 (Figure 4).

Figure 4: Cancer Mortality (Under 75s)



Drivers of Progress

This solid record of achievement in recent years has resulted from a number of factors:

- **A more comprehensive approach to cancer prevention** – including, most notably, the leadership shown by the introduction of a ban on smoking in public places in 2005
- **Expansion of screening programmes** – the upper age limit for breast cancer screening was raised to 74 and a national bowel cancer screening programme for men and women aged 50 to 74 is now being rolled out across Scotland
- **Faster access to services** – updated guidelines for the referral of patients with suspected cancer were issued in 2007. A £50 million diagnostics programme has seen waiting times for eight diagnostics tests including CT, MRI and endoscopy reduced significantly
- **Access to new technologies** – more and better equipment such as linear accelerators, CT, MRI, endoscopy and a new clinical PET service
- **Expanded workforce** – at least 300 additional staff working across cancer and related services, including more doctors (for example surgeons, radiologists, oncologists), nurses, pharmacists and other healthcare professionals
- **Significant additional investment** – *Cancer in Scotland* was backed up by an additional investment of £25 million each year. In addition, a £40 million capital equipment programme has transformed radiotherapy services in all five cancer centres, £100 million has been provided for the new Beatson West of Scotland Cancer Centre and £27.5 million has been invested through the New Opportunities Fund (now the Big Lottery Fund) in a range of prevention, patient support and palliative care facilities and services.

Going Forward

Better Health, Better Care Action Plan (2007) set out Scotland's national strategy for helping people to sustain and improve their health, particularly in disadvantaged communities, providing better, faster and more local access to healthcare. In doing so, it confirmed that cancer remained a national clinical priority and challenged patients, carers and NHS staff to work together to build on past achievements and develop a new action plan for tackling cancer in the years ahead.

This discussion document aims to stimulate a debate about future priorities for cancer. In particular it follows the direction of *Better Health, Better Care* in challenging us to think about what more can be done to:

- Improve cancer prevention through the creation of healthy environments and supporting healthy choices in our lives
- Tackle health inequalities in terms of outcomes and access to services
- Improve the quality of services across the six dimensions of healthcare quality (patient centredness, safety, effectiveness, efficiency, timeliness, equity)
- Ensure that our approach is developed and implemented in a mutual partnership between Government, NHS staff, patients and the general public.

2. PREVENTION

Better Health, Better Care set out a range of initiatives to improve and sustain the health of people living in Scotland. These include actions that can be taken by NHSScotland alone and those that can only be delivered by working together with partners in the public, private and third sectors.

There is overwhelming evidence that people's lifestyles and behaviours have a major influence on their subsequent health. Smoking causes over one in five of all deaths in Scotland and is the leading preventable cause of ill-health and premature death. Evidence is also accumulating that obesity and excess alcohol consumption may increase the risk of cancer.

Exposure to environmental carcinogens also increases the risk of many cancers. For example, exposure to radon in buildings causes lung cancers. The incidence of skin cancers in Scotland increased significantly over the second half of the 20th century and this has been linked with the increasing opportunity for holiday travel to sunnier climates, and with the use of artificial tanning devices.

The relative contributions of lifestyle factors and environmental carcinogens to the burden of malignant disease is difficult to assess, particularly since there is often a complex relationship between the two. However, in either case, where a causative link is evident, appropriate interventions can reduce the risks significantly.

A recent prospective study of over 20,000 people indicated that those who adopt four health behaviours – taking exercise, not smoking, eating five portions of fruit and vegetables and moderate alcohol intake – can live, on average, up to 14 years longer than those who adopt none of these behaviours. Although the trends were reflected most strongly in rates of cardiovascular disease, they were also apparent for deaths from cancer and other causes (Khaw et al, 2007).

It is clear therefore that many of the Scottish Government's broad health improvement initiatives have the potential to impact positively on cancer in Scotland. These include the commitments to:

- Publish a new smoking prevention action plan to build on previous action to ban smoking in public places and raise the minimum age for purchasing tobacco to 18
- Tackle alcohol misuse through cross-Government action, supported by an additional £85.3 million over 3 years to reduce alcohol related harm
- Work with NHS Boards to ensure consistent weight management strategies, including whole community approaches to tackling childhood obesity and a new Food and Health Delivery Plan which will set out action to encourage a healthier national diet

- Encourage physical activity by creating environments that support walking and cycling and working to ensure that we make the most of the opportunities provided by the Commonwealth Games in 2014
- An integrated focus on the earliest years of a child's life including action to enhance the availability of free school meals, encourage participation in physical activity and support Scotland's children in learning about health and wellbeing
- Identify and encourage simple health promoting actions that can be taken to improve the health of patients, staff and visitors across NHSScotland
- Introduce a new Environment and Health Strategic Framework that will provide a mechanism to co-ordinate and direct action on the key environmental impacts on human health
- Promote awareness and reduction of the risks of skin cancer from exposure to ultraviolet radiation from the sun and from artificial tanning devices.

