



WHERE NEXT FOR CANCER SERVICES IN SCOTLAND?

AN EVALUATION OF PRIORITIES TO IMPROVE CANCER OUTCOMES

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ABOUT CANCER RESEARCH UK

Cancer Research UK is the world's leading cancer charity dedicated to saving lives through research. We're the only cancer charity fighting all 200 types of cancer. Our pioneering work has been at the heart of the progress that has seen survival rates double in the last 40 years.

Our ambition is to accelerate progress so that three-quarters of people survive the disease within the next 20 years.

In 2015/16 we spent £404 million investing in research. We receive no government funding for our research. For more information on this report, or on our policy research more generally, contact policydepartment@cancer.org.uk

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LIST OF ACRONYMS

CNS	Clinical Nurse Specialist
DCE	Detect Cancer Early
DGH	District General Hospital
GGC	Greater Glasgow and Clyde
HEAT	Health Improvement, Efficiency, Access to treatment and Treatment
HIS	Healthcare Improvement Scotland
ICBP	International Cancer Benchmarking Partnership
IPTR	Individual Patient Treatment Request
ISD	Information Services Division Scotland (ISD)
LDP	Local Delivery Plan
MCN	Managed Clinical Networks
MDT	Multi-Disciplinary Team
NCCSG	National Cancer Clinical Services Group
NICE	National Institute for Health and Care Excellence
NSD	National Services Division
PACE	Patient and Clinician Engagement
PCE	Primary Care Engagement
PIN	Public Involvement Network
QPI	Quality Performance Indicator
RCAG	Regional Cancer Advisory Group
SACT	Systemic Anti-Cancer Therapy
SCIN	Scottish Clinical Imaging Network
SCT	Scottish Cancer Taskforce
SIGN	Scottish Intercollegiate Guidelines Network (SIGN)
SMC	Scottish Medicines Consortium

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EXECUTIVE SUMMARY

Incidence of cancer is rising, with one in two people born after 1960 expected to be diagnosed with cancer in their lifetime. This presents a huge challenge to all of the UK's health services.¹

While valuable progress has been made in improving cancer outcomes, with around half of UK cancer patients now surviving for ten years or more, UK cancer survival remains lower than in Australia, Canada, and several comparable European countries.^{2,3,4}

Cancer Research UK believes that in the next 20 years, with the right approach, three in four people can survive their cancer for at least ten years. Having high quality NHS cancer services across the UK is crucial if we are to reach this goal.

Cancer Research UK therefore commissioned the Institute of Health and Wellbeing at the University of Glasgow to investigate the state of cancer services in Wales, Scotland and Northern Ireland.

This report presents findings on Scotland and our ambition for the shape of cancer services in the future.

THE CANCER LANDSCAPE

Cancer incidence rates in Scotland have increased by 2% over the last decade (from 619 cases per 100,000 people between 2003-2005 to 632 cases per 100,000 people between 2012-2014). Over the same period the number of cases diagnosed has increased from around 27,500 to around 31,700.⁵ This incidence is expected to continue to rise and it is estimated that the number of new cases diagnosed in Scotland every year will increase by around a third by 2023-27.⁶ An ageing population is driving this in part, but preventable risk factors such as smoking are also contributing.

Cancers of the lung, breast, prostate and bowel together represent just over half of all cancer diagnoses in 2014.⁷ They are also the most common cancers worldwide.⁸

Cancer incidence also varies between demographic groups in Scotland. There were around 33,000 cancer registrations in the most deprived quintile of Scotland's population combined between 2009-2013, and more than 27,000 in the least deprived.⁹

Cancer survival in Scotland has been improving in Scotland for over 40 years.¹⁰ However, survival varies considerably by cancer type. In men, survival is lowest for lung, oesophageal and stomach cancers.¹¹ In women, survival is poorest for pancreatic and lung cancers.¹² Overall survival is poorer than many other comparable European countries.

Increasing cancer incidence will place additional demand on the NHS in Scotland. And as survival continues to improve, the NHS will need to be prepared to support more patients living with or beyond cancer.

NHS STRUCTURES, POLICIES AND LEADERSHIP

Spending plans set out in the Scottish Budget for 2015/16 show that £9.6 billion was allocated to the NHS and Special Health Boards. However, a breakdown of the expenditure on cancer services in Scotland is not currently available.

The recent Scottish Government cancer strategy, *Beating Cancer: Ambition and Action* ('Beating Cancer'), has committed an additional £100m to cancer over the next five years. This is a welcome development. While there is some indication of what this money will support, further transparency is needed on how spending on cancer is allocated.¹³

The NHS in Scotland is a devolved independent organisation, administered through 14 geographical Health Boards. A dedicated leadership structure is in place to oversee cancer services, split into two complementary pathways: a professional network that influences policy and practice and a managerial structure that is accountable for achieving targets set by the Scottish Government.

Overall, this structure was supported by stakeholders. Nonetheless, our research found that concerns exist about a perceived lack of clear leadership on some issues and lack of resources needed to implement some national policies.

RECOMMENDATIONS

- 1. The Scottish Government should publish a full implementation plan for the delivery of Beating Cancer. This should set out: the roles and responsibilities of cancer leadership bodies at national, regional and local levels, clear timings and how success will be measured. A national clinical lead for cancer to support this should also be considered.**
- 2. The Scottish Government and the Information Service Division should consider reporting NHS spend by clinical speciality.**

NHS PERFORMANCE ON CANCER

Performance data published by Information Services Division Scotland (ISD) shows that action is needed to improve some aspects of cancer services.

For example, the NHS in Scotland is consistently not meeting one of its waiting times targets – a clear indication that some aspects of the service are struggling to keep up with demand:

- The target for 95% of people with a suspicion of cancer referred via the urgent route to begin treatment within **62 days** of receipt of referral has not been met since 2013. Performance in the first quarter of 2016 was 90.2%.¹⁴
- The target for 95% of all patients diagnosed with cancer to begin treatment within **31 days** of decision to treat has performed better. It has been met since 2010, but the proportion of patients meeting the standard has been falling and this was missed in the most recent quarter. Performance in the first quarter of 2016 was 94.9%.¹⁵

The 31 day wait is holding up reasonably well, but does not capture the time it takes to diagnose patients. Poor and deteriorating performance in meeting the 62 day wait, compared to the 31 day wait, therefore indicates that patients are experiencing delays in being diagnosed. Concerns on this issue were also raised in the Early Diagnosis section.

Overall, stakeholders offered mixed views about the impacts of waiting time targets. Our research identified the contention they have a role in driving up standards, but can sometimes put adverse pressure on both clinicians and patients.

Nevertheless, it is clear that cancer services in Scotland, and most probably diagnostic services in particular, are struggling to cope with increased demand for their services as cancer incidence rises and that this should be addressed.

RECOMMENDATIONS

- 3. The Scottish Government should review capacity – both equipment and workforce – in diagnostic services with a view to providing additional resources to Health Boards to help them meet cancer waiting times.**
- 4. Scottish Government’s review of waiting times should ensure cancer targets are defined in a way that optimises their intended impacts – while maintaining the 62 and 31 day standards as a minimum. It should also consider expanding waiting times targets to include all types of cancer.**

EARLY DIAGNOSIS

Early diagnosis is critical to improving cancer outcomes. For example, when bowel cancer is diagnosed at stage one around 90% of patients survive ten years compared to just 5% for those diagnosed at stage four.¹⁶

Efforts to improve early diagnosis of cancer have tended to focus on a small number of cancer types that comprise the majority of cases – and indeed staging data is only publically available for these specific cancers. The focus of the Detect Cancer Early (DCE) programme for instance, has been breast, colorectal and lung.¹⁷ The DCE programme comprises both national publicity and Board-level initiatives to promote earlier detection and aimed to achieve a 25% increase in the proportion of stage 1 breast, colorectal and lung cancers between 2012 and 2015. However, progress has been mixed.

Overall, the data shows that in the four years the DCE programme has been running there has been significant improvement in the early detection of lung cancer, static performance in breast cancer, while early detection of colorectal cancer has been falling, in spite of increased screening uptake.¹⁸ This is a concerning finding, and one in need of further investigation. Further evaluation is needed to understand the impact of elements of the programme, and its ability to impact harder to reach communities.

Primary care plays a critical role in the early detection of cancers. Yet while a number of initiatives, both national and local, have been developed to support and encourage primary care in the areas of recognising symptoms and making appropriate referrals, further clarity on how to deal with cases where vague symptoms present remains an issue.

While views about one of these initiatives - direct GP access to diagnostic testing - were mixed, the overall decline in the 62 day waiting time standard indicates serious capacity issues with diagnostic services.

Other indicators reinforce this: in 2009, the Scottish Government set a national standard that patients should not wait any longer than six weeks to receive one of the eight key diagnostic tests and investigations.¹⁹ That targets has not yet been met and in 2015, around 67,200 patients waited longer than 6 weeks for a diagnostic test.²⁰ Beating Cancer commits to an additional £2 million per annum Diagnostic Fund for the next five year and the Scottish Government should ensure this funding alleviates pressure on diagnostics services swiftly and sustainably.

RECOMMENDATIONS

5. **The Scottish Government and the Information Services Division should collect and publish staging data on all cancer types.**
6. **The DCE programme should publish a clear evaluation of public awareness campaigns to understand their impact. As outlined in Beating Cancer, DCE should publish plans on how they will reach deprived, harder to reach communities where early detection of cancer remains poor.**
7. **The Scottish Government should explore best practice pathways for referral of patients with vague or non-specific symptoms, such as the Borders model, and consider whether national guidance should be updated to ensure consistent pathways for referral.**

ACCESS TO EFFECTIVE TREATMENT

Once a diagnosis is made, offering all patients timely access to high-quality, evidence-based treatments is crucial to improve survival.

Cancer drugs, radiotherapy and surgery are the three main types of treatment. Our research revealed areas for improvement in each category, as well as some themes across treatment types.

However, there is a lack of data on treatment activity in Scotland, specifically for cancer drugs and radiotherapy, making it difficult to assess progress. High-quality data is critical to evaluate performance and improvements.

The major questions in surgery centred on achieving a balance between local access to treatment versus the benefits of centralising smaller-volume surgery.

Views about the provision of radiotherapy were positive with regards equipment infrastructure. However, concerns were raised about whether this equipment was being used to its full potential to provide patients with the best treatments in all parts of the country. This is potentially due to workforce shortages.

We also heard doubts about the effectiveness of national radiotherapy leadership structures. The new National Cancer Clinical Steering Group (NCCSG) and its Radiotherapy Sub Group were created to provide a national lead on radiotherapy, and it will be important that they allocate the £50 million committed in Beating Cancer effectively.

The Scottish Medicines Consortium (SMC) evaluates new medicines and decides whether they will be made routinely available on the NHS. Stakeholders reported variations in access to approved medicines throughout Scotland, while regional differences in relation to individual patient treatment requests (IPTRs) were also a concern.

Due to the geography of Scotland, concerns were raised about barriers to access for patients living at a distance from treatment centres. Some stakeholders felt that such patients sometimes choose, or are given, treatment modes which are less than optimal to avoid travelling. Long travel times and variable support were also thought to delay some patients from starting treatment. It's therefore important that these factors should be prominent in

the planning of cancer services and accommodation provision, and new ways of working should be explored.

Finally, recruitment and retention of specialist staff formed a major theme of stakeholder concerns across treatment types.

RECOMMENDATIONS

- 8. The Scottish Government should ensure the NCCSG Radiotherapy Sub Group has the resources it needs to provide strong leadership in taking forward the commitments made in Beating Cancer to address inequality of access to modern radiotherapy. A national radiotherapy lead should be appointed to support this. Developing and reporting annually on a national dataset for radiotherapy should be a priority for this group.**
- 9. The Scottish Government and SMC should ensure equal access to new drugs across the country by considering mandating Health Boards fund them once approved. A national approach should also be taken to IPTRS to ensure consistent decisions for all patients in Scotland. A national dataset for chemotherapy should be developed to help understand outcomes and assess progress.**
- 10. The NSSCG should work to clearly define workforce capacity shortages in radiotherapy (via the Sub Group) and chemotherapy services and identify mechanisms to address this to ensure adequate resource is in place to provide access to the best, evidence-based treatments.**

1. THE CANCER LANDSCAPE

This chapter provides context for the subsequent analyses of leadership, performance, early diagnosis and access to treatment. We provide an introduction as to why Cancer Research UK commissioned this research. We then consider the broader context of the cancer landscape in Scotland, including which cancers are most common, how they vary between men and women, if they are changing over time, and if there are socio-economic differences in their occurrence.

Cancer survival in the United Kingdom (UK) has been improving over time – one in two cancer patients now survive their cancer for ten years or more compared to around one in four in the early 1970s. But while improvements have been made – particularly in breast cancer – UK survival in bowel, breast, lung and ovarian cancer, remains lower than in Australia, Canada, and several European countries.^{21,22}

These differences are largely due to better survival at one year after diagnosis in other countries. Researchers at the International Cancer Benchmarking Partnership (ICBP) have suggested that differences in individual, health-system, and clinical factors – such as diagnostic delay and access to optimal treatment – are likely explanations for the variations in relative survival.²³ Improving performance in early diagnosis and access to cancer treatment is therefore a priority evident in cancer plans for the nations of the UK.

Across the four nations of the UK, there are variations in the occurrence of cancer. Scotland has poorer outcomes than other parts of the UK across a range of measures. Overall, cancer incidence in Scotland is significantly higher than in England and Northern Ireland (though similar to Wales).²⁴ Mortality rates are also significantly higher in Scotland compared with the other nations.²⁵

Because of devolution, healthcare policy and organisational structures are also different in each country.

Cancer Research UK has previously published work analysing the implementation of the UK's cancer strategies²⁶ and the performance of cancer services in England.²⁷ With a view to supporting improvement throughout the UK, Cancer Research UK commissioned the Institute of Health and Wellbeing at the University of Glasgow to investigate cancer services in each devolved nation. This report assesses four aspects of cancer policy and practice in Scotland:

1. NHS structures and leadership in cancer;
2. Current performance in tackling cancer;
3. Performance in early diagnosis;
4. Access to effective treatments.

Primary prevention of cancer, screening and palliative care, while vital aspects of cancer services, have not been included in this analysis. Nor has the research environment been included within the scope of this report, but will be addressed in a future research report commissioned by Cancer Research UK. Reports on cancer services in Wales and Northern Ireland have been published separately.

This report brings together routine data on Scotland's cancer incidence, prevalence and survival with descriptions of cancer policies to assess performance. This is all in the context of

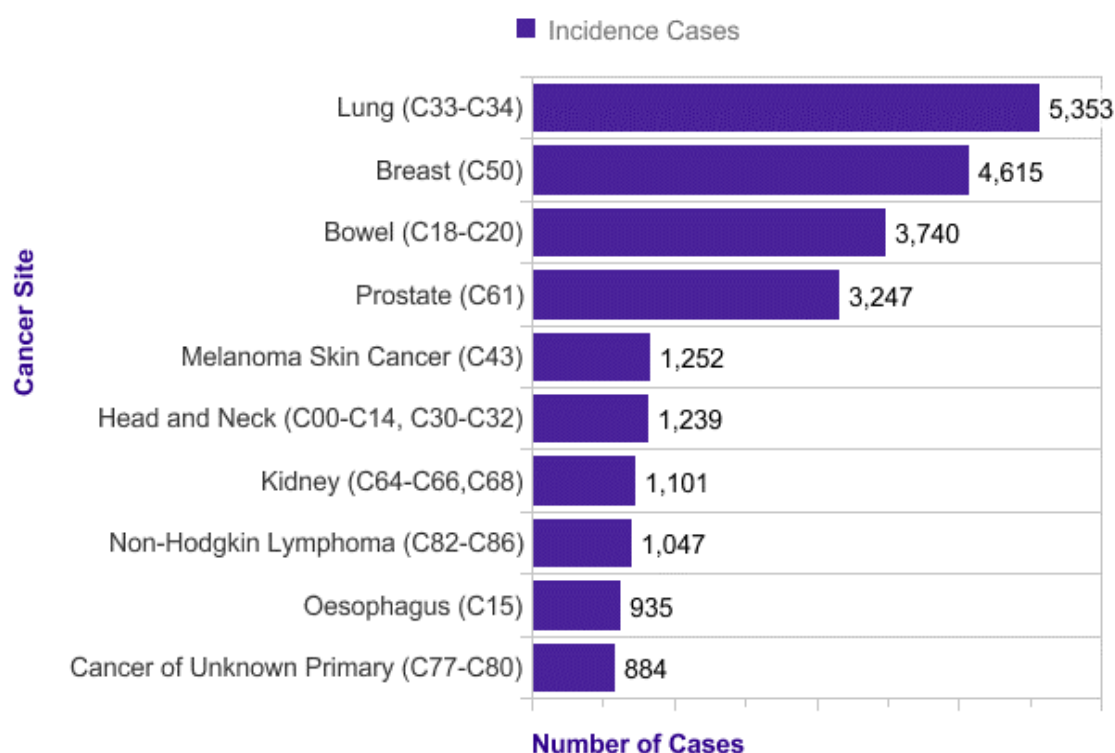
Scottish Government publishing a new and ambitious cancer strategy ‘Beating Cancer: Ambition and Action’ in March 2016.²⁸ This is very welcome as it provides direction, and importantly additional funding, for improvements to cancer services in Scotland over the next five years. While this research was completed before the publication of the strategy, it provides further insight on the performance of cancer services.

This report considers where improvements are needed, helping inform the actions set out in the new cancer strategy. An important component of the report is 27 telephone interviews with senior stakeholders – national policymakers, senior managers, clinicians and patient representatives – in Scotland.

1.1 INCIDENCE

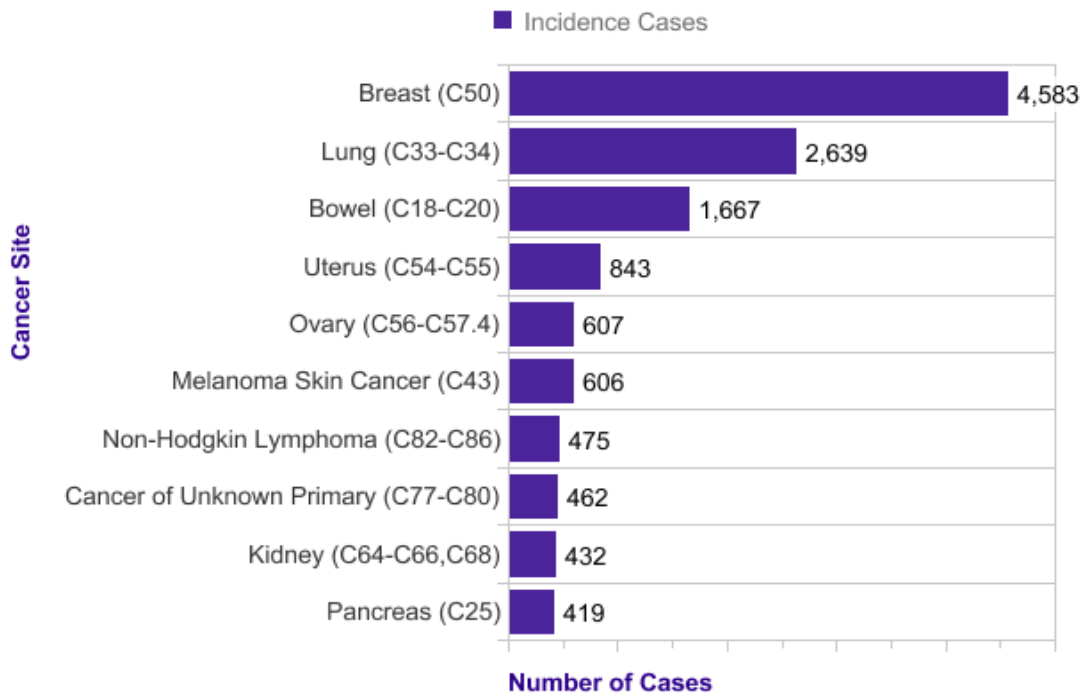
In 2014, more than 31,900 people in Scotland were diagnosed with cancer.²⁹ Lung cancer is the most commonly diagnosed in Scotland, followed by breast cancer and bowel cancer – Figure 1.³⁰ In women, breast, lung and bowel cancers account for 55% of all cancers diagnosed – Figure 2. In men, the most common cancers are prostate, lung and bowel, which comprise 51% of all cancers diagnosed – Figure 3.

FIGURE 1. TEN MOST COMMON CANCERS IN SCOTLAND, PERSONS, 2014



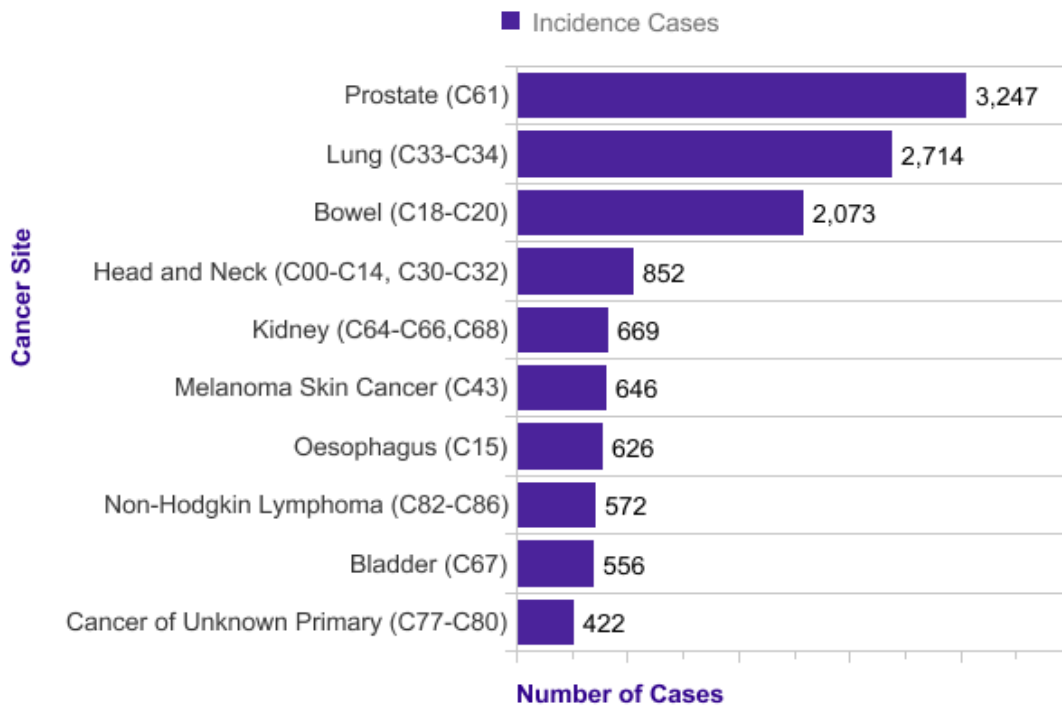
Source: Scottish Cancer Registry

FIGURE 2. TEN MOST COMMON CANCERS IN SCOTLAND, FEMALES, 2014



Source: Scottish Cancer Registry

FIGURE 3. TEN MOST COMMON CANCERS IN SCOTLAND, MALES, 2014



Source: Scottish Cancer Registry

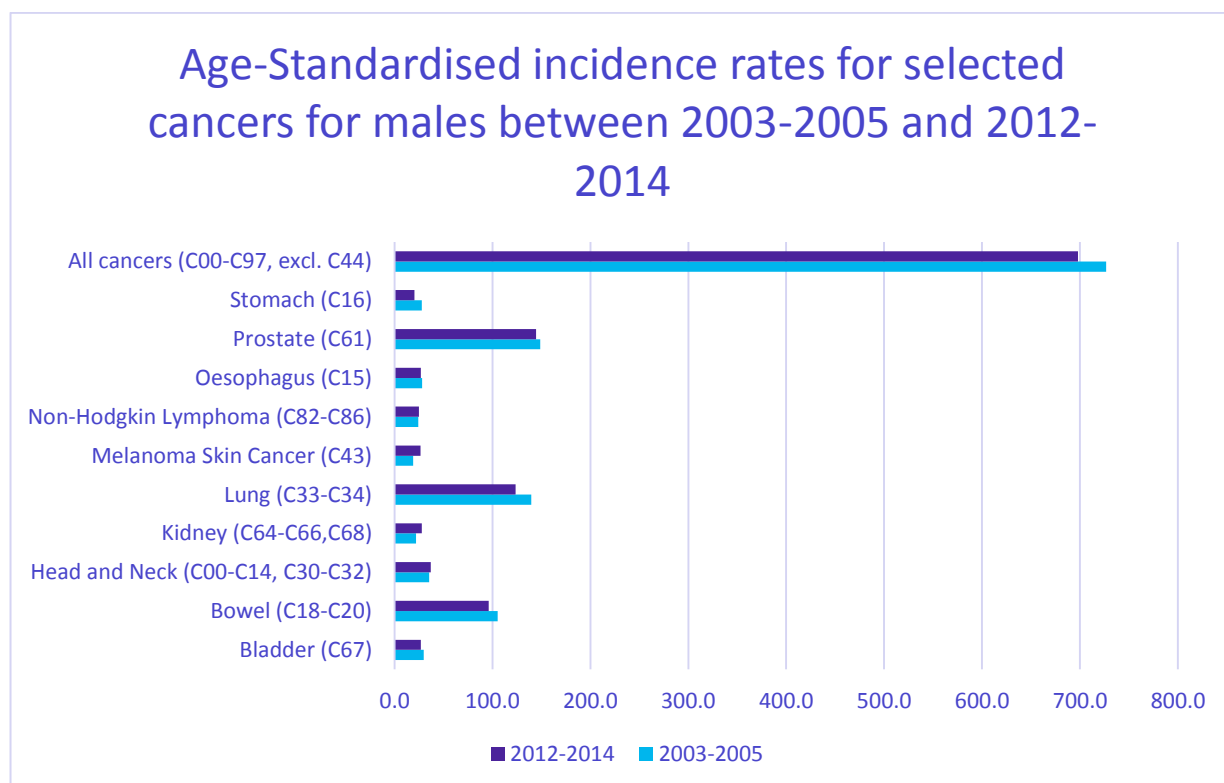
Overall, the number of new cancersⁱ diagnosed each year increased from around 27,500 in 2005 to more than 31,900 in 2014, although there are variations by cancer site and between men and women.³¹ Some of this increase will be due to a growing ageing population as well as preventable risk factors such as smoking and obesity.

Cancer incidence rates in Scotland have increased by 2% over the last decade (from 619 cases per 100,000 people between 2003-2005 to 632 cases per 100,000 people between 2012-2014).³²

In males cancer incidence rates have decreased by 4% over the last decade (from 727 cases per 100,000 males between 2003-2005 to 698 cases per 100,000 between 2012-2014). However, in females the rates have increased by 6% over the same period (from 558 cases per 100,000 females between 2003-2005 to 590 cases per 100,000 females between 2012-2014).³³In males prostate cancer incidence rates have decrease by 3% over the last decade. There has been a larger decrease in bowel cancer incidence rates over the last decade of 9%. A decrease of 11% has been seen in male lung cancer incidence rates, while kidney cancer in males has increased by 27% over the last decade – Figure 4.³⁴

In females bowel cancer incidence rates have decreased by 1% over the last decade. There has been a larger decrease in ovarian cancer incidence rates over the last decade of 12%. An increase of 13% has been seen in female lung cancer incidence rates, while kidney cancer in females has increased by 34% over the last decade – Figure 5.³⁵

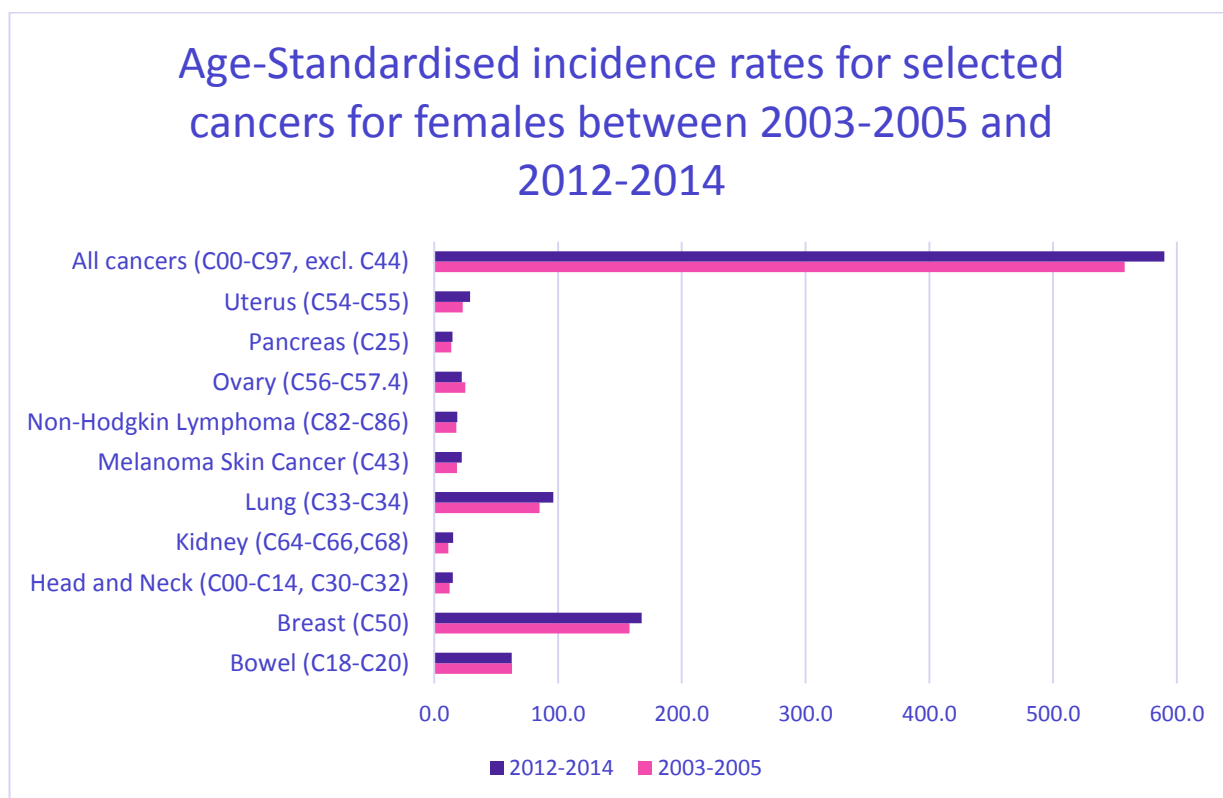
FIGURE 4. AGE-STANDARDISED INCIDENCE RATES FOR SELECTED CANCERS FOR MALES BETWEEN 2003-2005 AND 2012-2014.



Source: Calculated by the Statistical Information Team at Cancer Research UK, September 2016.

ⁱ Excluding non-melanoma skin cancers

FIGURE 5. AGE-STANDARDISED INCIDENCE RATES FOR SELECTED CANCERS FOR FEMALES BETWEEN 2003-2005 AND 2012-2014



Source: Calculated by the Statistical Information Team at Cancer Research UK, September 2016.

The age-standardised incidence rate for all cancers combined for males and females combined is predicted to increase by 5% between 2008-12 and 2023-27. Over the same period the number of new cases of cancer is predicted to increase from around 153,000 in 2008-12 to around 204,000 2023-2027, an increase of 33%.³⁶ Lung cancer is expected to remain the most commonly diagnosed cancer by 2023-27.³⁷ Increasing numbers of older people is the main reason for the predicted increased in cancer cases, as cancer is typically a disease of ageing, but changes in methods of detection and in exposure to risk factors (such as tobacco, obesity and alcohol) may also affect projections. The highest increases in incidence rates are projected in cancers of the kidney, cervix, malignant melanoma of the skin, Hodgkin’s Lymphoma and uterus. Six cancers are projected to decrease over this period: leukaemias, stomach, oesophageal, lung, ovarian and bladder cancers.

Overall, the incidence of cancer is significantly higher in areas of higher deprivation.³⁸ There were around 33,000 cancer registrations in the most deprived quintile of Scotland’s population combined between 2009-2013, and more than 27,000 in the least deprived.³⁹ This overall pattern is dominated by smoking-related cancers, particularly lung and head and neck cancers. Over the same period, for example, there were around 7,900 new cases of lung cancer in patients from the most deprived quintile but nearly 2,900 in the least deprived quintile. In contrast, there were more breast cancer cases in the least deprived quintile (around 4,900 cases between 2009-2013) compared with the most deprived quintile (around 4,000 cases during the same period). This it thought to be partly due to higher uptake of breast screening in less deprived areas⁴⁰. Prostate cancer is also more common among men from less deprived areas, with around 3,500 cases between 2009-2013 among men in the most affluent quintile, and more than 2,300 cases among the most deprived quintile.

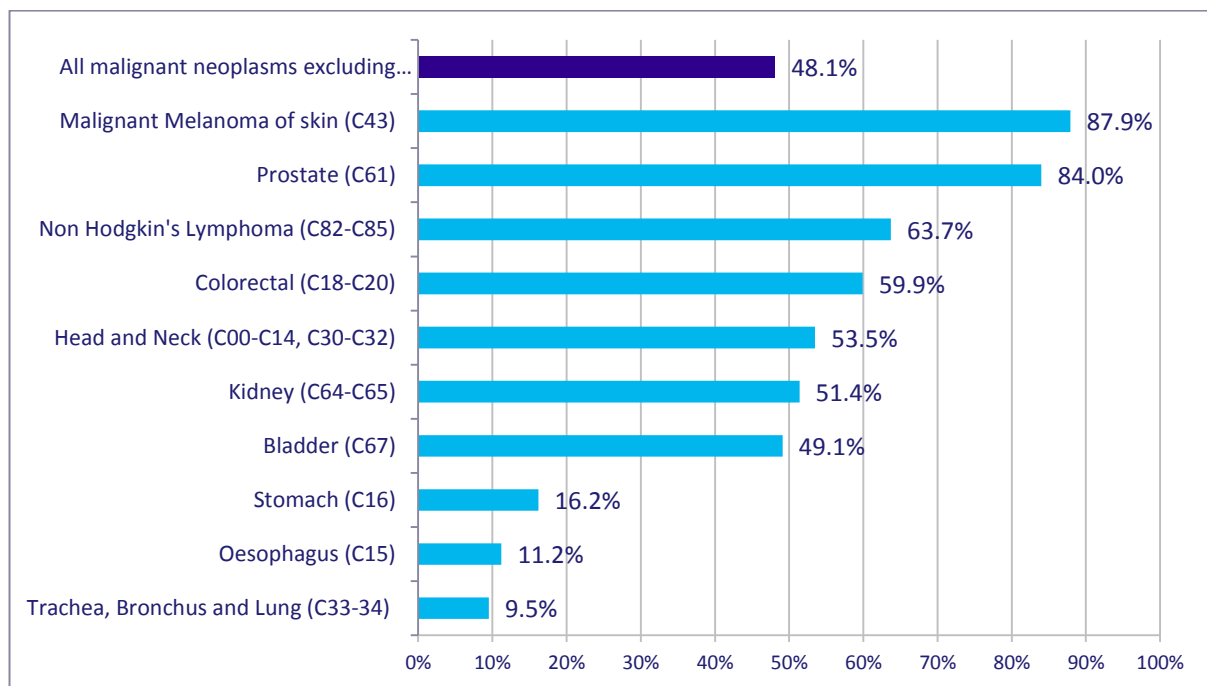
1.2 SURVIVAL

Survival from most cancers has been improving in Scotland for over 40 years.⁴¹ Survival from cancer may reflect a variety of things: the stage at diagnosis, other health conditions that a patient has, and the effectiveness of treatment.^{42,43} It is often reported as relative survival – that is, the proportion of patients who survive a given length of time compared with similar people in the general population without cancer. Where it is 100%, for example, this indicates that having cancer does not reduce survival compared to what would be expected for a healthy individual of the same age, sex and socio-economic group.

In men, five-year survival is among the lowest for lung, oesophageal and stomach cancers and highest for malignant melanomas, prostate, non-Hodgkin’s lymphomas and colorectal cancers - Figure 6.⁴⁴ In women, five-year survival is among the poorest for pancreatic and lung cancers and highest for malignant melanoma, breast and uterine cancers - Figure 7⁴⁵.