Public Health

Better Health, Better Care identified a range of opportunities to develop a more integrated approach to promoting and protecting public health in Scotland. This is being developed in conjunction with a range of partners and provides opportunities to:

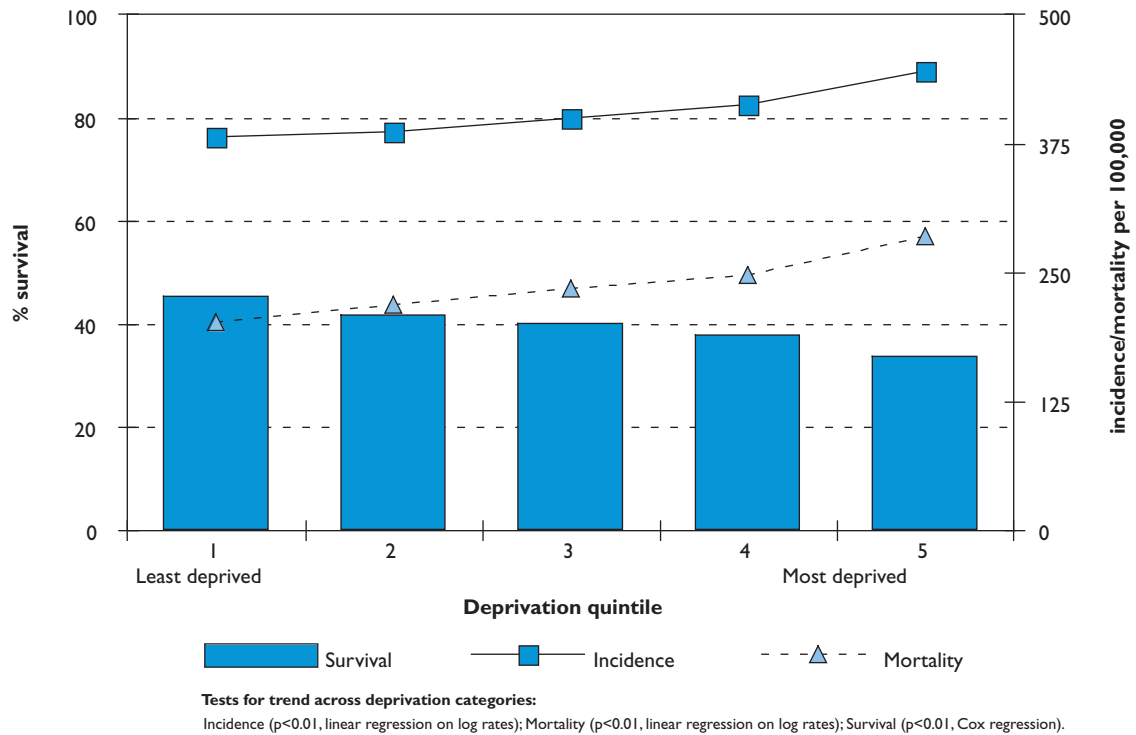
- Ensure the successful introduction of the planned HPV (human papilloma virus) immunisation programme to combat cervical cancer; which will be made available to all girls aged 12-13 from autumn 2008 and its accompanying "catch up" campaign for all girls aged up to 18 at the time of introduction
- Review and clarify the role of the Directors of Public Health in Scotland and develop regional managed public health networks
- Develop an integrated approach to key health promoting messages which better links and integrates the information available from both the third and statutory sectors
- Work with patients, carers and the third sector to improve the quality and accessibility of patient and public information.

Tackling Inequalities

Better Health, Better Care emphasises the priority that the Scottish Government attaches to tackling health inequalities. Given this determination, it is vital that the new strategy identifies actions that can be taken to address the fact that the most deprived members of the Scottish population have the greatest risk of being diagnosed with cancer and the lowest chance of survival (**Figure 5**).

Figure 5: All malignant neoplasms (ICD-9 140-208 excl. 173) Incidence¹, mortality¹ and cause-specific survival^{2,3} at 5 years by deprivation quintile

Patients diagnosed 1991-95



Source: ISD publication 'Trends in Cancer Survival in Scotland 1971-1995'

However, deprivation is only one of the areas of inequity that may be present across cancer provision and outcomes. Geographical influences also play a part (Campbell et al, 2000, 2001), as do factors such as age and sex (see Figures 1, 2, 3 and 4 above for gender differences). Epidemiological differences as a result of culture or race are also to be found.

All public services are subject to the requirements of the relevant equalities legislation and cancer services will be amongst the first to be looked at across NHSScotland to determine the current position. Action will be taken to address any issues identified, including action to ensure that services are accessible by people with mental health problems or communication difficulties.

¹ Age-standardised rates per 100,000 person-years at risk (European standard population).

² Adjusted for age.

³ Cases diagnosed in 1994 and 1995 do not have 5 years' follow up.

Issues to Consider

- How can we take full advantage of the opportunities for cancer prevention provided by the Scottish Government's programme to help people sustain and improve their health?
- What more can we do to improve public awareness about the risk factors associated with cancer and encourage lifestyle choices that mitigate against such factors?
- What more can we do to address inequalities in terms of both access and outcomes?
- What further opportunities are there for taking this whole agenda forward through cooperation and collaboration between the NHS and its partners, e.g. the third sector?

3. SCREENING

In its 2003 report, *Strategies to Improve and Strengthen Cancer Control Programmes in Europe*, the World Health Organisation (WHO) reaffirms the importance of earlier detection, whether through earlier presentation by individuals (requiring greater awareness of cancer and its signs and symptoms and/or taking more responsibility for personal health) or through organised national screening programmes.

Screening is offered to apparently otherwise healthy people, so that a small number who may develop cancer or who may, unknown to them, already have cancer at a very early stage, can be identified and offered early and effective treatment. An essential part of any cancer control plan is therefore population screening – where there is evidence of benefit and where there is a recognised clinically effective test and treatment.