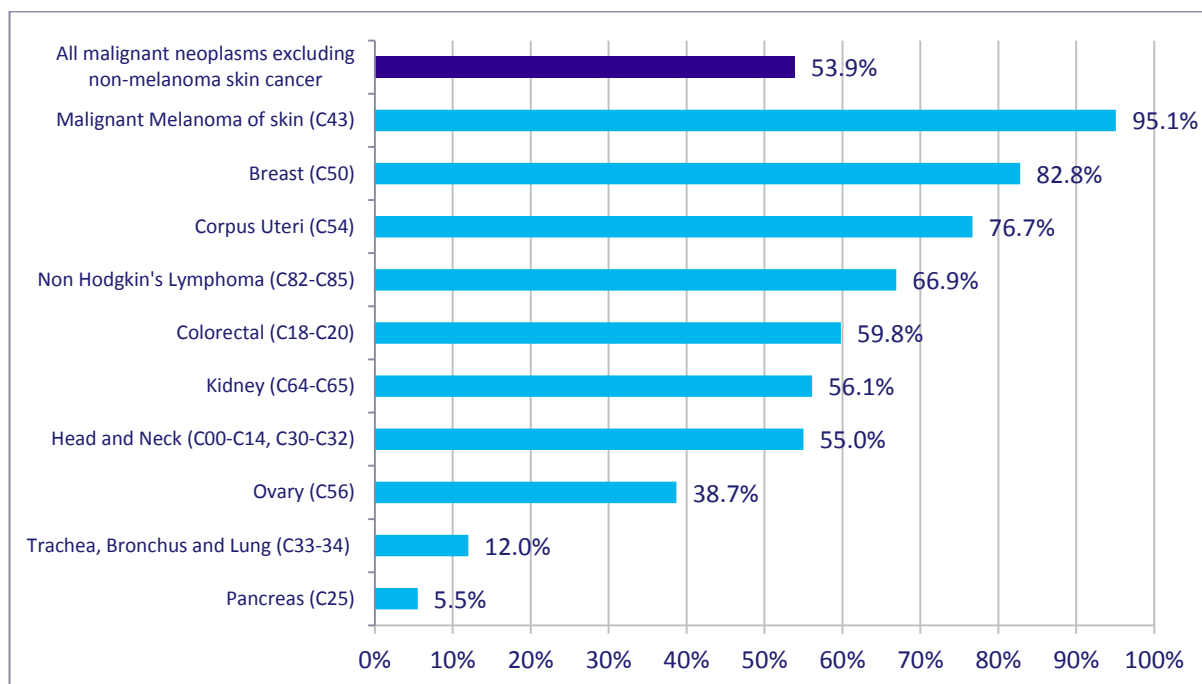
Stage-specific survival data are not routinely published but where analyses have been carried out,^{46,47,48} earlier stage at diagnosis is consistently associated with better survival. The International Cancer Benchmarking Partnership (ICBP) compared different staging systems and recommended consistent approaches to allow better comparisons between countries.⁴⁹

FIGURE 6. 5-YEAR RELATIVE SURVIVAL FROM CANCER, SCOTLAND, 2007-11, MALES.



Source: Scottish Cancer Registry

FIGURE 7. 5-YEAR RELATIVE SURVIVAL FROM CANCER, SCOTLAND, 2007-11, FEMALES.



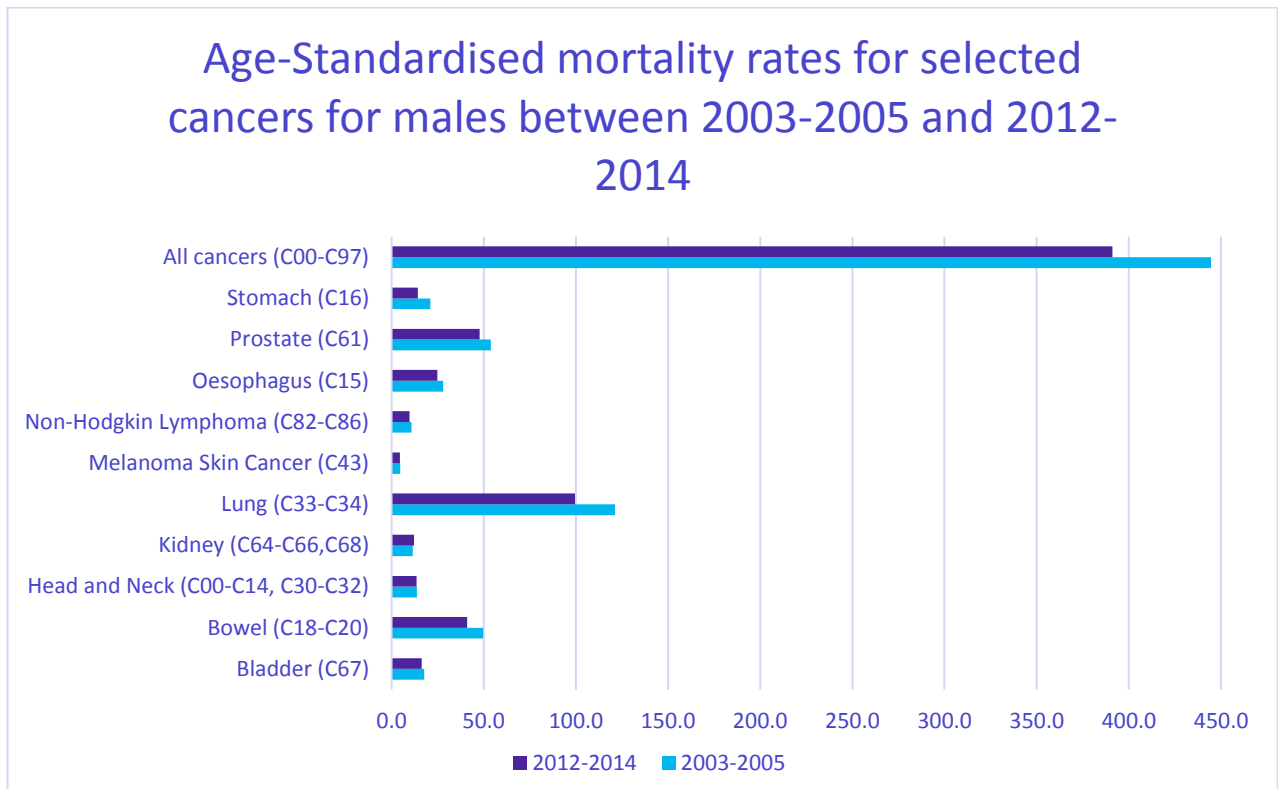
Source: Scottish Cancer Registry

There are several implications for early diagnosis and treatment that follow from survival data. Setting aside the need for primary prevention and screening, both of which are outwith the scope of this report, finding ways to diagnose cancer at an earlier stage will remain a priority for the foreseeable future.⁵⁰ There are currently debates about how some cancers might be detected at an earlier stage,⁵¹ and about which patients might benefit most from earlier symptomatic diagnosis.^{52,53} The focus in lung cancer has been on improving early detection and addressing the problem of delays. In contrast, colorectal cancer has been the subject of screening for several years, and new methods for detecting it will be introduced in 2017. Nonetheless, about a fifth of colorectal cancer cases present as emergencies and these are associated with poorer outcomes.⁵⁴

1.3 MORTALITY

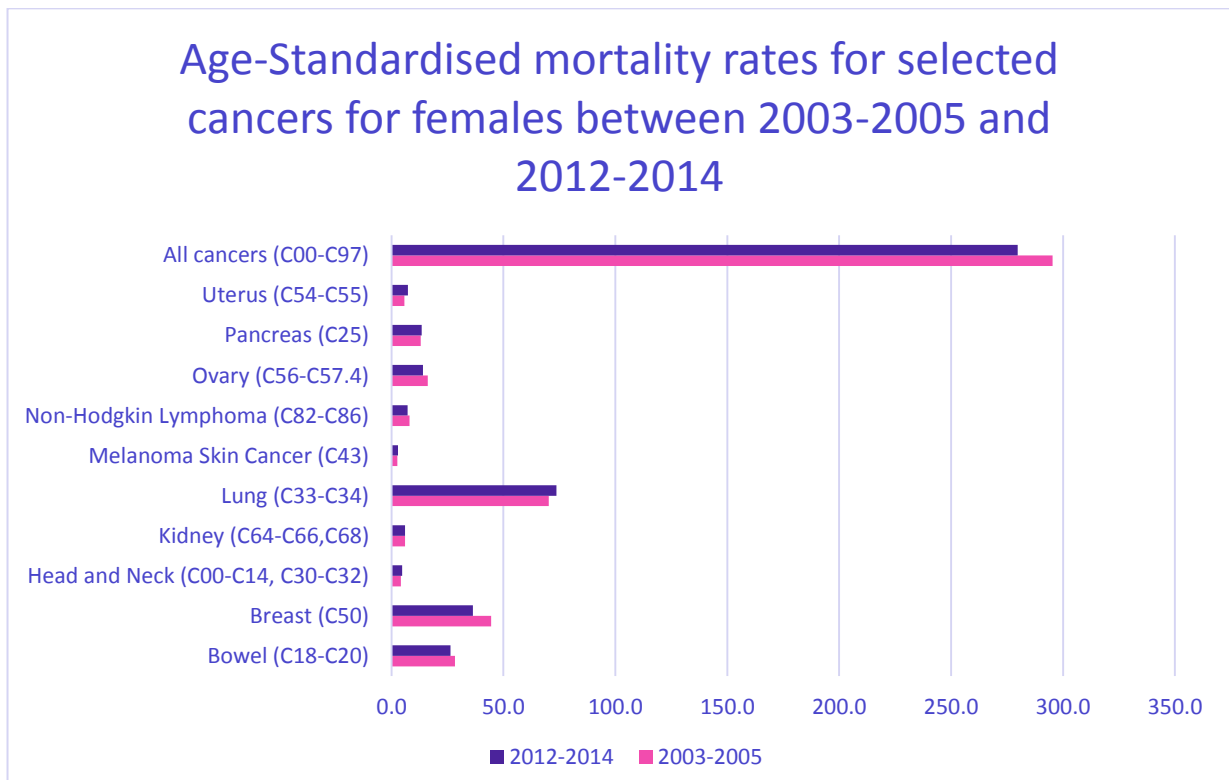
Lung cancers are the largest cause of cancer deaths in Scotland, representing around a quarter of all cancer deaths. The lung cancer mortality rate for males has fallen over the last decade (from 125 deaths per 100,000 between 2002-2004 to 100 between 2012-2014), whereas this has increased for women (from 70 deaths per 100,000 between 2002-2004 to 74 between 2012-2014) – Figures 8 and 9. This disparity between men and women largely reflect changes in their incidence – which can be attributed to historic tobacco consumption patterns - rather than any differential effects of treatment between the sexes. Prostate cancer and colorectal cancer have changed relatively little despite increases in the number of diagnoses. Mortality rate from breast cancer has fallen over the last decade; despite increases in its incidence, significant improvements in survival have occurred.

FIGURE 8. AGE-STANDARDISED MORTALITY RATES FOR SELECTED CANCERS FOR MALES BETWEEN 2003-2005 AND 2012-2014



Source: Calculated by the Statistical Information Team at Cancer Research UK, September 2016.

FIGURE 9. AGE-STANDARDISED MORTALITY RATES FOR SELECTED CANCERS FOR FEMALES BETWEEN 2003-2005 AND 2012-2014.



Source: Calculated by the Statistical Information Team at Cancer Research UK, September 2016.

1.4 PREVALENCE

Cancer prevalence provides a snapshot of people either living with, or surviving cancer. As the number of cancers being diagnosed increases and survival improves, the population living with or after cancer also grows.

Cancers with relatively high incidence and good survival are most prevalent. So among men, prostate cancer is the most prevalent with around 24,000 men being alive up to 20 years after being diagnosed with prostate cancer. Colorectal cancer, head and neck cancers and malignant melanoma of the skin are also highly prevalent.

In women, breast cancer is both common and survival is good, so prevalence is high, with around 46,400 women being alive up to 20 years after diagnosis. Colorectal, malignant melanomas and uterine cancers are also among the most prevalent. Around 4,100 females are alive up to 20 years after a lung cancer diagnosis, compared to more than 3,700 males.⁵⁵

Cancers of the lung, breast, prostate and bowel together represent just over half of all cancer diagnoses. While cancer survival has improved overall in Scotland, for most cancers survival is poorer than many other European countries.^{56 57} The number of new cancer diagnoses has increased over time and is predicted to continue to increase by around 33% by 2023-27, mainly due to a growing ageing population.

The largest numbers of prevalent cancers are of prostate, colorectal, uterine, head and neck, breast and malignant melanoma. There also remains variation in survival outcomes among different groups of patients. People who live in more socio-economically deprived areas are more likely to be diagnosed with cancer, but there are higher incidence rates for some cancers - including prostate and breast - in more affluent areas. Given the high incidence figures for these cancers, this can have the effect of diluting otherwise stronger deprivation links across all cancers.

Increasing incidence of cancer highlights the scale of the demand the NHS must be prepared to meet. And as survival continues to improve, the NHS must also be prepared to support more patients living with or beyond cancer.

2. NHS STRUCTURES AND LEADERSHIP IN CANCER

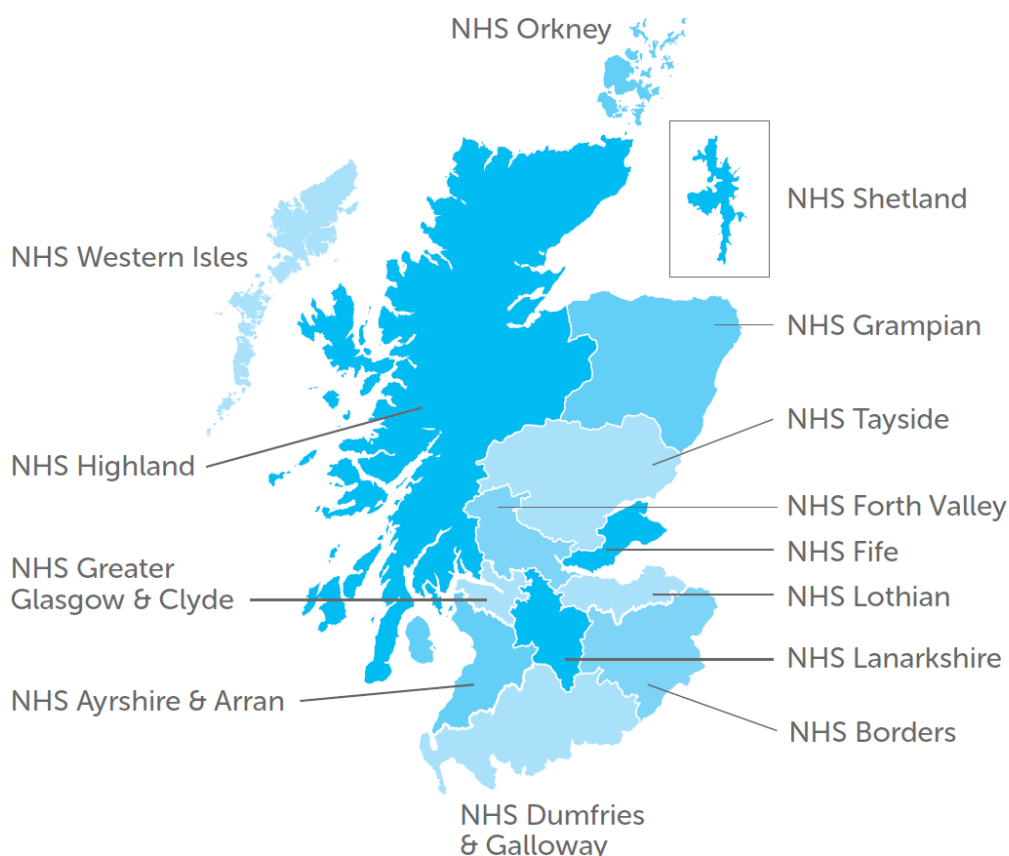
This section explains the way the NHS is organised in Scotland. It describes structures in place to provide leadership, and outlines current policies and priorities for cancer services.

Aspects of the role and effectiveness of cancer leadership at national, regional and local levels were commented on widely throughout our interviews with stakeholders. Common themes are presented here in relation to each of these levels and also by topic. Views about national leadership were expressed in general terms by some stakeholders. More commonly, comments related to particular aspects of cancer services directed at national level. Where these comments relate specifically to early diagnosis or access to effective treatment we include these comments later, in appropriate chapters of the report.

2.1 NHS SCOTLAND ORGANISATION

Health has been a devolved responsibility since 1999 and NHS Scotland has been an administratively independent organisation since its inception in 1948. NHS Scotland is the responsibility of the Health and Social Care Directorate of the Scottish Government. At the time of writing, changes to bring about the integration of health and social care are being implemented and any impacts on how cancer services are delivered is not yet clear. There are fourteen geographically-based regional NHS Health Boards that plan, commission and deliver local NHS services – Figure 10 – plus seven non-geographic Special Health Boards which provide national services.

FIGURE 10. MAP SHOWING 14 REGIONAL NHS HEALTH BOARDS⁵⁸



One of the seven Special Health Boards is Healthcare Improvement Scotland (HIS). A key part of HIS is the Scottish Intercollegiate Guidelines Network (SIGN), which develops evidence-based clinical practice guidelines for NHS Scotland, including some for cancer.

2.1.1 CANCER SPEND

Since 1999 the Scottish Government has decided what resources are to be devoted to the NHS, in the context of devolved public expenditure. The Scottish Budget sets out funding for health and wellbeing⁵⁹. Spending plans for 2015/16 show that £9.6 billion was allocated to the NHS and Special Health Boards.