Current Screening Programmes

The current screening programmes comprise:

- The **Scottish Breast Screening Programme** (SBSP) – set up in the late 1980s with the aim of contributing to the reduction in mortality rates from cancer; this programme is subject to rigorous quality assurance and is reviewed regularly to ensure that practice keeps up with emerging evidence. Women aged 50 to 70 are invited to attend for screening every 3 years and women over 70 can request a screening appointment. In light of the evidence that perhaps as many as an additional 275 very early cancers can be detected by taking 2 views at every round of screening, all services in Scotland are planning to introduce this over the next 2 years. Up until now women have had 2 views taken only at the first round of screening with double reporting at every round (i.e. 2 different radiologists looking at and confirming the results of the screening mammogram). In 2005-06, over 166,000 women were screened and 1,348 cancers were detected.
- **Cervical Cancer Screening** – women aged 20 to 60 are invited to attend once every 3 years. Statistical evidence indicates that as a direct result of the cervical cancer screening programme as many as 250 cases of cervical cancer are prevented each year in Scotland. Over the last few years the introduction of new technology – liquid based cytology – has seen a significant improvement in the way cervical smears are processed. This, coupled with a new, more effective IT system for calling up women for testing, has resulted in a much faster turnaround time so that women now generally get their results within 14 days of having their smear (previously it may have taken up to 6 weeks to get results back). The cervical screening programme is also subject to rigorous quality control/quality assurance including routine monitoring of attendance. If we are to maintain the excellent progress made in reducing mortality from cervical cancer it is vital that all women attend for their routine smear test and we will therefore be looking at ways to ensure that the importance of screening and awareness of its benefits are better communicated and understood. This will be especially important with the roll out of the HPV vaccination programme. In 2006/07 over 400,000 smears were taken in Scotland and approximately 3.5% showed some degree of pre-cancerous change, thus enabling early and effective intervention.

- **Scottish Bowel Cancer Screening Programme (SBCSP)** – this is currently being implemented across Scotland and will be provided by every NHS Board by the end of 2009-10. Men and women aged 50 to 74 will be invited to participate every 2 years by sending a sample to the national screening laboratory for testing (known as the faecal occult blood test (FOBT)). It is anticipated that when fully implemented the bowel cancer screening programme may save up to an additional 160 lives each year by detecting cancers in the early stages of development or by detecting pre-cancerous polyps which can then be removed. In the latter cases, individuals who need it can then be routinely monitored so that if a cancer does subsequently develop it will be found at its very early stages when much more amenable to successful treatment. The effectiveness of the SBCSP will also be subject to rigorous quality control/quality assurance including monitoring of attendance.

There is evidence that uptake of screening appointments – for breast, cervical and bowel screening where it is currently available – is variable across the country. The uptake of bowel screening between men and women also varies with fewer men than women opting to participate and we need to seek out ways to drive out inequities in uptake.

Research

New screening programmes are introduced only after there has been rigorous assessment via, for example, multi-national clinical trials, to ensure that any programme will be safe and effective. The UK National Screening Committee is the recognised body that advises UK Health Ministers on matters relating to the introduction of new screening programmes and on the evidence for modification and/or enhancement of existing national screening programmes.

Research is underway in a variety of areas and may in time provide evidence to support the National Screening Committee in making recommendations on new opportunities for screening. These include lung cancer, where a call has been made by the UK National Cancer Research Initiative (NCRI) for a spiral CT screening lung cancer screening proposal in high risk groups. The UK Collaborative Trial of Ovarian Cancer Screening involves some 200,000 women aged 50 to 74 from across the UK, which is assessing the effectiveness of (a) an annual CA 125 blood test and (b) annual trans-vaginal ultrasound. This trial, known as UKCTOCS started in 2000 and results are not expected until approximately 2012.

Cancer Genetics Services

Since the late 1990s, formalised cancer genetics services have been co-ordinated via 4 Regional Genetics Centres supported by a group of cancer genetics associates working in primary care. These services are aimed at supporting people who may be at greater risk of developing breast, ovarian or colorectal cancer because of an inherited genetic pre-disposition. Anyone who is concerned that they may be at increased risk of developing cancer because of their family history can be referred for appropriate risk assessment and advice. All NHS family history clinics work within referral, surveillance and management guidance which was issued in 2001 (NHS HDL(2001)24) and updated for breast cancer assessment in 2007 (NHS HDL(2007)8) to take account of the latest evidence.

We are also in an age in which detailed analysis of the cancer cell can influence many aspects of patient care: helping to direct treatment; helping to deliver prognostic advice to patients and identifying those patients requiring the most urgent/immediate treatment. Our aim must be to incorporate genetics tests rapidly into treatment strategies. Action is therefore required to better co-ordinate our approach, improve research and development and ensure that we make best use of our highly trained healthcare professional staff across all aspects of genetics services.

Issues to Consider

- How should we develop our approach to screening in Scotland?
- What more can we do to raise awareness, encourage participation and reduce inequalities in uptake of existing screening programmes?
- What does the research base tell us about how to derive greatest value from future screening programmes in Scotland?
- What more can we do to ensure cancer genetics services are positioned to play their full part as technology develops and knowledge grows of the impact of genetics in prevention, diagnosis and treatment of cancer?

4. DIAGNOSIS AND TREATMENT

iGPs have a significant role to play in the early detection of cancer and patients are encouraged to contact them if they are concerned about possible symptoms. GPs are trained to recognise these symptoms (though this is not always easy) and refer patients for further specialist investigation. There are now a range of referral guidelines and protocols which are designed to ensure that the person is referred to the right specialist and receives the correct investigations in a timely fashion. Updated Scottish Referral Guidelines for People with a Suspicion of Cancer were issued in February 2007 (NHS HDL(2007)9).