There is no breakdown of the proportion of the NHS budget that goes to cancer services in Scotland. Scottish Health Service costs are reported annually by Information Services Division Scotland (ISD) but costs are reported by sector (hospital, community, family health) as opposed to clinical speciality. However, the recent cancer strategy has committed 'at least' £100m additional investment in cancer services over the coming five years.⁶⁰

The NHS Scotland Local Delivery Plan represents the contract between the Scottish Government and NHS Boards. It specifies targets and strategic priority areas for the financial year. NHS budgets for treatment and care are held by NHS Boards. The Boards are charged for treatment of cancer patients, typically but not exclusively at their regional cancer centre, on the basis of a three year funding agreement. The share attributed to each board in the region is determined by the national resource allocation framework and also takes into account any significant change in activity. From time to time the Scottish Government contributes funds directly to specific initiatives, such as capital funding to support the establishment of the Beatson satellite radiotherapy facility.⁶¹

2.2 CANCER LEADERSHIP

The Scottish Cancer Taskforce (SCT) was set up to oversee the actions outlined within Better Cancer Care, An Action Plan 2008 and will continue to do so for Beating Cancer: Ambition and Action 2016 ('Beating Cancer'). The SCT is the lead cancer organisation in Scotland, reporting directly to Government. In addition, the National Cancer Clinical Services Group (NCCSG) was set up in 2014 under the auspices of the National Planning Forum and is linked to the SCT – Figure 11. The NCCSG remit is described as follows:

- The NCCSG will develop and oversee a sustainable national approach to the planning and delivery of specific cancer services, for agreed and identified complex cancers to ensure world class treatment and quality of care. The NCCSG will also have national oversight across all cancer services ensuring that potential risk areas in the service are identified and action taken as early as possible.
- This work will be taken forward collaboratively with local and regional cancer services, National Services Division (NSD), primary care and Scottish Government Health and Social Care Directorate colleagues as appropriate.⁶²

The NCCSG remit and focus will alter to support the operational delivery of Beating Cancer. Regional cancer leadership in NHS Scotland is organised into three geographical areas – the West of Scotland, South East of Scotland and North of Scotland. Each regional network co-ordinates the work of several Health Boards, as follows:

West of Scotland Cancer Advisory Network - WoSCAN including Greater Glasgow & Clyde, Lanarkshire, Ayrshire and Arran and Forth Valley Health Boards. The regional cancer centre is the Beatson, Glasgow.

South East of Scotland Cancer Advisory Network - SCAN including Lothian, Fife, Borders and Dumfries and Galloway Health Boards. The regional cancer centre is at the Western General Hospital, Edinburgh.

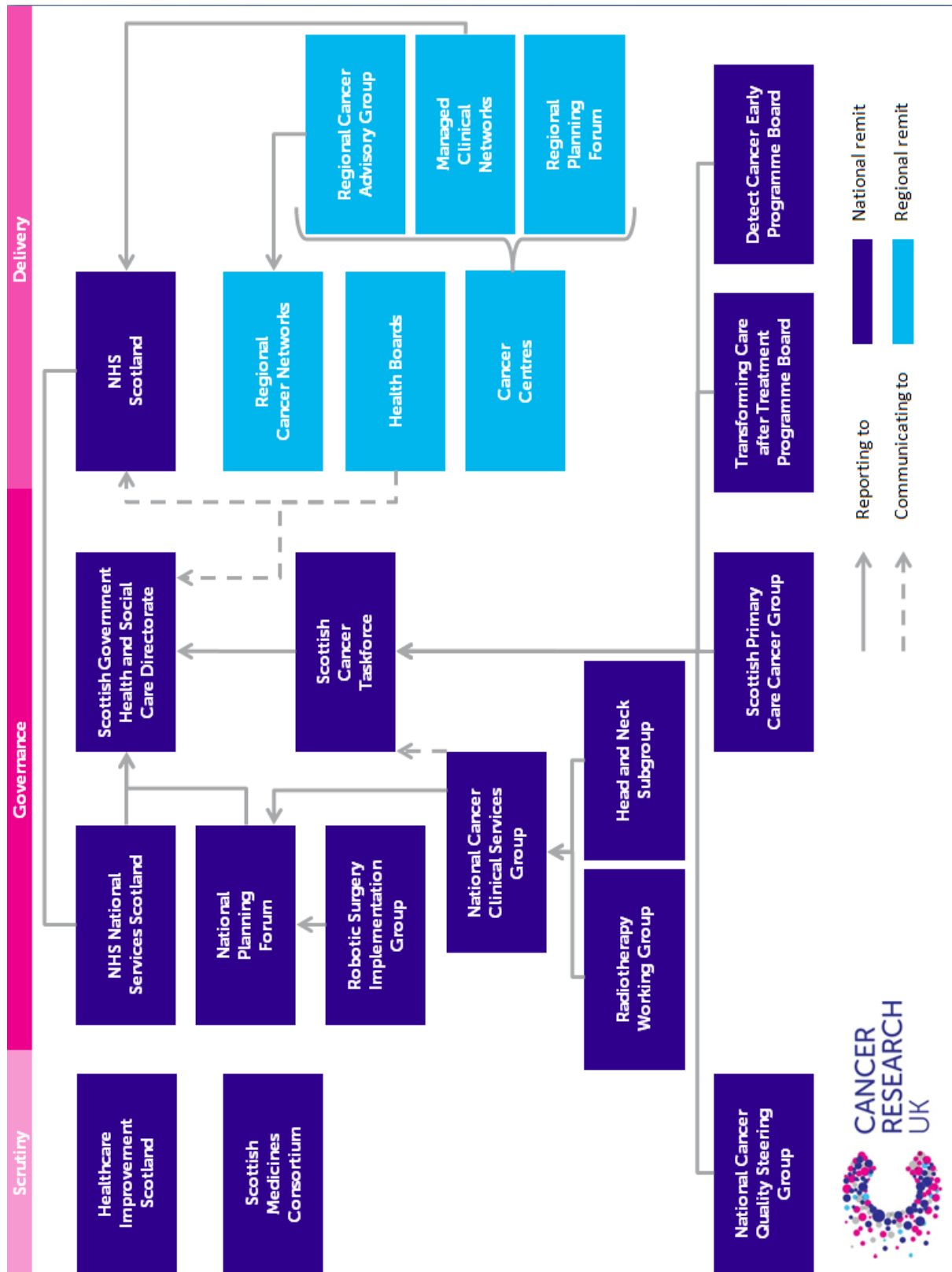
North of Scotland Cancer Advisory Network – NoSCAN including Tayside, Grampian, Highland, Western Isles, Orkney and Shetland. Three specialist cancer centres exist at: Ninewells Hospital, Dundee; Aberdeen Royal Infirmary; and Raigmore Hospital, Inverness.

Each region has a Regional Cancer Advisory Group (RCAG), which is a sub-group of the Regional Planning Forum. Its role is to provide clinical leadership and advise the Regional Planning Forum and NHS Boards on strategic issues affecting cancer services. The RCAGs are made up of clinical leads from site-specific Managed Clinical Networks (MCNs) and are chaired by the Chief Executive of a member NHS Board.

Site-specific MCNs exist for most cancers in each region. MCNs bring together professionals from primary, secondary and tertiary care and from all of the NHS Board areas in the region.

At Board level a clinical lead for all cancers is designated.

FIGURE 11: SCHEMATIC SHOWING CANCER LEADERSHIP STRUCTURE IN SCOTLAND



2.3 CANCER POLICIES AND PRIORITIES

The Scottish Parliament passes legislation about the NHS. The Scottish Government sets national cancer service priorities and actions. These policies map the direction of travel for quality improvement in cancer care. Guidelines, Quality Performance Indicators (QPIs) and targets will almost certainly align with government policy. Given that – as this report comes to find – targets influence clinical performance and prioritisation, it is therefore the case that Scottish Government policy prioritisation can significantly impact overall performance in cancer care. The key cancer policy statements since 1999 are listed in Box 1.

BOX 1: SCOTTISH GOVERNMENT CANCER POLICY

Cancer in Scotland: Action for Change 2001
Cancer in Scotland: Sustaining Change 2004
Better Cancer Care: An Action Plan 2008
Better Cancer Care, an Action Plan Progress Report December 2010
Detect Cancer Early 2012-15
Cancer Plan for Children and Young People in Scotland 2012-15
Beating Cancer: Ambitions and Action 2016

The World Health Organisation says that national cancer strategies are vital to driving improvements in cancer care. They make best use of resources over a long time period to reduce cancer incidence and mortality. As seen in Box 1, Scotland has now produced three cancer strategies. The most recent strategy, Beating Cancer, commits at least £100m additional investment in cancer over the next five years. Its ambitions include:

- More people surviving cancer for 1, 5, and 10 years
- Closing the gap in survival rates between Scotland and the best countries in Europe
- Reducing health inequalities
- Better involving cancer patients and their families in decision making and being able to make the right decisions for them on the basis of full information
- Radically improving patient experience and quality of life, including end of life
- Reducing the growth in the number of people diagnosed with cancer
- More equitable access to services and treatment

To fulfil the ambitions above, the strategy sets out 50 specific actions. It is early days, but it will be vital to continuing improvement in cancer services and, ultimately, cancer outcomes, that the actions in the strategy are implemented in full.

2.4 INTERVIEWEE VIEWS ON POLICY AND LEADERSHIP

Our interviewees' views about policy and leadership inevitably reflect the position they occupy in cancer structures. For some in a national position, insights about services on the ground are generally gained indirectly through meetings and reports. Others involved at a national strategic level have current hands-on experience of both clinical practice at Board level and clinical leadership at regional level. We also talked to people who view services from a local perspective, particularly those working in areas removed from the regional cancer centres.

2.4.1 NATIONAL LEADERSHIP

A recurring theme identified in comments from regional and board level respondents was that national leadership was lacking to some extent. Policy directives and good advice might be issued but there was a perception that national bodies lacked the authority to put them into practice. It remains to be seen whether Beating Cancer will help provide an effective framework for national leadership, to drive change. Lack of co-ordinated national clinical leadership at Board level was another significant theme when stakeholders were asked about important influences on services.

“...there are directives, so chief executive letters about chemotherapy and that sort of thing but while I think there is a good deal of co-operation within [regions] I don’t really sense that Scotland as a whole has really got itself geared up so that there is proper co-ordination between the various regions”. (Clinical lead)

“... I think that there’s a lack of national leadership in cancer services. ...we have geographical differences in what we do, but fundamentally we’re all doing the same thing to very similar people. ...And I think actually where there’s focus on the health boards [to give] leadership ... I think there are weaknesses there and I think there’s a distinct role for stronger cancer specific leadership at a national level”. (Oncologist)

This view of national leadership was illustrated in comments about workforce and radiotherapy planning. For example, the advisory structure for radiotherapy, in the perception of one respondent, has ‘disintegrated’ to the detriment of the service:

“We have five radiotherapy centres in Scotland and there is a sense that each of them is off doing its own thing whereas previously we did have ... some sort of national strategy”. (Oncologist)

This respondent was aware of recent changes in national leadership of radiotherapy (see section 5) but felt that the new arrangement was inadequate compared with the Scottish Radiotherapy Advisory Group (disbanded in 2012).

We refer earlier in this section to the setting up of the NCCSG to take a national coordinating role in developing sustainable cancer services. In this regard, we found some questioning of whether the challenges around workforce planning in particular were being addressed nationally (stakeholder comments about the workforce issues faced by services are presented in Section 5). There was a lack of feedback from both Boards and Government as to what workforce planning was being undertaken.

“I think that Scotland has a real problem with its workforce, currently and in the future, and I see very little evidence of that being realistically looked at and tackled”. (3rd sector director)

A perceived lack of clarity in how services are managed nationally was apparent again in other views, including that of a respondent (with a regional role) that there were ‘too many levels of bureaucracy’ between the ward level and the Scottish Cancer Taskforce.

“...there are some things that seem to be discussed endlessly at multiple different committees and I’m sure there could be a more streamlined way of doing things”. (GP)

Some respondents were concerned about national investment decisions. For example, high value equipment like robotics for surgery being introduced where evidence is still uncertain about its benefits.

The perspective of those in a leadership role provides a marked contrast to some of the national stakeholder views. One such respondent saw their role as:

“...galvanising the consultant workforce to take ownership of whatever the problem was instead of buck passing constantly to St Andrews House (Scottish Government Health Department)”. (National interviewee)

Another aspect of national leadership which was touched on was the challenge of changing attitudes or behaviour. Several respondents stressed the need for Government to back up their policy directives with funding in order to promote real change. In this regard, it appears the additional investment committed with the new cancer strategy will help answer this. However, there were also views that clinicians and Health Boards are not always able or willing to respond promptly to initiatives that ‘make complete sense nationally’ (a point illustrated in relation to ‘Detect Cancer Early’ in Section 4).

2.4.2 REGION LEADERSHIP

As noted earlier, MCNs and the Regional Cancer Advisory Groups (RCAGs) provide clinical leadership regionally. In the view of one respondent, the MCNs have evolved in each region to meet their ‘local circumstances and needs’ since RCAGs were set up in 2001.

The diversity of the networks was reflected in comments from across the country about their effectiveness. Not all of the three were felt, by national stakeholders, to be good at regional coordination. However, perspectives heard from lead clinicians (from different regions) were of the region as a planning unit rather than an association of Boards, which does imply success in terms of regional coordination.

Consistent with the RCAG remit, regional clinical leadership was not seen as having an influence on how much Boards could spend on cancer services. The limits of the influence which MCNs have was clearly illustrated by respondents who were keen to see a strategic decision made in the area of lung cancer diagnosis: to create an automatic trigger for a respiratory referral in the event of an abnormal chest x-ray.

“The network is quite good in terms of developing network wide protocols which apply regionally. The protocols where they require specific resource or specific changes in service delivery are that the network does not have the power to implement those. ... So even if we wrote a network protocol that said this is what ought to happen, it won’t necessarily go forward unless it has [Board] management buy-in. I guess the management buy-in is more likely to come if what you’ve got is a kind of national strategy rather than just the regional network”. (Oncologist)

On the other hand, we heard an example of ‘added value’ provided via an MCN in the development of regional pathways where ‘we can bring the key people round the table and facilitate that discussion unsullied by money’ – and reach a consensus quite separate from discussion between separate Boards about who was paying for what.

Some respondents felt that the regional network was effective in ensuring equal access to resources within the region for smaller Boards and strong regional leadership was also seen as valuable in encouraging participation in MCNs. Clinicians at Board level and GPs felt they benefitted from their MCN in various ways:

- provision of good quality information e.g. literature searches and guidelines

- updates on policy changes
- a clear focus on clinical management using audit data
- opportunities for contributing to guidelines
- sharing good practice and information between as well as within regions

This positive view of regional clinical leadership was qualified by one leading clinician who felt that while the networks are ‘reasonably effective’ they can ‘falter’ through lack of clinician ‘buy-in’:

“It comes down to time in some cases to lack of organisation in others and lack of will in others. So I think there will be a variety of potential reasons for lack of engagement”. (Clinical director)

This respondent felt that the freeze on distinction awards, whereby clinicians could earn status and extra remuneration, has been ‘extremely unhelpful’ by removing an incentive for clinicians to engage in extracurricular activity such as MCN work.

Duplication of effort by regions was mentioned as a risk. One example given was the development in two separate regions of protocols for a particular off-label drug (see Section 5).

2.4.3 BOARD LEVEL LEADERSHIP

In Scotland each NHS Board manages the budget for their area as well as the services themselves. Budgets for cancer services are not ring-fenced.

Clinical directorship at Board level is regarded by many as the decisive influence on services. The way this might work was described by one oncologist.

“Each Health Board has a clinical lead for all cancers they set the tone, they set the policy. ... If you've got a clinical director who believes that we should be doing the best with what we've got right now, then the priority will be audit, and ... it will be very process related as opposed to looking at the bigger picture and saying, this disease kills the majority of our patients, we should be looking at new treatments. So ... the local leadership has an enormous influence, I would say.” (Oncologist)

Another respondent described the challenge as coordinating the whole range of medical professionals in primary and secondary care to ‘sing from the same book’:

“I find that locally engaging our acute director has been the most useful way to tie things together”. (Clinical lead).

We talked to a Clinical Nurse Specialist (CNS) with relatively long service who felt that there had been significant progress in clinical governance in the past 10 years or so. In her view, the role of the multidisciplinary team, better communication and tracking and clear guidelines have brought more standardised individual care leading to greater participation in clinical trials and wider choice of treatments. This view was echoed by a surgeon in another region who expressed great pride in the local unit:

“I'd like to think that the Government, and the Scottish Health Department, had a real steer and influence on the cancer policy, but in reality, on the day to day running of patients with cancer, it comes down to local arrangements, having a really good local unit, local referrals, interdisciplinary referrals within one unit. And that's where the quality gains are to be made”. (Surgeon)

2.4.4 THIRD SECTOR AND PATIENT INFLUENCE

Major charities were seen as influential as campaigners or lobbyists for particular treatments or as participants in service development programmes. The Scottish Cancer Coalition – a partnership of 21 charities – publishes its own priorities but we were unable to quantify its influence on cancer policy. Patients were also mentioned by a few stakeholders as having an influence by lobbying their Members of Scottish Parliament (MSPs) or securing media coverage. One charity we spoke to described its role in the new medicines process (see Section 5).

Patient representatives play a part on some national and regional bodies although, according to one stakeholder, they tend to be the same individuals and a wider range of patient voices need to be heard on these bodies. The same respondent felt that Scotland did not do well in terms of patient and public involvement, describing the Scottish Cancer Coalition as...

“...always a body that is consulted with. However, to call it influential I think would be a stretch”. (3rd sector director)

When asked what kind of influence patients have, one lead clinician replied:

“...on our [network] groups, there’s tumour specific groups. We have patient partners. ... if the patients don’t like something they can go to a MSP and they can challenge decisions, they can challenge process, but I would say mainly it’s working in a collaborative way with the clinicians in the tumour specific groups”. (Regional clinical lead)

2.5 SUMMARY

The NHS in Scotland is a devolved independent organisation, administered through 14 geographical Health Boards. Around £9bn was spent on the NHS in 2015/16. However, a breakdown of the expenditure on cancer services in particular is not currently available. The recent cancer strategy has committed an additional £100m to cancer over the next five years, and while there is some indication of what this money will support, further clarity is needed on how spending on cancer is allocated across the NHS.

At the national level, the Scottish Cancer Taskforce and the National Clinical Cancer Services Group are the bodies responsible for policy direction and oversight of some cancer services respectively. At the regional level cancer services are co-ordinated through three geographical networks, each of which includes several NHS Health Boards. These networks operate through professional influence, guidance and co-ordination. At the local level, Health Boards respond directly to government targets for cancer care.

Cancer networks do not have managerial authority over constituent Health Boards. Thus, cancer leadership in Scotland follows two complementary pathways: a professional network that influences policy and practice and a managerial structure that is accountable for achieving targets set by the Scottish Government. Overall, this structure was supported by stakeholders. Nonetheless, stakeholders expressed concerns about lack of clear leadership on some issues and lack of resources needed to implement some national policies.

Cancer charities and patient groups or individuals were seen as influential as campaigners but we were not able to quantify what influence they have on policy making.

RECOMMENDATIONS:

- 1. The Scottish Government should publish a full implementation plan for the delivery of Beating Cancer. This should set out: the roles and responsibilities of cancer leadership bodies at national, regional and local levels, clear timings and how success will be measured. A national clinical lead for cancer to support this should also be considered.**
- 2. The Scottish Government and the Information Service Division should consider reporting NHS spend by clinical speciality.**

3. NHS PERFORMANCE ON CANCER

NHS Scotland has several leading national drivers for improving performance in cancer care. As described in Section 2, a major driver of improvements in cancer services are national strategies with dedicated resource associated with them, such as the recent strategy published by Scottish Government. This section outlines the other main drivers of improvements – official guidelines, quality performance indicators (QPIs) and targets (now known as Local Delivery Plan (LDP) standards) – to try to understand how NHS cancer services are currently performing.

The ability to measure success or otherwise of many of these drivers rests on the ability to access quality supporting data. Scotland's cancer registry and associated analysis by ISD provides a very precise account of population level indices like survival and mortality, but is not resourced to measure other areas. Non exhaustive examples include tumour staging, radiotherapy treatment and systematic anticancer therapies, where formal recording and analysis of key data could inform service planning and assessments, ultimately improving cancer outcomes. Often good datasets exist but are not integrated with others to offer meaningful analysis. The work of the Innovative Healthcare Delivery Programme will be vital in bringing these data sets together.

Patient experience data offers another view on NHS performance and results of the first Scottish Cancer Patient Experience Survey (2015/16) were published in June. Overall, respondents had positive perceptions of the care they received. Of the 5,000 patients surveyed, 94 per cent of patients rated their care as seven out of 10 or higher.⁶³

The survey results showed patients were particularly positive about the coordination of their care, with 90 per cent of patients considering it to be 'very good' or 'good'. Patients were generally less positive when asked about the non-clinical information they had received from hospital staff, with 23 per cent of those who wanted it receiving no information about the impact of cancer on their day-to-day activities.⁶⁴

While the results of the survey were published after the Scottish Government's launch of Beating Cancer, the Scottish Government said the survey results would help shape the development of the actions within that plan.

3.1 CLINICAL GUIDELINES

The Scottish Intercollegiate Guidelines Network (SIGN), part of Health Improvement Scotland develops evidence-based clinical practice guidelines for NHS Scotland. However, these are exactly that: guidelines, and open to interpretation. Box 2 lists current SIGN guidelines for cancer.

Whether guidelines influence or simply endorse practice remains unclear.⁶⁵ Further research is needed to describe the influence of guidelines in comparison to other factors. Local guidelines and protocols on patient management may also be produced but these have not been identified in this report.

BOX 2: CURRENT SIGN CANCER GUIDELINES

Management of primary cutaneous squamous cell carcinoma (2014)

Management of lung cancer (2014)

Management of epithelial ovarian cancer (2013)

Treatment of primary breast cancer (2013)

Long term follow up of survivors of childhood cancer (2013)

Diagnosis and management of colorectal cancer (2011 revised 2015)

Scottish Referral Guidelines for Suspected Cancer (2014)

3.2 QUALITY PERFORMANCE INDICATORS

Better Cancer Care included a commitment to develop quality indicators for cancer services. The continued development of quality indicators is identified as a priority in the new cancer strategy. To develop these indicators, the Scottish Cancer Taskforce established the National Cancer Quality Steering Group (NCQSG) in 2010, which has responsibility for:

- Developing a number of indicators of tumour specific national quality performance indicators (QPIs) as a proxy measure of quality care.
- Overseeing the implementation of the national governance framework that underpins the reporting of performance against these national QPIs.

There are now 21 QPI sets (see Appendix 2). There is a strong emphasis on driving improvements in relation to treatment. Data collection started in 2012 for breast and renal cancer cases. The QPIs are developed collaboratively with the Regional Cancer Networks.⁶⁶ NHS Boards report against QPIs as part of a mandatory, publicly reported, national cancer quality programme.⁶⁷ QPIs should therefore have more influence than guidelines.

According, to Health Improvement Scotland: “The overarching aim of the cancer quality work programme is to ensure that activity at NHS board level is focused on areas most important in terms of improving survival and patient experience whilst reducing variance and ensuring safe, effective and person-centred cancer care.”⁶⁸

The Information Services Division (ISD) now has a rolling programme of publishing three tumour specific reports annually. To date, QPI reports are available for breast, upper gastrointestinal (g/i), lung, colorectal, melanoma, and head and neck cancers.⁶⁹

As an example, a recently published QPI report is for colorectal cancer.⁷⁰ Performance was measured by ISD using clinical data provided by each Health Board relating to patients diagnosed with colorectal cancer for the period from April 2013 to March 2014. The report concludes that overall performance against the 11 indicators was generally good across all NHS Boards but there is ‘room for improvement’ because no individual Health Board met all 11 targets. A summary of overall Scotland performance against the 11 indicators is provided in Box 11 (see Appendix 3).⁷¹ These reports do not provide commentary or a critique of performance but are designed to simply report performance against agreed targets in tabular format. Plans are in place, however, for Healthcare Improvement Scotland to host an expert

group that will review these national results, compile a national report and write to individual Regional Cancer Advisory Groups, highlighting areas of good practice and variance. Where required, NHS boards will be requested to submit improvement plans, which will be reviewed by the expert group and the Scottish Cancer Taskforce.⁷²

The QPI process is relatively new and appears to be welcomed by clinicians because it is based on quality rather than timelines. They see it as a means of raising standards and of drawing attention to deficiencies so that resources can be better focussed. In the following example, one respondent describes how QPIs can act as a driver for improved surgical practice.

“... one of the QPIs has been set about the extent of nodal staging at the time of surgery and the number of nodes that need to have been receptors at the time of operation in order to give you a very definite and robust staging post-operatively. What we’re looking for now is something that is rather more sophisticated in terms of wanting [surgeons] to do nodal dissections that stage the patients thoroughly in terms of us then judging what post-operative radiation or chemo they need. The QPIs are defining how many nodes you need to get good quality staging and most of the time we’re not getting that from the surgeons”. (Oncologist)

Commenting on the process of developing the QPIs, other respondents felt that the level of engagement by clinicians was impressive: again the focus on quality rather than timelines (as in waiting times) was what appealed to them:

“... that’s bread and butter to us.....and I think that’s why we got through the work programme so quickly, because we had such good buy in from the clinicians; but equally that puts the pressure on us to deliver now”. (Regional clinical lead)

The QPI process can also play a part in promoting the kind of reconfiguration of services which many now see as necessary:

“... the days now of nobody quite knowing what everybody else is doing are gone and nowadays there are more specialisms. For certain tumours ... people need to be doing critical numbers of procedures to actually enhance outcomes, so I think these days there’s a greater understanding of that and a greater transparency”. (GP)

Beating Cancer set out actions for Health Improvement Scotland to continue developing a range of quality performance indicators for specific cancer types. This is welcome, but HIS should also consider publishing these data on a more frequent basis than the current three year intervals.

3.3 WAITING TIME TARGETS

Each year since 2006/07 the Scottish Government agreed a suite of national NHS performance targets for cancer known as HEAT targets (Health Improvement, Efficiency, Access to treatment and Treatment). These were designed to contribute towards delivery of the Scottish Government's Purpose and National Outcomes and NHS Scotland's Quality Ambitions.⁷³ NHS Boards were required to report performance data relating to these targets and as a consequence, targets are also likely to lead to improvement. In 2015, HEAT targets were replaced by Local Delivery Plan (LDP) Standards, with the majority of LDP Standards being former HEAT targets, including targets for the Detect Cancer Early programme, cancer waiting times and the treatment time guarantee. Performance against these standards is

reported annually in ‘Scotland Performs’.⁷⁴ In our interviews the term ‘target’ was used consistently to refer to LDP standards. We use both terms in this report.

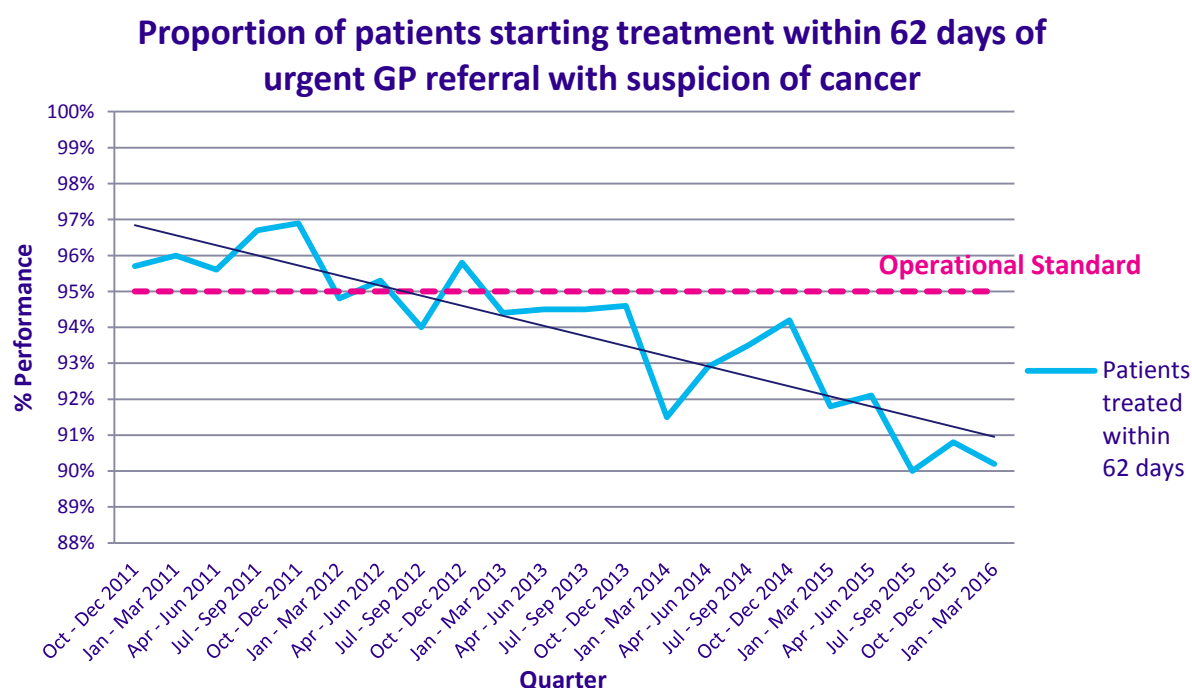
The LDP standards mainly focus on waiting time to treatment. Waiting time targets exist to ensure swift diagnosis and access to treatment. In Scotland, waiting times are not recorded for all cancer types, but for ten of the commonest: breast, cervical, colorectal, head and neck, lung, lymphoma, melanoma, ovarian, upper GI and urological.

Current LDP standards for waiting times are as follows:

- 95 per cent of those referred urgently with a suspicion of cancer to begin treatment within 62 days of receipt of referral. (“the 62 day standard”)
- 95 per cent of all patients diagnosed with cancer to begin treatment within 31 days of decision to treat. (“the 31 day standard”)

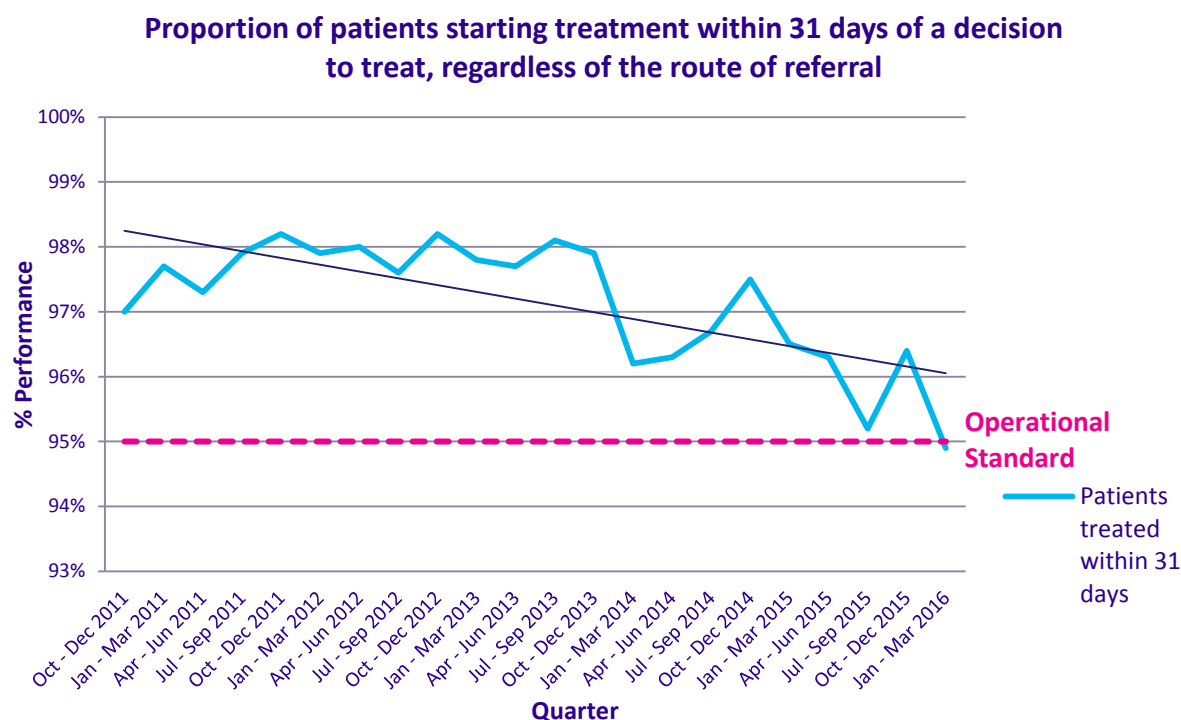
Waiting time statistics are published quarterly online by ISD. The most recent statistics relate to the quarter ending 31 March 2016. For that period, the 62 day standard for urgent referrals was only met by three of the 14 Health Boards. Breast cancer and melanoma cases were the only ones out of ten cancer types where the standard was met with over 95% of patients starting treatment within 62 days. Overall, only 90.2% of patients started treatment within 62 days. This compares with 90.8% in the previous quarter. Scotland has not met the 62-day standard since Oct-Dec 2012 – FIGURE ⁷⁵

FIGURE 12. PERFORMANCE AGAINST 62-DAY CANCER WAITING TIME TARGET, OCTOBER-DECEMBER 2010 TO JANUARY-MARCH 2016 SCOTLAND (COURTESY OF CRUK).



Until the most recent quarter, ending 31 March 2016, the 31-day standard had been achieved consistently in Scotland since its introduction, albeit with a reduction from about 98% to just over the 95% target from the end of 2013 to the end of 2015. In January-March 2016, the standard was narrowly missed with 94.9% of eligible patients starting treatment within 31 days of decision to treat - Figure 13. This is a decrease from 96.4% in the previous quarter. In the quarter ending 31 March 2016, the 31-day standard was met by 11 of the 14 NHS Boards, and for all cancer types except urology (85.1%).

FIGURE 13. PERFORMANCE AGAINST 31-DAY CANCER WAITING TIME TARGET, OCTOBER-DECEMBER 2010 TO JANUARY-MARCH 2016, SCOTLAND (COURTESY OF CRUK).



What seems clear from these targets is that NHS cancer services are struggling with the increased demand associated with increasing cancer incidence. The downward trend of missing the 62 day wait over the last few years, as well as in the recent most quarter failing to meet the 31 day wait after some quarters of decline, indicates that while diagnostic services are struggling the most, treatment services are also starting to feel the pressure of increasing demand.

A further standard aims to increase the proportion of people diagnosed in the first stage of breast, colorectal and lung cancer by 25% by 2014-15. This standard is discussed in Section 4. In addition, generic standards, which by definition impact upon people diagnosed with cancer, have been set. For example, one target is that ‘90% of planned/elective patients to commence treatment within 18 weeks of referral.’ In June 2016, 87% of patients were seen within the 18 week Referral to Treatment standard.⁷⁶

Targets were most often referred to by stakeholders in terms of what helped or hindered meeting particular targets. Increased demand for cancer services and its impact on waiting time targets was a commonly expressed concern, backing up the downward trend in performance highlighted in Figures 12 and 13. One respondent commented that targets which had been met in the past were now proving difficult to meet:

“... performance was seen to fall off and I think that’s largely twofold in origin: one is that there’s just more patients around, there are more cancers and more patients to be treated”. (Regional clinical lead)

We also heard differing views about the value of these targets *per se*. On the positive side, one clinician favoured education of GPs, secondary care and the public about the potential value of waiting time targets and the role they can play in highlighting bottlenecks or deficiencies in the diagnostic pathway, enabling resources to be targeted appropriately.

3.4 SUMMARY

As well as national strategies, NHS performance on cancer is influenced by guidelines, quality performance indicators (QPIs) and targets. It is unclear to what extent clinical guidelines influence practice except where they are used to produce measurable targets or indicators. There are 21 QPIs for cancer in Scotland, and Healthcare Improvement Scotland plans to review and report on national results. Stakeholders were generally positive about the benefits that QPIs brought to the quality of clinical care and service configuration. We are pleased that Beating Cancer has committed to the continued development of QPIs. We would encourage Health Improvement Scotland to consider reporting these data on a more regular basis.

Scotland has not met the 62-day standard for urgent referrals to begin treatment since 2013. The 31-day standard of over 95% of patients starting treatment after a decision to treat had been met since 2010. However the proportion of patients meeting the standard has been falling and in the most recent quarter, ending March 2016, the standard was missed for the first time. It is clear that cancer services, and most probably diagnostic services in particular, are struggling to cope with increased demand for their services as cancer incidence rises. In light of this, targets are an invaluable tool for identifying issues with services, and – where missed – resources should be diverted to support improvements as appropriate.