If cancer is diagnosed, there are many health service staff who are involved in caring for patients – the primary care team, the consultant surgeon, oncologist, specialist nurses, pathologists, radiologists, palliative care specialists, haematologists, pharmacists, allied healthcare professionals, administrative support staff and operational managers to name but a few. Modern healthcare is complex and relies on highly skilled people using the most up to date evidence and equipment to provide the best care possible for patients. We therefore need to support and develop innovative healthcare models which ultimately improve delivery of patient care, through early cancer detection, investigation, diagnosis and treatment.

Surgery is the most common form of treatment for most people with cancer; dependent on the type of cancer they have. Scotland has a highly trained and effective surgical workforce who are committed to continuous quality assurance and routinely audit their practice.

Chemotherapy involves the use of cytotoxic drugs to destroy cancer cells. Its use has expanded over time. The delivery of outreach services provided by specialist clinicians and the administration of chemotherapy by local doctors and nurses, offers an increasing number of patients the opportunity to receive treatment closer to home without the need to stay in hospital.

All chemotherapy services in Scotland – regardless of whether they are delivered locally or in a cancer centre – must meet the stringent standards set out in NHS HDL(2005)29. Only if these standards are demonstrably met is it possible for local hospital(s) or services to provide chemotherapy treatments.

Radiotherapy is a highly complex and specialised form of treatment for cancer. It may also be used to relieve some of the symptoms of cancer and it remains widely accepted that radiotherapy will continue to be an essential component of cancer treatment for many years to come. The *Radiotherapy Activity Planning Report (2011-15)* (2006) set out the current and projected needs for “external beam” therapy in Scotland and it is essential that we continue to work with experts to ensure that the planning assumptions used in this work are reviewed and updated regularly.

Radiotherapy can be given from outside the body by machines (linear accelerators) using beams targeted at the cancer. It can also be delivered internally (referred to as brachytherapy), using radioactive sources which are placed in the body close to the tumour site.

All 5 of Scotland's cancer centres are now equipped with state-of-the-art linear accelerators and related equipment, such as CT simulators and highly sophisticated treatment planning systems. The number of linear accelerators has increased from 21 in 2002 to 24. A further (25th) linear accelerator due to become available in Inverness by 2009, where building work is underway to create the additional space required to house that as well as a new CT simulator for treatment planning.

There is ongoing debate about how best to provide radiotherapy treatment as locally as possible while still maintaining specialist expertise required to deliver this treatment. Some of the treatments are highly specialised and require expert planning and delivery. However, other treatments are more straightforward and there may be further opportunities to evolve the organisation of radiotherapy to meet the projected increase in cancer cases and deliver treatments locally.

Recent incidents, both in Scotland (Scottish Executive, 2007) and in France (Inspection générale des affaires sociales, 2007), have highlighted again the risks to patients undergoing radiotherapy treatment, and the vital importance of ensuring that treatments are planned and delivered with the utmost care. In this regard, the Scottish Government is continuing to work with the 5 radiotherapy centres in Scotland to further develop provisions for enhancement of patient safety.

Issues to Consider

- How do we continue to improve diagnostic and treatment services?
- How should we support the future development of surgical skills within NHSScotland's workforce?
- What are the future priorities to ensure safe and effective radiotherapy, chemotherapy and drug treatments across Scotland?
- What more can we do to ensure cancer genetics services are positioned to play their full part as technology develops and knowledge grows of the impact of genetics in prevention, diagnosis and treatment of cancer?
- How do we balance the need to ensure local access and convenience with the need to maintain specialist expertise and capacity?

5. PALLIATIVE CARE

Palliative care and end of life care are integral parts of care delivery for people living with cancer; sometimes called survivorship, and for those people who, unfortunately, subsequently die from cancer. Palliative care is not just about care in the last months, days and hours of a person's life. It is also about enabling someone to live with a life-threatening condition, maintaining as far as possible, improving quality of life for patients and their families. As well as controlling pain and other distressing symptoms, it is about helping patients and their families cope with emotional upset and practical problems of the situation, helping people to deal with spiritual questions which may arise from their illness, and supporting family and friends in their bereavement.

Better Health, Better Care confirmed that by March 2008 a plan will be published that will bring a single, comprehensive approach to palliative care across Scotland. Our strategic approach will reflect the recommendations of the report from the Scottish Partnership for Palliative Care: *Palliative and End of Life Care in Scotland: The Case for a Cohesive Approach*. It will ensure that the planning and provision of services fully recognise the needs of patients and carers; and that the professionals who provide care are able to do so in a way which is integrated and in the most appropriate setting in line with the patient's wishes wherever possible.

Issues to Consider

- There are numerous examples of excellent palliative care in Scotland. How do we ensure that this happens more systematically?
- What are the key issues for people with cancer and their carers when considering palliative care services?
- How do we balance the need to ensure local access and convenience with the need to maintain specialist expertise and capacity?

6. ASSURING QUALITY OF CARE

Multi-disciplinary teams (MDTs) are internationally recognised markers of quality in cancer services. MDTs discuss all new cases and agree on their recommendations for the optimal treatment(s) available for each patient. This means that patients can be confident that decisions made about their treatment and care derive from the collective knowledge and expertise of medical, nursing, pharmacy and other relevant healthcare professionals, working together in an integrated fashion.

Clinical standards for breast, lung, colorectal and ovarian cancer were set out by the Clinical Standards Board for Scotland³ in 2001. These will be updated by NHS QIS in 2008. In addition, NHS QIS will publish new clinical standards for all cancer services during 2008 which will allow a greater range of services to be subject to external independent scrutiny. Clinical audit is essential to measure the quality of care, enable meaningful comparison between and across multiple services and to provide the information needed to support any action required to ensure continuous improvements in cancer services.

Cancer networks are responsible for assessing the quality of care provided across cancer services and there are many examples of this across all tumour types and throughout NHS Boards. For example, using CSBS clinical standards, assessments of the quality of services provided have been carried out by breast and colorectal cancer networks. Such nationwide collaboration and comparison across cancer clinical networks will continue to be a key feature of our approach to quality assurance. It is therefore important that we develop more formalised arrangements to enable us to benchmark care against that provided in other countries and make such quality data publicly available in a meaningful and understandable way.

Research/Clinical Trials

There is significant evidence that outcomes are improved for those patients treated in environments where research is the norm or for those patients who are involved in cancer trials. At any one time there are a variety of new treatments and novel drugs being tested in the NHS to establish whether they offer benefits over the current standard therapies. Through the Chief Scientist Office (CSO) cancer research is well funded with £55 million being spent in support of research carried out in Scotland in 2006-07 (14% of UK total). During that year CSO also spent £2.9 million on directly funded research projects and initiatives as well as £10 million to support cancer research within the NHS.

Our aim is to integrate research into routine care and improve patient care by speeding up access to best care and treatment across the country. In 2001, evidence suggested that with the exception of haematological malignancies (particularly childhood leukaemia), relatively few patients with cancer participated in clinical trials. The Scottish Cancer Research Network (SCRN) was therefore established with the aim of at least doubling entry to cancer trials and latest figures confirm that it has helped increase participation from 3.7% of cancer incident cases in 2002-03, to 13.9% in 2005-06. SCRN has also increased the number of patients outwith the major cancer centres able to take part in a clinical trial. However, it should be noted patient participation in cancer trials fell quite significantly in 2006-07, both in Scotland and across the rest of the UK. In addition, considerable differences are still apparent when recruitment to trials in different tumour types is examined, e.g. 30% of breast cancer patients are taking part in trials compared with 6% of prostate cancer patients or 3.1% of lung cancer patients.

Waiting Times

Cancer in Scotland confirmed that “to increase the probability of treatment success while at the same time minimising patient anxiety and stress, delays in investigation, diagnosis and subsequent treatment of cancer must be eliminated wherever possible”.

Considerable progress has been made in recent years in improving waiting times for cancer services and most NHS Boards now meet the 31 day waiting time targets for urgent referral to treatment for children’s cancers and leukaemia. The 31 day target from diagnosis to treatment for breast cancer target is subject to variation in some instances but is also normally met in most NHS Board areas.

In 2008-09, NHS Boards will continue to assess their performance against the various national waiting times targets for cancer services, including the maximum 62 day wait from urgent referral to treatment for all cancer types. This target has proved extremely challenging over the past few years, but improvements have been made, particularly over the past year and it is predicted that the target will be met for the first time from the end of 2007. This will be enormously beneficial in terms of reducing periods of anxiety and uncertainty for patients, their families and carers.

Both in the context of improving patient experience and the potential benefits for outcomes of earlier diagnosis and treatment, we will be looking at options for new cancer waiting times targets. These must be designed to be as inclusive as possible and meaningful for our patients.

Issues to Consider

- Which aspects of the suggested quality assurance programme should be prioritised to ensure continuous improvements in the speed of access to and quality of care for people with cancer? What more needs to be done to eliminate variations in practice across cancer centres and/or specific tumour services?
- How might we best formalise a publicly reported quality assurance programme for cancer services using comparative clinical audit?
- Is there a need to look at the way cancer audit is organised in Scotland and determine if the current configuration will enable us to meet the challenges to cancer care over the next few years?
- What information should be routinely available to the patients and carers to allow them access to data on service quality and how should this be presented?
- How could we encourage greater participation in clinical trials?
- What further opportunities do you see for taking this forward through cooperation and collaboration between the NHS and its partners, e.g. the third sector?
- In looking at options for new cancer waiting times targets, how could efforts be targeted to be more inclusive and meaningful for clinicians and patients, secure rapid access to diagnosis and treatment and at the same time ensure sustainable, equitable and qualitative improvements in cancer care?

7. PUTTING PATIENTS AT THE CENTRE

Earlier diagnosis and new treatments have enabled people with cancer to survive longer than ever before. We therefore need to develop new methods of care which enable people to lead healthy, normal lives while at the same time ensuring that they receive the appropriate follow up by the right staff in the right place. We also need to ensure that services are sensitive to the particular issues experienced by older people given our ageing population and the higher incidence of cancer and multiple long term conditions amongst older age groups.

Supported Self Management

As many more people are surviving cancer, some of whom may also be living with one or more other long term conditions, it is becoming increasingly important to consider what support and services are required to help people to maximise their independence, including their rehabilitation. A good example of how we have started to make inroads across these important areas is through the development of a model of supported self management. This is being developed across all stages of the 'patient journey' for cancer and the key elements of the model include better information, questions and prompts on how to 'navigate the system', knowing who to contact and what skills are necessary to be able to 'self manage'. From discussions held with patients, carers and healthcare professionals, it is clear that supported self management is about encouraging and supporting people to be as active as they can be, recognising that this may fluctuate for people throughout their pathway of care. Supported self management is about what can be *added* to the existing services, not *instead* of existing services and about working together in a supportive way throughout the whole patient journey of care. There are already many existing examples of good practice in supported self management occurring in parts of Scotland.