RECOMMENDATIONS:

- 3. The Scottish Government should review capacity – both equipment and workforce – in diagnostic services with a view to providing additional resources to Health Boards to help them meet cancer waiting times.**
- 4. Scottish Government’s review of waiting times should ensure cancer targets are defined in a way that optimises their intended impacts – while maintaining the 62 and 31 day standards as a minimum. It should also consider expanding waiting times targets to include all types of cancer.**

4: EARLY DIAGNOSIS

In this section we present policy and practice initiatives taken to improve early diagnosis. We then discuss factors found to influence patient pathways up to the point of diagnosis and comments made by stakeholders in relation to early diagnosis. These factors include: public awareness; access to GPs; the role of GPs and their access to diagnostic testing; and diagnostic capacity.

There is evidence that barriers to symptomatic presentation in the UK may partly explain poorer outcomes relative to some other countries. The International Cancer Benchmarking Partnership (ICBP) found that people in the UK were less likely to be aware that increasing age was a risk factor for developing cancer, and they also reported more barriers to seeking a doctor's opinion. However, their awareness of cancer symptoms was similar to other countries and regions (Australia, Canada, Scandinavia).⁷⁷

There is also evidence that delays in referral and diagnosis could have an impact on survival. The ICBP analysis of ovarian cancer identified that a higher proportion of women in the UK have unstaged cancers, albeit a similar distribution of stages amongst those that were recorded. Net survival for ovarian cancer was lowest in the UK compared to other ICBP countries and this was principally observed in women with more advanced stages of disease. The authors suggest that there "may be some diagnostic delay" in the UK although this would not explain overall poorer survival. A vignette study by the ICBP indicated that lower readiness to investigate or refer to secondary care was associated with poorer overall survival in each country.⁷⁸

It is clear that earlier diagnosis is crucial to improving survival in many cancer types.⁷⁹ Some cancer types are more amenable to this, for example breast and skin cancers that have specific symptoms. But particular challenges are present in cancers where symptoms are vague.⁸⁰ Pancreatic cancers, for example, are among those with the poorest survival but symptoms are non-specific and therefore hard to detect. Denmark has pioneered multidisciplinary diagnostic centres (MDC) to facilitate early diagnosis in cases with non-specific symptoms (see box 3). In England, the ACE Programme is testing similar centres.⁸¹

BOX 3: ACCELERATE, COORDINATE, EVALUATE (ACE) PROGRAMME

The Accelerate, Coordinate, Evaluate (ACE) Programme, which was launched in June 2014, is a unique initiative funded by Cancer Research UK and Macmillan Cancer Support. ACE is an early diagnosis programme, scheduled to run for three years, to support NHS England's Domain 1 objective of 'preventing people from dying prematurely'.⁸²

The first wave of the programme incorporates 60 projects which are currently exploring innovative approaches to achieving rapid diagnosis. These include referral pathways from primary care professionals other than GPs, primary care engagement to overcome barriers to uptake of cancer screening, and exploring how to streamline lung cancer diagnostic pathways.

The second wave of the programme will support six pilots in England trialling a new one-stop diagnostic pathway for patients with non-specific but concerning symptoms; an approach incorporating a Multidisciplinary Diagnostic Centre (MDC). As recommended in the Independent Cancer Taskforce report, the pilots aim to test the effectiveness of the referral route in the NHS in England.

As highlighted earlier, the Scottish Government has a policy objective to improve early diagnosis of cancer. Better Cancer Care, the last cancer strategy, identified two main strategies to improve early diagnosis: screening programmes and raising public cancer awareness. Beating Cancer also places a strong emphasis on early diagnosis, building on these priorities. As we have already mentioned, screening is beyond the scope of this report.

Detect Cancer Early (DCE) was launched in February 2012 with the aim of improving overall five year survival for people in Scotland diagnosed with cancer⁸³. Box 4 lists the full DCE programme objectives.

The programme's activity covers three broad areas:

- Public awareness and behaviour influencing, including working to raise the public's awareness of the national cancer screening programmes, and the early signs and symptoms of cancer to encourage them to seek help earlier
- Primary Care cancer symptom management and referral, including working with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing suspected signs of cancer
- Managing Demand for Cancer Screening and Diagnostics, including ensuring there is sufficient capacity in the screening programmes and diagnostic departments to meet the expected increase in those choosing to take part.

BOX 4: DCE OBJECTIVESⁱⁱ

'To increase the proportion of people with stage 1 disease at diagnosis (as a proxy indicator of survival outcome) and to use performance against a HEAT Target as a lever for a whole systems approach to improvement.

To improve informed consent and participation in national cancer screening programmes to help detect cancer earlier and improve survival rates.

To raise the public's awareness of the national cancer screening programmes and also the early signs and symptoms of cancer to encourage them to seek help earlier.

To work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access.

To ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part.

To ensure that imaging, diagnostic departments and treatment centres are prepared for an increase in the number of patients with early disease requiring treatment.

To strengthen data collection and performance reporting within NHS Scotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral and survival.

To facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit.'

ⁱⁱ Reproduced with permission of the Scottish Government

The first objective listed above is an LDP standard, defined originally as a HEAT target, which states that the percentage of people diagnosed at stage 1 for breast, colorectal and lung cancer (combined) is to increase by 25%. If achieved, the national rate of stage 1 diagnosis for this group of cancers would be 29%. The national baseline for this target was 23.2% (based on 2010/2011).

The latest staging data, published in July 2016, for the period January 2014 to December 2015, show that 25.1% of people were diagnosed with breast, colorectal and lung cancer at stage 1 (combined figure across the three cancer types). While improvements have clearly been made - this is an 8% increase in stage 1 diagnosis compared with the baseline (2010 and 2011 combined) - the standard has not been met in the final year of the LDP.⁸⁴ Indeed, none of the NHS Boards had reached the target 29% for stage 1 diagnosis in 2014/15, though rates varied (for mainland Boards) from 20.1% in Grampian to 28.6% in Fife.

Over this two year period, 40.5% of female breast cancers were diagnosed at stage 1, 15.4% of colorectal cancers and 17.9% of lung cancers. The corollary is that overall, 25.8% of breast, colorectal and lung cancers were stage 4 (metastatic) at diagnosis. Individually, these vary considerably between cancers, with stage 4 disease comprising 46.2% of lung cancer diagnoses, 22.9% of colorectal cancer diagnoses and 5.3% of female breast cancer diagnoses. Patients from more deprived areas are more likely to be diagnosed at later stages of their cancer.⁸⁵

There was a small overall (1.9%) increase in the proportions of stage 1 cancer diagnosed over the four years of the DCE programme, accompanied by a large (3.5%) reduction in unknown stage recording, suggesting that some of any observed change must be due to information biases.

Overall, the data shows that in the four years the DCE programme has been running there has been significant improvement in the early detection of lung cancer, static performance in breast cancers, while early detection of colorectal cancer has been falling, in spite of increased screening uptake. This is a concerning finding, and one in need of further investigation. Developing a better understanding of the causes of these trends will be vital in helping to increase the earlier detection of these cancers.

We did not identify reliable national data on stage at diagnosis for other cancers. The availability of this type of data for other cancers could inform future planning and priorities, however, and ultimately help improve cancer outcomes.

4.1 PUBLIC AWARENESS

The DCE programme initiated marketing campaigns that were aimed at increasing public awareness of symptoms, in the case of breast, bowel and lung cancer, and increasing uptake of screening for bowel cancer. The campaign consisted of TV, radio, digital media, outdoor posters, PR and field activity.

A summary of the results of the evaluation of the DCE social marketing campaign, 'Cancer. Don't get scared get checked' has been published.⁸⁶ Results are summarized in Box 5, which shows that the campaigns generally had a positive impact on awareness of symptoms.

BOX 5: RESULTS OF 'CANCER. DON'T GET SCARED GET CHECKED' EVALUATION

'Spontaneous awareness of the 'getting checked early' message amongst women increased from 57% before the campaign to 64% post campaign and from 54% to 67% amongst those aged 55-64yrs.

Those claiming to self examine increased from 65% to 70%.

Of those who had seen TV advertising about cancer, 18% recalled specific aspects of our campaign (significantly more than the recall on the 'Be clear on Cancer' campaign from NHS England, which ran at the same time).

Prompted recognition of the campaign across all aspects (radio, TV and posters) reached 85%, which is very high.

The main message take out from those who have seen the campaign is 'get checked' at a high level of 81%.

Just under half of our audience feel more confident about approaching their GP as a result of seeing the campaign, particularly 40-64s and DEs.

Over half of our audience stated the advertising would make them get checked earlier if they had signs/symptoms.'

Other actions to meet DCE objectives were essentially delegated to Boards. They were allocated 'lump sums' to use as they saw fit to achieve the programme aims, much of which we were told was spent on expanding diagnostic capacity. A respondent with a leading network role described how the process worked:

"...there's certainly a government focus on earlier diagnosis that has filtered down – it's come with money – it has filtered down through the health boards, through the service, into primary care, into the general public; I do feel it has been well researched in terms of trying to identify the barriers to people coming along earlier on. And we now have to wait for the full evaluation of the impact of that..."
(Regional clinical lead)

In general DCE received qualified support from clinicians. A 'downside' of the programme, from many perspectives, is the difficulty of demonstrating the impact of the programme on survival outcomes to politicians and the public, and a few respondents were sceptical about the impact of DCE in the absence of any data.

"...my general feeling is that this is a very difficult thing to do and I'm not convinced that we have necessarily achieved anything clearly demonstrable in terms of catching cancers earlier as part of the programme". (Clinical lead)

Most respondents had something to say about the limitations of the programme and the intractability of the problem. This was a fairly typical comment.

"I think there are genuine efforts being made to engage with GPs and to make the public aware of the importance of early diagnosis ... I remain uncertain how effective that is going to be and I think we've just got to wait and see. I'm not sure that there are any other obvious things that you can be doing to actually improve the rates of early diagnosis... most of the things that could be done are either in progress or being looked at". (Oncologist)

The main barrier to early diagnosis in general was seen as the reluctance of many patients to act on their symptoms at an early stage. Characteristics such as old age, ‘Scottish stoicism’, not wanting to ‘worry the doctor’ and social deprivation were seen as contributing to unwillingness to visit the GP with symptoms and hence to late diagnosis of cancer. One respondent in a remote part of Scotland felt that reluctance to visit the GP was widespread in such areas and that this kind of stoicism masked the needs of the population and contributed to poorer services. A national level view reflects this concern:

“I think there's a significant amount more that we could be doing to raise awareness - without alarming the public and that's always the difficulty - of what might be symptoms of cancer and encouraging them to go to their GPs to get early investigation”. (National interviewee)

This was felt to be particularly significant for lung cancer:

“...one of the challenges for lung cancer especially is that the demographic for lung cancer ...is a socio-economically deprived population, typically elderly and typically male and those are the people who are probably least responsive to public health campaigns”. (Oncologist)

A kind of fatalism (the ‘big C’ attitude) was seen by some as accounting for the lack of response to campaigns particularly amongst older people. A new campaign called the ‘wee c’ was launched in August 2015 aimed at overcoming some of the fear and fatalism which discourages people from presenting with potential signs and symptoms⁸⁷. The campaign was initiated by the Scottish Government in partnership with Cancer Research UK and involves other leading cancer charities.

These findings, particularly the difficulty in raising awareness in hard to reach groups, are also reflected in the recent cancer strategy. As such, Scottish Government has committed to continuing the DCE programme, with a focus on trying to reach people who are most likely to present at later stage of disease. This is a welcome move.

4.2 THE ROLE OF PRIMARY CARE

A number of initiatives, both national and local, have been developed to support and encourage primary care in the crucial role of recognising symptoms and making appropriate referrals. The primary care interface with secondary care, in particular access to diagnostic testing, was also a focus of DCE objectives.

In 2006-07, a locally enhanced service in primary care collected data on times from patients first noticing symptoms, through to GP referral and being seen by a hospital consultant. Analysis of the outcomes showed that time from first presentation to referral varies by cancer type although it is unclear why these variations exist and what interventions could be effectively implemented to address the problem.⁸⁸ These questions are topics of ongoing discussion and debate.

4.2.1 REFERRAL GUIDELINES

Scottish referral guidelines for suspected cancer have been developed to support improvement in early diagnosis. They were first published by the Scottish Government in 2002 and subsequently revised in 2007 and 2014⁸⁹. These guidelines provide referral timelines, pathways, and guidelines for a wide range of cancers. In 2015 a short version of

the referral guidelines was issued to be used for quick reference by GPs during consultations, and in 2016 an app was launched for the same purpose.⁹⁰

GPs interviewed welcomed the new referral guidelines published in 2014 and the summary guide in 2015 (described in Section 3.1). One respondent who had been involved in their development at national level described the process adopted: the National Institute for Health and Care Excellence (NICE) guidelines were reviewed along with guidelines from other countries and all the 'best points' brought together.

"[The new guideline] wasn't hugely different from the previous guideline but we ... kept it nice and brief and useable. We looked at the draft of the NICE guideline that came out in December last year ... and tried to look to see, are there any ideas in the English draft that would conflict with what we were saying in the Scottish guidelines that we had published and ...there was no real conflict". (GP)

However helpful for GPs when deciding how to respond to 'red flag' symptoms, the referral guidelines were not thought to have the same value in achieving early diagnosis of cancer in cases where symptoms were more 'vague', or in certain cancers (e.g. ovarian), which tend not to present at an early stage. This was a major concern expressed by hospital based clinicians as well as GPs:

"I think, the use of urgent pathways ... has been very good for people whose tumour fits in a specific pattern for the referral for a particular speciality but, I think, there [are] massive issues with people who don't, necessarily, fit in an obvious category..."(GP)

"... referral guidelines have helped standardise referral pathways, against targets that came in as ... waiting time initiatives ... [but] I work with a practice where we don't have targets attached to them, and patients' pathways can still be very lengthy. So I suspect there's still inequity across different tumour groups". (GP)

An issue, commonly raised by GPs and others, is that some consultants refer patients back to their GP when the result of the requested diagnostic test is negative, without apparently investigating symptoms and taking a view on what other route might be appropriate.

"... you can't just refer somebody in with abdominal pain, and put a scope down them and say not on my patch without investigating if that pain, or weight loss, or whatever's not still ongoing". (GP)

Whilst this point was addressed in the referral guidelinesⁱⁱⁱ it clearly remains a concern.

There was also perceived to be a lack of consistency between hospitals in referral pathways.

"...in some services if a GP refers a patient up for a chest x-ray and that chest x-ray is abnormal the hospital will have in place an automatic trigger for an abnormal chest x-ray to get a referral to a respiratory clinic but that doesn't happen uniformly across all hospitals. So in some places if a GP refers a patient up and the

ⁱⁱⁱ For patients with persisting symptoms it is not acceptable to simply exclude cancer without providing an assessment of the likely underlying cause. This may involve individual hospital specialities making internal referrals to their colleagues to help determine the nature and cause of the patient's symptoms. These internal referrals should be undertaken with the minimum of delay and with good communication to both the patient and GP. [Scottish referral guidelines for suspected cancer. August 2014]

x-ray is abnormal that report will go back in due course to the GP which may take some time. The GP is left to decide whether or not to act on it and there are additional delays and so on that go into that more prolonged pathway so I don't think it's a consistent pathway across the whole region". (Oncologist)

This respondent took the view that at both regional and national level there should be a directive to ensure that all hospitals had a system in place whereby abnormal chest x-rays triggered a respiratory referral.

Another approach to improving patient pathways was adopted by a clinic (in NHS Highland) employing a specially trained nurse to vet all GP letters and determine which test is appropriate or whether to refer them straight to the consultant's clinic:

"We've done that for a year or so ...there was scepticism from some colleagues to start with. But, you know, I think, now, it's been universally accepted... So you don't have the two week wait ... you make sure that everyone is seen in a very timely fashion, and that's a resource issue. It doesn't have to be a qualified consultant that sees patients. I think we should be much smarter about educating other healthcare workers, to make assessments about whether patients go straight to test". (Surgeon)

4.2.2 DIRECT ACCESS TO TESTS

A further solution being pursued currently at national level (by the Primary Care Cancer Group and the Scottish Clinical Imaging Network (SCIN)) is to extend GPs' direct access to diagnostic testing and to achieve a standard approach across Scotland. This approach is described in the referral guidelines (see box 6).

BOX 6: SCOTTISH REFERRAL GUIDELINES FOR SUSPECTED CANCER. AUGUST 2014

NHS boards have well-established urgent suspicion of cancer referral pathways to facilitate prompt diagnosis of cancer. These pathways function particularly well in cases where symptoms and signs are suspicious of a specific tumour type. However, for those patients with vague symptoms (such as unexplained weight loss and fatigue) there is potential for delay in reaching a diagnosis. To minimise this risk, direct access to imaging for primary care practitioners enables the differential diagnosis to be narrowed and referral to the appropriate secondary care specialty to be made, thereby reducing delays.⁹¹

Although the stakeholder views we received related primarily to radiology services, the Scottish Government has publicly acknowledged that there is pressure on endoscopy services too, as diagnostic waiting time statistical releases confirm.⁹²

Views differed somewhat (among national level stakeholders interviewed) as to how well this was currently working across Scotland. One took the view that all Boards now facilitate primary care direct access to imaging, whilst another said that being able to refer directly to CT and MRI was 'a problem in some parts of Scotland'.

"I suspect that in many, indeed most, areas of Scotland radiology services are under enormous pressure with staff vacancies in some areas. I suspect that boards are worried about x-ray departments being inundated and overwhelmed if they allow more direct access. In those areas where it is being allowed and where there as I say more direct communication available between GPs and the radiology workforce, that has been shown not to be the case". (National interviewee)

An audit carried out by Scottish Primary Care Cancer Group suggested that variation in terminology and pathways descriptions was masking actual variation in direct access.

Some respondents believed strongly that the key to success in improving early diagnosis of complex cases lies with the direct contact between the GP and the radiologist so that a discussion about the most appropriate test can take place. We were told that in a number of NHS Board areas this way of working is now established but that it is more challenging for more densely populated areas. The aim of the work involving SCIN was to devise 'a more realistic level of access' to meet that challenge.