In thinking about what NHSScotland needs to do to further develop and deliver supported self management, patients, carers and healthcare professionals identified shared key themes. These include:

- the importance of clear and open communication between patients, carers and healthcare professions
- supported education and training to give people the confidence and skills to feel ready to take more responsibility for their health
- education and training for staff; creating a system of information flexible to person's need; and focusing on the patient experience and developing possibilities for intervention across the pathway.

From 2008, *Better Together*, NHSScotland's Patient Experience Programme will empower patients, carers and healthcare staff across Scotland to work together to improve our services for the benefit of patients. Preliminary work within the programme is being focussed on improving the experiences of people with cancer and the programme provides us with a huge opportunity to tap into the experiences of our patients and use them to drive improvements in the services we offer.

One of the areas that will be tackled is access to advice and support. To achieve this, the Independent Advice and Support Service was launched by the Minister for Public Health in September 2007. Funded by NHS Boards in a strategic partnership with a consortia of local Citizens Advice Bureaux, the service will provide information about a wide range of issues, including advice about access to benefits and support services.

Safety

Patient safety is paramount at all times. The Scottish Patient Safety Alliance (SPSA), launched in 2007 and co-ordinated by NHS QIS, will aim to reduce healthcare associated infection, adverse surgical incidents, adverse drug events, improve critical care outcomes, organisation and leadership on safety. *Better Health, Better Care* confirmed that Scottish Government will support the SPSA to deliver significant improvements to safety in all major NHS hospitals in Scotland.

Issues to Consider

- How can we further improve the experience of patients with cancer?
- How can we further improve the information that is available to support patients, their families and carers? What information gaps exist at present for public/patients and how are these best addressed?
- How can we work more effectively with the third sector in meeting these objectives?
- How could the model of self care management be implemented across the pathway of care?
- What approaches need to be considered to deliver the services required to meet the survivorship needs of patients living with cancer and patients living with cancer as well as other long term conditions?
- How can we further improve rehabilitation for people with cancer and how can their needs be better supported?
- How do we ensure better integration and continuity of care?
- Have you had any recent personal experiences that might help shape and inform future actions across Scotland?

8. DELIVERY

NHSScotland makes a significant investment every year in the delivery of cancer care across primary, community, acute and tertiary services. As demand continues to grow and new opportunities emerge, it is incumbent on NHS healthcare professionals to ensure the best possible use of the available resources.

New Cancer Drugs

The Scottish Medicines Consortium (SMC) has a remit to examine the clinical and cost effectiveness of all newly licensed drugs in Scotland and provide advice to NHS Boards on their use. Regional cancer networks have established robust horizon scanning mechanisms that identify new drugs that are likely to become available post clinical trials and enable NHS Boards to make appropriate financial provision for their introduction.

Cancer networks support NHS Boards to deliver the range and quality of services required to meet the needs of their local populations. Therefore, they must keep abreast of clinical and technological developments and patient/carers' experiences by, for example, addressing variations in clinical practice, where progress has already been made through the development of agreed clinical protocols. Scottish Intercollegiate Guidelines Network (SIGN) clinical guidelines for specific tumour types, hand in hand with routine clinical audit, also underpin quality assurance (see also under *Assuring Quality of Care*).

Service Planning

There are three regional cancer networks – West of Scotland (WoSCAN), South East Scotland (SCAN) and North of Scotland (NoSCAN). Each of these is responsible for the planning of cancer services and is supported to do so through a Regional Cancer Advisory Group (RCAG), chaired by an NHS Board Chief Executive. These networks have proved extremely valuable in implementing the actions set out in *Cancer in Scotland: Action for Change*, clarifying the complexities of clinical pathways and service delivery and supporting continuing qualitative improvements in the delivery of care.

Better Health, Better Care committed to reviewing planning arrangements across NHSScotland at a national, regional and local level. This it argued, would require the development of an agreed planning framework covering all services, which clarified roles and responsibilities at each level of planning and ensured an integrated approach to financial, service and workforce planning. There are also potentially further opportunities to improve planning and service delivery by:

- providing Community Health Partnerships with a broader range of delegated resources and greater flexibility in decision making
- reviewing the purpose, objectives and ways of working of Scotland's Special NHS Boards to ensure that they maximise the value they can add to NHSScotland as whole, and
- enhancing the role of managed clinical networks more generally across Scotland to ensure effective clinical leadership in the development of services.

e-Health and Cancer Services

Clinical care requires a variety of sophisticated data capture, information storage and communication processes. There are a plethora of e-health support systems across NHS Board areas and over time significant efforts have been made to ensure that these systems can (where possible) be “joined up” to provide a cohesive eHealth approach across the country. This process will be reflected in the new e-Health strategy for NHSScotland due to be published in spring 2008.

The development of the Generic Clinical System (GCS) is well underway, providing a confidential, comprehensive and powerful tool that brings together information on all aspects of clinical care without the need for paper records. Work is progressing on a regional basis on systems for breast cancer (SCAN), gynaecological cancers (NoSCAN) and head and neck cancers (WoSCAN). It has also been agreed to begin planning the development of systems for colorectal and lung cancer services within NoSCAN and SCAN respectively.

GCS offers the prospect, not only of clinical record keeping to support patients and healthcare professionals, but also of a confidential and robust method of electronic data capture. A GCS waiting times module has also been developed that has been piloted in 2 NHS Board areas and is now capable of being rolled out to provide electronic means of gathering performance information.