"...it may be that we can't have one pattern fits all, because of the particular geography we have in Scotland and the size of the services and so on". (Regional clinical lead)

One respondent involved at national level was optimistic in spite of the current difficulties.

"The big boards are now having to actually implement a duty radiologist system which I think is something that we should have done ages ago not just to discuss with the GP but also to discuss with secondary care specialists about imaging instead of in an ad hoc way trying to find somebody you may want to talk to. I think a duty radiologist is a sensible move".

"... Certainly the system for direct to CT imaging for these complex cases I think will come across Scotland without that much difficulty". (GP)

Some resistance from GPs was reported in terms of seeing this as extra work being placed on primary care. A more serious concern from local level was probably that there were 'not enough staff on the ground in radiology' (GP).

GPs in two areas reported on the effectiveness of direct access in their areas: one described the tracking system to ensure that imaging reports were responded to appropriately by the GP who had requested them. Opening up diagnostics to GPs could relieve some of the pressure of targets by deferring the start of the waiting time until the tests are completed. But others expressed mixed feelings about the ability of radiology services to cope with greater demand.

One GP, talking about the 'real tension in the system' created by the opening of a new hospital, expressed the view that:

"... there potentially are ways to look at some of the steps in the pathway but I think at the moment the real anxiety is that if you start opening up diagnostics then the system will grind to a halt". (GP)

"I'm certainly familiar with the Borders model whereby you're able to have that discussion between the GP and the radiologist who then looks at the most appropriate way of taking forward investigations. I think the difficulty with that, or the difficulty that's been mooted in Glasgow would just be that the volume of demand means that you're almost taking a radiologist out of their day job, as it were to actually manage that process and that's an anxiety". (GP)

BOX 7: BORDERS MODEL

Borders Model: 'open' access to imaging has existed for twenty years. It was introduced by forward thinking radiology department and results have been impressive. Currently work is being undertaken locally to use routinely collected data to demonstrate effectiveness to government policy makers.

The further work (referred to above) ongoing at national level aims to disseminate the experience of those Boards where direct access is prevalent. The question of diagnostic capacity is also under review and new money for diagnostics has been committed in Beating Cancer. A strong view that any policy (such as DCE) likely to lead to greater use of diagnostic services should be 'properly assessed and costed and worked through' was expressed by a leading specialist.

4.2.3 FURTHER INITIATIVES IN PRIMARY CARE

A good example of an attempt to change professional behaviour can be found in relation to screening programmes. In a two year initiative, DCE used the GP contract to promote greater engagement by GPs in screening programmes. Some GPs we spoke to believed that this type of pump priming might not be sufficient to change behaviour in the longer term.

Another initiative directed at the primary care role is the Primary Care Engagement (PCE) Programme (a Cancer Research UK funded programme)⁹³. In partnership with the Scottish Government's DCE team a project was started in Glasgow in 2012/2013 to work intensively with general practice to achieve earlier diagnosis of cancer in primary care, and therefore improvement in cancer outcomes, by:

- Working with local partners to assess where there is the greatest need for improvement locally (a particular geography or an aspect of the cancer pathway)
- Influencing uptake of best practice in a range of ways including providing training
- Facilitating local solution-finding and implementation
- Gathering local intelligence and insights for new opportunities to support improvement
- Working as a long-term partner of local professionals and organisations

External evaluations have suggested that the work of the programme has helped GP practices to increase the uptake of improvement activities (such as plans, significant event analysis, audit, use of risk assessment tools); reduce variation in referral, conversion and detection rates; raise awareness, and encourage practices to discuss cancer and review their performance against best practice; and influence wider strategies and processes e.g. referral forms.

4.3 DIAGNOSTIC CAPACITY

As mentioned above, some respondents believed strongly that the key to success in improving early diagnosis of complex cases lies with the direct contact between the GP and the radiologist so that a discussion about the most appropriate test can take place:

"I suspect that in many, indeed most, areas of Scotland radiology services are under enormous pressure with staff vacancies in some areas. I suspect that boards are

worried about x-ray departments being inundated and overwhelmed if they allow more direct access. In those areas where it is being allowed and where there as I say more direct communication available between GPs and the radiology workforce, that has been shown not to be the case". (National interviewee)

Similarly, some doubted whether strong national policy statements about GP access to diagnostics would be effective when it came to each individual Health Board deciding whether or how to implement the policy:

"... looking at it from the Health Board perspective it can be quite difficult for Health Boards to implement something new and to change something...if there are not additional resources to do so". (GP)

Other barriers to progress we were told about included: concern that there were 'not enough staff on the ground in radiology' (GP); fears that diagnostic services would be unable to manage the increased demand generated; relationships between primary care and radiology departments; GPs resistance to having 'extra work dumped on them'. As highlighted in Section 3, the fact that the 62 day wait has been missed for over two years now is a clear indication that diagnostic services are struggling.

There was a perception that the initiatives we have described, such as DCE, to promote early diagnosis cause short-term increases in numbers of patients and pressures on services. Referring to the breast cancer symptom awareness campaign one leading clinician remarked:

"... my goodness, that was successful in that we had a careful and a well-informed marketing programme, and the public responded dramatically, to the extent it nearly broke the back of the services. ... We will have to say that not just as a result of this campaign but as a result of a whole variety of other factors, we are seeing – particularly for breast clinics – a sustained increase in referral rate to the clinics and that is causing a pressure.We're now seeing over 22 worried well to each woman that we're diagnosing with cancer; so we're finding more cancer but we're getting inundated with more of the worried well; and it's trying to get a balance". (Regional clinical lead)

Some respondents felt there was already pressure on diagnostic capacity, without the added impact of public awareness campaigns and direct access to testing for GPs. The problem was manifested in a shortage of radiology staff, vacant posts, and backlogs of routine chest x-rays waiting to be reported. One surgeon mentioned that the shortage of staff was exacerbated by the 'greater emphasis on radiologists being required to attend multi-disciplinary teams (MDTs), which is a labour intensive process' (Surgeon). Outsourcing had been tried in one area but was not seen by our respondent as a good solution as inside knowledge of hospital pathways is needed to provide a good service.

"So we need to get the manpower sorted out but that's going to take a long, long time before we can get that improved". (GP)

A stakeholder with a national remit took the view that a lot of work had been done to scope diagnostic services before launching the DCE programme, and that Health Boards could cope with the increased pressure. Nevertheless, it was always recognised that the ability to cope with additional pressures arising from DCE initiatives should not be 'taken for granted'.

"... before we do anything to raise further awareness or look at other cancers, we need to be very carefully mapping out what's already there and what might need to be done

to expand service capacity”. (National interviewee)

“while it’s useful to have a policy such as DCE, it...there’s no point in having that policy if there are not resources in place to deliver it”. (Clinical director)

4.4 SUMMARY

Survival from the most common cancers – those of the trachea, bronchus and lung – remains among the poorest of all cancers. Overall incidence and outcomes compare poorly to both the rest of the UK and many other comparable European countries.^{94 95} So there is much to be gained from a continued focus on early diagnosis.

Efforts to improve early diagnosis of cancer have tended to focus on a small number of cancer types that comprise the majority of cases. The focus of the DCE programme for instance, has been breast, colorectal and lung.⁹⁶ However, this leaves a large minority given less of a priority.

When prioritising cancer types for DCE programme efforts, this should consider overall impact: the level of incidence and the potential of achieving early diagnosis should be judged in combination. This may mean that more common cancers are prioritised as this would lead to the highest level of benefit for the population. It must be acknowledged that with limited resources difficult decisions need to be made, including recognition that those with less common cancers could also benefit from efforts to improve earlier diagnosis by addressing capacity issues.

The recent cancer strategy has outlined continued commitment to the DCE programme, including new work on malignant melanoma and targeting awareness campaigns on hard to reach groups.

Major national drivers to promote earlier cancer diagnosis in the past 3-4 years have included waiting time targets/standards, public awareness campaigns as part of DCE, and updated SIGN referral guidelines, including more flexibility for referring patients with vague symptoms. The DCE programme comprised both national publicity and Board-level initiatives to promote earlier detection and aimed to achieve a 25% increase in the proportion of stage 1 breast, colorectal and lung cancers between 2012 and 2015. However, it seems little improvement has been made.

Overall, the data shows that in the four years the DCE programme has been running there has been significant improvement in the early detection of lung cancer, static performance in breast cancers, while early detection of colorectal cancer has been falling, in spite of increased screening uptake.⁹⁷

The critical role of primary care has been supported by the development of referral guidelines in accessible formats. However, while these were seen to be helpful, further clarity on how to deal with cases where vague symptoms present remains an issue.

Views about direct access to diagnostic testing were mixed. Work undertaken at national level suggested that differences in terminology made it difficult to establish a clear picture of the degree to which direct access was in place across Scotland. In parts of the country where such arrangements existed, GPs felt they were effective and that when used responsibly the impact on diagnostic capacity was manageable. However, others felt that diagnostic capacity was already under pressure and that further resources were needed before direct access was introduced as standard practice. While some areas may be better set up than others, the

overall decline in the 62 day waiting time standard indicates serious capacity issues with diagnostic services. Other indicators reinforce this: in 2009, the Scottish Government set a national standard that patients should not wait any longer than six weeks to receive one of the eight key diagnostic tests and investigations.⁹⁸ That targets has not been met and in 2015, more than 67,200 patients waited longer than 6 weeks for a diagnostic test.⁹⁹

RECOMMENDATIONS:

- 5. The Scottish Government and the Information Services Division should collect and publish staging data on all cancer types.**
- 6. The DCE programme should publish a clear evaluation of public awareness campaigns to understand their impact. As outlined in Beating Cancer, DCE should publish plans on how they will reach deprived, harder to reach communities where early detection of cancer remains poor.**
- 7. The Scottish Government should explore best practice pathways for referral of patients with vague or non-specific symptoms, such as the Borders model, and consider whether national guidance should be updated to ensure consistent pathways for referral.**

5: ACCESS TO EFFECTIVE TREATMENT

In this section, we consider the policies and recent developments that are impacting on access to effective treatments.

Particular reference is made to the availability of new medicines, which has been a particular political priority in Scotland since the Scottish Parliament Health & Sport Committee launched an inquiry into access to new medicines in 2013. This resulted in the Scottish Government implementing reforms to the Scottish Medicines Consortium (SMC). A review of these reforms, led by Dr Brian Montgomery, was announced in January 2016, and was ongoing at the time of writing.

We then consider workforce issues affecting access to treatment and travel and transport barriers which are of particular concern in Scotland. Stakeholders' views are integrated within each subsection. The main concern for many was the ability of services to meet current and anticipated increased demand, caused in large part by the ageing population and the availability of new treatments.

Cancer treatments vary according to the site and stage of the disease and other clinical factors, but they broadly fall into three approaches: surgery, systemic anti-cancer therapy (SACT) and radiotherapy. SACT includes chemotherapy, biological agents and hormone therapies. The geographical provision of each of these treatments differs. The majority of surgery for breast and colorectal cancers, for example, is provided at local hospitals throughout the country. Smaller volume and specialist surgery may be limited to fewer centres of excellence. SACT may be provided either at specialist cancer centres, at local hospitals or taken at home, depending on whether it is being given through an intravenous line or orally, for example. Radiotherapy is provided at cancer centres that have linear accelerators to deliver the treatment – there are five radiotherapy treatment centres in Scotland with an additional satellite service linked to the Beatson West of Scotland Cancer Centre (“the Beatson”).

National policy for access to treatment is embodied in waiting time targets, clinical guidelines and quality performance indicators discussed earlier and not repeated here. Of particular note, is the focus on meeting treatment targets in QPIs (see Appendix 3). Other relevant policies relate to access to new drugs, radiotherapy and acute oncology.

However, what is evident from our research is that there is very little data to tell us more about access to treatments. Lack of data on access to radiotherapy and chemotherapy treatments in particular hold back the ability to assess the service and understand where improvements are needed. For example, it is not clear what proportion of patients in Scotland receive Intensity Modulated Radiotherapy – a modern type of treatment that around 50% of patients receiving curative radiotherapy should have access to. The Scottish Government must make collecting and publishing data on access to treatment a priority as it takes forward Beating Cancer.

5.1 SURGERY

There is a general consensus amongst respondents that surgery is best carried out in units with high volumes of cases.¹⁰⁰ The national position is expressed by one respondent as follows:

“... there is emerging evidence in some areas that you get better outcomes with higher volume... Clearly if there is evidence that outcomes are better, the more procedures are done in a given centre then we have to follow that evidence. That is something that is under scrutiny at the moment”. (National interviewee)

It follows that there is an evolving interest in introducing national specialist units to operate on less common cancers where volume is low and Scottish Government’s National Clinical Strategy (Feb 2016) articulates some of this. Centralisation and specialisation of care may, however, create problems of access for some patients due to travel and transport difficulties.

In some Board areas general surgeons in hospitals remote from the cancer centre are unlikely to undertake cancer surgery now, unless (as in one example we were given) they have specific experience in the type of cancer surgery and they are able to undertake a sufficient number of operations to maintain their expertise.

MDT working is known to contribute to good treatment outcomes¹⁰¹ but can be difficult to achieve when they are all concentrated in a single hospital.

“... thoracic surgeons for lung cancer for the [region] [are] all based in one hospital and in order to engage them in MDT decision-making within all of the separate [District General Hospitals (DGHs)] has required us to either get the surgeons to come out to the different DGHs or to link in by telelink. That works variably well in different hospitals in terms of how good the links are and how committed the surgeons are to being involved in that”. (Oncologist)

Robotic surgery was the main innovation we heard about in relation to surgery. Evidence about its benefit is still emerging and costs were seen by stakeholders to be high both for the equipment and the staff training. The first provision in Scotland was made available in Aberdeen in August 2015 and is partly paid for by UCAN (prostate cancer charity).

5.2 RADIOTHERAPY

From 2012 to 2014, national responsibility for radiotherapy coordination and planning was undertaken by the Radiotherapy Programme Board (reporting to the Scottish Cancer Taskforce) which replaced the Scottish Radiotherapy Advisory Group. There was then a hiatus until a Radiotherapy sub group of the new National Cancer Clinical Services Group was created to provide a national lead on radiotherapy. It is likely this group will have a significant role in the allocation of the large sums of new investment committed in Beating Cancer.

There are now five radiotherapy treatment centres in Scotland with an additional satellite of the Beatson opened in Lanarkshire in late 2015. A national linear accelerator refresh programme has been in place for over 15 years and therefore generally equipment is in line with the latest technologies. The first Scottish radiotherapy patient survey was completed in 2014 and reported generally positive experience (see box 8).

We refer in Section 2 to concerns about the need for stronger national leadership in radiotherapy. This view reflects the report on UK radiotherapy services published by Cancer Research UK and Tavistock in 2014,¹⁰² which concluded that there was ‘a clear need for better national leadership to promote coherence and collaboration’ between the three MCNs.

BOX 8: SCOTTISH RADIOTHERAPY PATIENT SURVEY, 2014

[Results] show that most patients are very positive about their radiotherapy care: 97% rated their overall care as excellent or very good, and 82% as excellent. And patients were particularly positive about staff: 91% said that staff always took account of what mattered to them; and 97% of patients said that staff always treated them with compassion and understanding.

But there is also some room for improvement. Around a quarter of patients said that either they were only involved 'to some extent' (21%) or 'not as much as they wanted' (4%) in decisions about their care and treatment. Over a third of patients indicated that either the amount of information given at the start of their radiotherapy was only 'satisfactory' (36%) or was 'poor' (1%). And over one quarter of patients (26%) indicated that hadn't had a regular formal review of their treatment.

The report shows the different scores in Radiotherapy centres across Scotland, and there is some excellent practice in many areas: lots to be learned and shared.¹⁰³

Some stakeholders however had more positive views about the service. National policies to deliver radiotherapy technology and equipment were described by one stakeholder as 'safe effective and robust':

"We do have a national system in place which is designed to ensure that all of the cancer centres within Scotland have access to the same machinery and technology which will deliver state of the art radiotherapy treatment to patients. So that has been going on for best...about ten years now I think". (Clinical director)

"I think for national purchasing of equipment, again there's a mechanism which works very well and trying to rationalise, for example, our linear accelerator replacement programme; national coordination made that work, whereas before it was done on a regional or board basis and that wasn't as efficient". (Regional clinical lead).

"we're pretty fortunate in that we have access to all the latest technology and the new techniques and as [regional centre] certainly has been moving forward in leaps and bounds in terms of the use of new technologies so we are well provided for there". (Oncologist)

However, utilisation of the equipment seems to be held back by staffing issues (as described in the workforce section below). In one region with a particularly busy breast unit we were told that they had been...

"...trying to do seven day working, or six day working, and changing hours of staff, and changing opening hours as well..." (GP)

It is clear Scotland has in place a robust programme to provide up-to-date equipment, but it appears that this equipment is not being used to its full potential across a range of cancer indications and boards areas. Publicly available data on the delivery of modern radiotherapy techniques is extremely limited and the service would benefit from this being resolved to fully understand current delivery, and where improvement is required. Limited evidence from freedom of information requests and anecdotal evidence does suggest there are significant differences in the types of radiotherapy that patients will receive and benefit from in different board areas.

This is recognised in Beating Cancer’s action, “to see that everyone who would benefit from it has access to advanced radiotherapy”¹⁰⁴, which is welcome.

5.3 ACCESS TO NEW MEDICINES

The Scottish Medicines Consortium (SMC) evaluates new medicines and decides whether they will be made routinely available on the NHS. The Consortium is made up of lead clinicians, pharmacists and health economists together with representatives of Health Boards, the pharmaceutical industry, patients and the public. The criteria used to make assessments about which drugs will be routinely available to patients are set out in Box 9.

In 2014 the Scottish Government set up a New Medicines Fund with a budget of £40m. This amount was doubled in 2015, and was most recently stated to be £90m.¹⁰⁵ The Fund replaced the Rare Conditions Medicines Fund set up in 2013. The New Medicines Fund utilises the rebate to the Scottish Government made by the pharmaceutical industry as part of the Pharmaceutical Price Regulation Scheme.