Clinical Leadership

Recognised specialists provide clinical leadership for each of the 3 regional cancer networks and managed clinical networks for specific tumour types. Given the breadth of the challenges and opportunities identified in this discussion document there may also be a case for reappointing a national lead clinician charged with engaging clinicians throughout Scotland in the development and delivery of national cancer policy.

Issues to Consider

- How could cancer networks be developed further to ensure efficiency and effectiveness of cancer care? Is the current balance optimal? What further steps do you think should be considered? Are you aware of duplications of work which could be eliminated?
- Is there a need for a new lead clinician role to drive change and support clinical leads and networks across NHSScotland?
- Which aspects would you prioritise to maximise efficiency and effectiveness of cancer services?
- What are the most important factors which should be taken into account when considering the optimum use of resources? How should we engage people in these decisions?
- What further opportunities do you see for taking this forward through cooperation and collaboration between the NHS and its partners, e.g. between and across cancer networks?
- What should we do to ensure continuing focus on e-health and tele-health to support clinicians and to underpin continuous improvement in cancer services?
- How can the new e-health strategy better support quality assurance and help make best use of available resources?
- Which key performance indicators would best focus NHSScotland on continuing to ensure the most efficient and effective cancer services possible?

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GLOSSARY

Brachytherapy	Radiotherapy delivered using an internal radiation source close to the surface of the tumour. Used most commonly for gynaecological tumours.
CA 125	Cancer antigen 125 (antigens appear soon after the infection of a cell by virus, but before virus replication has begun).
Cancer	Abnormal growth of cells which tend to proliferate in an uncontrolled way and in some cases, metastasize. Cancer is not a single disease but a group of more than 100 different and distinctive diseases. Cancer can occur in any tissue of the body and has many different forms. Most cancers are named after the type of cell or organ in which they originated.
Chemotherapy	The use of cytotoxic drugs which interfere with the process of cell division to destroy malignant cells.
CT (Computed Tomography)	An x-ray technique using a scanner which takes a series of images across the body which can be viewed in 2D (dimensional) or 3D form.
Cytology	The study of cells.
Cytotoxic	Chemicals that are directly toxic to cells, preventing their reproduction or growth.
e-Health	The use of electronic communication and information technology in the healthcare sector.
Endoscopy	Visual inspection of a body cavity using an endoscope, which is a flexible viewing instrument.
Epidemiology	The branch of medicine that deals with the study of the causes, distribution, and control of health-related problems or disease in populations.
External beam radiotherapy	Radiotherapy treatment delivered as a series of short daily treatments in the radiotherapy department, using a linear accelerator. In the majority of cases, this treatment is delivered on an outpatient basis.
Haematologist	A doctor who specialises in the medical study of the blood and blood-producing organs.

Health Technology Assessments (HTA)	The HTA programme, part of the National Institute for Health Research, works to provide all those who make decisions in the NHS with high quality information on the costs, effectiveness and broader impact of health care treatments and tests.
Horizon Scan	The systematic examination of potential threats, opportunities and likely future developments, strengths and weaknesses to planning.
HPV (Human papilloma virus)	The HPV is a risk factor for cervical cancer, transmitted through intimate contact, including sexual intercourse. Vaccines are now available to prevent infection to help prevent this type of cancer.
Incidence	The number of new cases/episodes in a defined population within a given time period.
Invasive	Cancer that can/has spread from its histological original site.
ISD (Information & Statistics Division)	Scotland's national organisation for health information, statistics and IT services.
Leukaemia	The abnormal growth and development of the white blood cells.
Linear accelerator	A treatment machine generating megavoltage x-rays or electrons. Also called a LINAC.
Lymphoma	Cancer of the lymphatic system/lymph nodes.
Malignant	Cancerous. Malignant tumours can invade and destroy surrounding tissue and have the capacity to spread.
Mammogram	A diagnostic image of the breast.
MCN (Managed Clinical Network)	The term Managed Clinical Network is used to refer to a way of working which relies on clinicians being part of a 'virtual' organisation and which actively involves patients in service design and focus.
Melanoma	A tumour arising from the melanocytic system of the skin and other organs.

Metastasize	Spread of cancer cells.
Mortality	The number of people who have died from cancer and is usually expressed as the number of deaths each year in a specified area.
Mortality rates	The number of people who die from cancer per 100,000 population.
MRI (Magnetic Resonance Imaging)	An imaging technique based on magnetism, radio waves, and a computer to produce images of body structures. It provides superior soft tissue definition of many tumours compared with CT.
National Clinical Dataset Development Programme (NCDDP)	Data Standards are created to support the three purposes of health and care data: care, share and compare. Clinical data standards are different from clinical standards. Clinical data standards provide the means to record care in a consistent manner.
National Services Division	Part of National Services Scotland, which plans and funds services on a national basis ensuring equity of access and high levels of clinical quality.
Neoplasm	Abnormal new growth or proliferation of cells/tissue that shows a lack of cellular organisation and function. May be benign (non-cancerous) or malignant.
NHS QIS (Quality Improvement Scotland)	NHS Quality Improvement Scotland is a Special Health Board, acting as the lead organisation in improving the quality of healthcare delivered by NHSScotland.
NoSCAN	North of Scotland Cancer Network.
Oncology	The branch of medicine that deals with cancer.
Palliative care	Providing relief and support, but not cure.
Pathologist	A doctor who specialises in identifying diseases by microscopically studying cells and tissues.
Positron Emission Tomography (PET)	PET is a non-invasive diagnostic imaging technique that combines computed tomography and small amounts of a radioactive substance. It provides functional information about the tumour and its site and size.

Radiotherapy	The use of radiation to destroy malignant tumours while minimising the damage to normal tissue.
SCAN	South East Scotland Cancer Network.
Scottish Intercollegiate Guidelines Network (SIGN)	Improving the quality of care for patients in Scotland by reducing variation and outcome through the development of national guidelines containing recommendations for effective practice, based on current evidence.
Screening	Examination of people with no symptoms to detect unsuspected disease.
Simulator	A diagnostic energy x-ray machine used for localisation of treatment areas and for verification of treatment plans prior to starting treatment.
Survival rate	The percentage of people still alive 1, 3, 5 and 10 years after they have been diagnosed with cancer. The 5 year survival rate is often quoted.
Tumour	An abnormal mass of tissue that results from excessive cell division that is uncontrolled and progressive, also called a neoplasm. Tumours can be benign (not cancerous) or malignant.
Ultrasound	An imaging technique using high-frequency sound waves. Useful in the diagnosis of tumours.
WHO	World Health Organisation is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends.
WoSCAN	West of Scotland Cancer Network.
X-ray	A type of irradiation used for imaging purposes, which uses energy beams of short wavelengths that can penetrate most substances except heavy metals. The image is captured on photographic film.

HOW TO GET INVOLVED

This document sets out some of the approaches that we believe are necessary to meet our strategic objective of providing better cancer care in Scotland. We invite you to take part in a discussion about these approaches, to help shape our priorities and in particular, define the actions that you would like to see prioritised by the Scottish Government and NHS Scotland over the next few years. It reflects our commitment to consult and involve as many people as possible in the development of our plans. This will help us to build and sustain a consensus behind the approach we take as a nation to promoting and protecting our health and wellbeing.

Ways that you can get involved in this discussion:

1. By completing and returning the enclosed Feedback Form. The Feedback Form is also available online at <http://www.scotland.gov.uk/Topics/Health/health/cancer> where you may either complete it online or download it for completion.

Please complete the **Respondent Information Form**, which you will find attached to the Feedback Form or on our website, to ensure that we treat your response appropriately. Thank you.

2. By participating in one of the discussions we are planning across Scotland, details of which will be available on our website:

<http://www.scotland.gov.uk/Topics/Health/health/cancer>

3. You can email us at: bettercancercare@scotland.gsi.gov.uk

This consultation can be viewed online on the Scottish Government website at:

<http://www.scotland.gov.uk/Topics/Health/health/cancer>

You can telephone Freephone 0800 77 1234 to find the location of your nearest public internet access point.

If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly. You should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

What Happens Next

We will consider all responses and views received by the closing date, Monday 5 May 2008 and publish the final action plan in summer 2008.

Comments and Complaints

If you have any comments about how this discussion exercise has been conducted, please send them to:

Sarah J Grierson
Cancer & Genetic Team
Scottish Government
St Andrew's House
Regent Road
Edinburgh
EH1 3DG
Telephone: 0131 244 5180

We would also welcome your feedback on the document. Please complete the Feedback and Respondent Information Forms enclosed.

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FEEDBACK FORM

Thank you for taking the time to contribute to the Better Cancer Care discussion. Please refer to the prompting questions under the 'Issues to Consider' at the end of each section within the document. You do not need to answer all the questions. All responses will be considered. Please use a separate sheet if necessary, clearly indicating the section to which your comment relates. Thank you.

***You may download or complete this Feedback Form online at:
<http://www.scotland.gov.uk/Topics/Health/health/cancer>***

SECTION 2 : PREVENTION

Please provide comments / suggestions on *Prevention*

SECTION 3 : SCREENING

Please provide comments / suggestions on *Screening*

SECTION 4 : DIAGNOSIS AND TREATMENT

Please provide comments / suggestions on *Diagnosis And Treatment*

SECTION 5 : PALLIATIVE CARE

Please provide comments / suggestions on *Palliative Care*

SECTION 6 : ASSURING QUALITY OF CARE

Please provide comments / suggestions on *Assuring Quality Of Care*

SECTION 7 : PUTTING PATIENTS AT THE CENTRE

Please provide comments / suggestions on *Putting Patients at the Centre*

SECTION 8 : DELIVERY

Please provide comments / suggestions on *Delivery*

GENERAL COMMENTS / SUGGESTIONS YOU WOULD LIKE TO MAKE

RESPONDENT INFORMATION FORM

Please complete the details below and return it with your response by Monday 5th May 2008. This will help ensure we handle your response appropriately. Thank you for your help.

Name:	
Postal Address:	

1. Are you responding: (please tick one box)
- (a) as an individual (go to 2a/b and then 4)
- (b) **on behalf of** a group/organisation (go to 3 and then 4)

INDIVIDUALS

- 2a. Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government website)?

YES (go to 2b below)

NO, not at all We will treat your response as confidential

- 2b. **Where confidentiality is not requested**, we will make your response available to the public on the following basis (**please tick one** of the following boxes)

Yes, make my response, name and address all available

Yes, make my response available, but not my name or address

Yes, make my response and name available, but not my address

ON BEHALF OF GROUPS OR ORGANISATIONS

3. The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government website). Are you content for your group's or organisation's **response** to be made available also?

YES

NO We will treat your group's or organisation's response as confidential

SHARING RESPONSES/FUTURE ENGAGEMENT

4. We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Government to contact you again in the future in relation to your consultation response?

YES NO



**Please return your completed Feedback Form
and Respondent Information Form by Monday 5th May to:**

Better Cancer Care Feedback
Cancer & Genetics
Scottish Government
St Andrew's House
Regent Road
Edinburgh
EH1 3DG

Thank you for your feedback