BOX 9: SMC CRITERIA

Before the SMC accepts a medicine for use by the NHS in Scotland, it needs to find out: how effective the medicine is; which patients would benefit; whether it is as good as or better than medicines the NHS already uses to treat the particular condition; and whether it is good value for money. [SMC]

Patient and Clinician Engagement (PACE) meetings are sometimes held to discuss medicines for end of life conditions and very rare diseases. Commenting on the new SMC process for assessing drugs (PACE), one cancer charity director interviewed was concerned about the lack of feedback to organisations which make submissions. The same respondent also felt that when their organisation chose not to make a submission about a new drug, that also should carry some weight in the process.

The main problem raised by respondents was about equity of access to new cancer drugs¹⁰⁶ and there have been concerns raised publicly over access to some drugs that may be available in England and not in Scotland.

Developments in drug policy in England should be given consideration, here. The Cancer Drugs Fund, which provided access to non-NICE approved drugs is now being incorporated into NICE’s appraisal process. It remains to be seen how this might impact on discrepancies between drug approvals in Scotland and England.

An oncologist highlighted funding restrictions affecting the use of standard chemotherapy agents:

“The finances are so restricted now, that really we're being asked to justify every prescription for some of these, what we would think were more standard anti-cancer agents. You know, say they cost £500 a cycle, then we will be asked to justify that, and if there isn't very strong evidence. ...the level of evidence that's now being asked for, by some of these [local Medicines Management] committees, it doesn't exist, and it will never exist”. (Oncologist)

Other oncologists we talked to were very concerned about barriers to accessing new drugs for their patients. One respondent said that the number of drugs which are licensed for use but cannot be prescribed in Scotland is growing:

“... something that makes me extremely uncomfortable, because I've got little doubt that it's not very long before it will have an adverse impact on patient outcome. It may have already happened, to be honest with you”. (Oncologist)

Developments in personalised medicine were also seen as a growing challenge...

“With cancer treatments going down the personalised medicine route that needs access to these new drugs and that's going to prove very expensive, so I see that being a big barrier. It is starting to happen. The biobanks are very involved in that and they are looking at testing biopsy samples when they come in for specific mutations. There are a few studies going on just now where it will be normal practice for patients' treatment to be tailored towards the mutations they've got. ...It will be [more expensive], because it's not just the drugs you are looking at, it's testing of the biopsy samples as well”. (CNS)

Although the main issue relating to drugs was about costs, even introducing off-license drugs that are much less costly and not driven by commercial considerations there may be disincentives for clinicians to prescribe them:

“Just because something is cheap doesn't mean to say the service can cope with it... ...if you're using a drug within licence, liability rests with the manufacturer if there are any issues, but once you go off-label, the Health Boards then become liable”. (Pharmacist)

One respondent described the lengthy procedure for getting an off-license drug approved by the MCN and then included in the individual NHS Board formularies via the regional prescribing advisory group. With meetings only taking place quarterly the time barrier can be significant.

Regional differences in access to funding for drugs not approved by SMC are also a source of concern. According to one clinician this variation has only arisen recently:

“... Up until about 18 months ago... if the SMC had not said yes, it was a 'no' and that was the same across the country. ...And then there was a fairly dramatic turnaround basically for political reasons ... We don't have a cancer drugs fund in Scotland, okay? So the health boards were told ... you've got to start allowing people access to drugs prior to an SMC review, and even after an SMC 'no' in some circumstances. And this has led to a huge inter-regional variation where some people are clearly accessing drugs in one area where the same individual would not have accessed them in another area. I know this because I get phoned up by my colleagues in the other areas”. (Oncologist)

This view that regions were operating with different criteria in relation to individual patient treatment requests (IPTRs) was endorsed by a number of respondents:

“there is huge heterogeneity across Scotland, in terms of which, whether you're likely to get [IPTRs] approved or not. ... there is absolute zero doubt that there is a massive difference in terms of a patient's likelihood of getting access to these new drugs, dependent on where they live in the country”. (Oncologist)

One respondent advocated a strategy to improve access to new drugs involving harder negotiation with pharmaceutical companies to make the drugs more affordable for patients.

“Allied to that we need to get better at choosing the patients in which these therapies will work. We know that a lot of them are gene mutation specific and, therefore, we

need to get better at doing the genetic tests before prescribing the drugs. Otherwise not only is a lot of money going to be wasted, but patients who will not benefit from these therapies are going to be exposed to them and they are not without side effects". (National interviewee)

Another respondent highlighted the implications for participation in clinical trials of SMC decisions not to license certain drugs.

"There's a big question mark over our ability to participate in future clinical trials, of the next tranche of treatments. Because what is now regarded as a standard of care, may contain these new agents. And it will be expected, for the next tranche of trials, when you add in the next agent, that the current standard of care will be available in the country. And now, we cannot say that for Scotland, because in many diseases, the standard of care [includes] new agents not approved to be given here, because of the cost". (Oncologist)

Aside from this issue, access to clinical trials was not an area of major concern to stakeholders although it was acknowledged that patients who were remote from regional centres were less likely to participate because of travel and accommodation requirements.

While not the focus of this report, the importance of clinical research – and a favourable environment for conducting it – should be acknowledged.

5.4 ACCESS TO CHEMOTHERAPY

Access to standard chemotherapy was described as an emerging problem in one region and was currently under review: increased activity was not matched by an increase in capacity 'over the past eight years'. According to a respondent, the increased activity is due in part to new treatments but also to changes in practice which means that existing treatments are used earlier than previously and there are 'more lines of treatment for individual cancer types' (Clinical director). Respondent views differed as to whether variation in availability of chemotherapy existed across Scotland.

In the West of Scotland region all four Boards share the same chemotherapy prescribing IT system. It is hosted by Greater Glasgow and Clyde (GGC) but the other Boards share the decision making responsibility:

"... in terms of chemotherapy, the electronic chemo-prescribing service ... that's a really good example of co-operative working where that group doesn't have the responsibility for patient care directly but it's a co-operative of people who do have responsibility ... I think it does reduce the burden of decision making at a local level". (Clinical lead)

In one of the regions, a pharmacist described how the regional advisory group was able to work collaboratively to guide the local Board drug and therapies committees:

"... the regional groups can only ever be advisory, but there's an understanding and operational procedures are in place that, basically, say if we put forward implementation advice for SMC on regional development, they will approve, so we have consistency". (Pharmacist)

According to some respondents, new chemotherapy regimens were found to build up pressure on services: more cancers, hence more patients, are treatable; patients survive for

longer; and more supportive care is needed to become available. One area was conducting an in depth review of chemotherapy services to try to meet this challenge. They had started conducting patient reviews by telephone rather than clinic appointments in some cases and providing a 'two step' process whereby patients assessed for chemotherapy could start treatment the following day.

5.5 WORKFORCE ISSUES

The difficulty of recruiting and retaining skilled staff is the single biggest concern of stakeholders. The problem of oncology vacancies was mentioned several times by stakeholders. ISD workforce statistics show that clinical oncology vacancies were consistently high, running at 83.5 WTE (whole time equivalent) as against 145 WTE in post for September 2015, and indexing at over 80 WTE since September 2010¹⁰⁷. One stakeholder described the problem as 'cyclical'...

"...there are times where radiographers for radiotherapy treatment are difficult to come by. There are other times when it's pharmacy staff. There are other times when it's medical staff and nursing staff". (Clinical director)

We also heard about several initiatives being taken at Board, or clinic, level to improve efficiency in the deployment of staff and equipment. Measures taken included: training and retaining junior staff, concentrating skilled staff at particular sites, employing clinical staff more efficiently across regions, and employing nurses to save consultants' time in processing referrals.

Other factors seen as creating increased pressure on services were demographic change, the availability of new treatments, and technological change, but these were seen to a large extent as being outwith the control of the NHS. A recent national audit of the NHS in Scotland also highlighted the challenge in some areas of recruitment and retention. The Audit reported a national shortage of staff in certain clinical specialties, including oncology¹⁰⁸.

Stakeholders acknowledged the effort required by Boards and Regional Centres to recruit and retain staff of all kinds:

"...like the other UK countries we are, perhaps, struggling a bit to ensure that all our vacancies are filled, and we need to make more effort to train, and recruit into these posts, not just medical posts, but across the whole range of treatment delivery, cancer treatment delivery" (National interviewee)

Another aspect of the ability of the major treatment centres to absorb pressure relates to both physical and workforce capacity. In one view, the NHS 'never' anticipates increased demand by building extra capacity in advance.

"...we never actually address the issue of building the capacity until it's arrived, often because there's a bit of a never never, you know, involved with SMC decisions. Or they'll say, well, we're not going to put the capacity in because the SMC may say no. And we've got this with radium at the moment where we acknowledge we cannot deliver this drug without additional capacity, and that because it's a more technically complex treatment. (It) means actually changing the layout of a building, involves getting extra staff employed and nobody's going to employ those staff until we know it's definitely going ahead. So that's going to put a lag in the system". (Oncologist)

As previously outlined, national leaders recently responded to multiple pressures by setting

up (in 2014) the National Cancer Clinical Services Group. From the national government perspective the group was set up:

“...in recognition that we want to ensure equality of access across the country and that there may be services from more complex cancers where we need to look at reconfiguration and service design issues”. (National interviewee)

The objective was expressed, by a clinician, as:

“... to look at these very operational nitty gritty issues and to come up with some solutions... This new group is going to be looking at these more prospectively ... to avoid, sort of, crisis situations”. (National interviewee)

From what we were told by stakeholders, the group is to focus on specific cancer sites starting with head and neck cancer. Another priority for the group is radiotherapy services. Those who helped form the group were enthusiastic about the possibilities created:

“So I do think that the National Cancer Clinical Services Group ... now gives us a platform to address (resource issues), which we didn't have before. ...And I think from that point of view it's certainly a very positive thing”. (S63)

Membership of the group includes regional cancer clinical leads and network managers. Some Health Board level respondents did not appear to be aware of the work of the NCCSG, and there was no public information about it.

5.6 ACCESS AND GEOGRAPHY

A number of access issues raised by stakeholders related to the geography of Scotland: providing good quality services for sparsely populated areas; transport and accommodation for people attending cancer centres from remote and rural areas; regionalisation of some services. Patients living at a significant distance from the major treatment centres experienced a range of difficulties in accessing treatment mainly related to transport. The GPs we interviewed were particularly focussed on this issue.

For patients living on the islands the problem is most acute in that travel is restricted by ferry and flight timetables. The journeys involved can be too much for some patients meaning that the best treatment may not be available to them.

“...there are occasionally patients where there could be issues of transport, they might have different treatments. It might not be that they're denied treatments, but they may not be offered, perhaps, maybe the best treatments. But maybe they have second line treatment if it means having some treatment here”. (GP)

For others who make the journey, the logistics of organising transport and suitable accommodation are quite demanding. Escorts can be subsidised if the patient is assessed as needing such support and in certain cases NHS staff are provided.

“...sometimes very difficult, because we then have to decide that, as a GP, whether we think this patient is deserving to have an escort, which is always quite difficult. It's quite difficult to turn round and say no, sometimes, although we have to, because again, we have to keep to our targets for that”. (GP)

On the mainland, remote and rural areas can be very far from treatment centres even where this is provided at DGHs. One GP based in an area at some distance from the regional cancer

centre was optimistic to some extent:

“People in Stranraer are 70 miles away from our district general hospital and then they’ve got another 70 miles to get to Edinburgh which is the treatment centre. So there are great distances that make it really quite taxing for an ill patient going for radiotherapy. So they’re trying to get more treatment closer to home and we’ve got chemotherapy being given out in Stranraer. We’ll be looking at various other systems where it can be done more locally”. (GP)

Staff based in the regional centres were more inclined to talk about the efforts being made to overcome the problem.

“We’ve also looked at equity of care and making sure that the one stop (breast cancer) clinic is available for all of our patients in NHS Lothian”. (Regional clinical lead)

GPs, whilst understanding the importance of regional centres of excellence, particularly for rarer treatments, stressed the need for staff in those centres to be more aware of the repercussions for patients of travelling long distances for treatment.

“I think some of it is just common sense and practical measures such as not giving someone an appointment at nine o'clock in the morning if they have to travel seventy miles to attend that appointment. Or if someone is having to travel somewhere by public transport for long distances it's important that, you know, we don't give them bowel preparation to take the night before so that they have an extremely uncomfortable and potentially undignified travel to hospital”. (GP)

We heard a national level comment about the shortage of oncologists being most pronounced in areas remote from the central belt and in the small tumour groups. As some treatments become more technologically complex and require higher levels of skill, the need arises for regionalisation or concentration of services to ensure adequate ‘throughput’ to maintain skill levels and outcomes. The comments quoted below both refer to the small size of Scotland as a whole and imply that a national approach should be taken in order to better assess where care should be provided and help address inequalities of access.

“There are cancers such as pancreatic cancer, liver cancer, oesophago-gastric cancer... they're relatively rare, or low volume, and I think if we want to get the best outcomes for our patients, on a national and international stage, I think, across Scotland, which is a small healthcare region, comparatively, we need to have some honest discussions about where those patients are looked after”. (Surgeon)

“We’re a small country, and we have to be cleverer about what our demand is, and could be..... And that may not mean providing very advanced treatments in every single area, but having a national approach to that... So, there shouldn’t be inequity. Obviously, you can’t have expensive highly advanced technologies being provided in every community post ... but there has to be a tipping point where you’ve to look at throughput, and maintaining expertise versus patient access, and getting that balance absolutely right”. (National interviewee)

5.7 SUMMARY

We considered the three main modalities of cancer treatment: surgery, radiotherapy and SACT. The major questions in surgery were in achieving a balance between local access to treatment versus the benefits of centralisation of smaller-volume surgery. The National

Cancer Clinical Services Group has a remit to review how surgical services are configured for the less common cancers.

Radiotherapy is now provided across five centres in Scotland with the recent addition of a satellite service to the Beatson in the West of Scotland region. Views about the provision of radiotherapy were positive on the whole, with some questions about whether equipment was being used to its full potential in all parts of the country. We heard doubts about the effectiveness of new national leadership structures.

The Scottish Medicines Consortium decides on the availability of new pharmacological treatments although stakeholders reported variations in access to new treatments throughout Scotland. We were also told that SMC decisions not to license certain drugs might adversely affect the ability for Scottish hospitals to participate in clinical trials. We heard that increasing complexity of SACT treatment meant that suitably qualified specialist nurses were not always available to administer it.

The geography of Scotland and the location of services create barriers to access for patients living at a distance from treatment centres. This was an area of concern for many stakeholders, some of whom felt that such patients sometimes choose, or are given, treatment modes which are less than optimal to avoid travelling. It's therefore important that these factors should be prominent in planning of cancer services and accommodation provision and new ways of working explored.

Recruitment and retention of specialist staff and training requirements for new treatments were major issues for stakeholders. Shortages of oncologists were particularly acute in some areas.

There is a lack of data on treatment activity in Scotland, specifically for cancer drugs and radiotherapy, making it difficult to assess progress. High-quality data is critical to evaluate performance and improvements.

RECOMMENDATIONS:

- 8. The Scottish Government should ensure the NCCSG Radiotherapy Sub Group has the resources it needs to provide strong leadership in taking forward the commitments made in Beating Cancer to address inequality of access to modern radiotherapy. A national radiotherapy lead should be appointed to support this. Developing and reporting annually on a national dataset for radiotherapy should be a priority for this group.**
- 9. The Scottish Government and SMC should ensure equal access to new drugs across the country by considering mandating that Health Boards fund them once approved. A national approach should also be taken to IPTRS to ensure consistent decisions for all patients in Scotland. A national dataset for chemotherapy should be developed to help understand outcomes and assess progress.**
- 10. The NCCSG should work to clearly define workforce capacity shortages in radiotherapy (via the Sub Group) and chemotherapy services, and identify mechanisms to address this to ensure adequate resource is in place to provide access to the best, evidence-based treatments.**

6: CONCLUSIONS AND RECOMMENDATIONS

In 2014 more than 31,900 people were diagnosed with cancer in Scotland. That number is likely to rise in the coming years. The outcomes achieved for these people have been improving over time. Better Cancer Care, the cancer strategy that ran from 2008, supported that improvement.

Comparisons with other comparable European countries suggest that further improvements might be made, however, and Cancer Research UK believes these outcomes can be improved significantly.

The current cancer strategy for Scotland, Beating Cancer, is an opportunity to accelerate progress. The strategy is very welcome as it provides direction, and importantly additional funding, for improvements to cancer services in Scotland over the next five years, however it is vital that the action it results in enables the NHS in Scotland to meet rising demand while continuing to improve outcomes.

This report has explored a range of sources to understand the current performance of cancer services and identify areas for improvement, helping inform the actions set out in the new cancer strategy. Across leadership arrangements, performance management levers, early diagnosis and access to effective treatments we have identified possible improvements.

More clarity on national leadership structures, supporting the appropriate allocation of resources to implement Beating Cancer, would be beneficial. In performance management, a review of cancer waiting time targets to ensure they are defined in a way that optimises their intended impact would be beneficial – maintaining the existing standards as a minimum.

To support early diagnosis, action is required to ensure that a wider range of data is publically available to understand the impact of awareness campaigns. Increased diagnostic capacity is also needed, both in terms of workforce and equipment.

Access to specialist cancer treatments and drugs requires reform to address leadership and workforce issues, and achieve greater consistency for patients across Scotland.

We make recommendations, below, outlining the changes we believe would be beneficial.

6.1 RECOMMENDATIONS FOR POLICY

- 1. The Scottish Government should publish a full implementation plan for the delivery of Beating Cancer. This should set out: the roles and responsibilities of cancer leadership bodies at national, regional and local levels, clear timings and how success will be measured. A national clinical lead for cancer to support this should also be considered.**
- 2. The Scottish Government and the Information Service Division should consider reporting NHS spend by clinical speciality.**
- 3. The Scottish Government should review capacity – both equipment and workforce – in diagnostic services with a view to providing additional resources to Health Boards to help them meet cancer waiting times.**
- 4. Scottish Government's review of waiting times should ensure cancer targets are**

defined in a way that optimises their intended impacts – while maintaining the 62 and 31 day standards as a minimum. It should also consider expanding waiting times targets to include all types of cancer.

5. The Scottish Government and the Information Services Division should collect and publish staging data on all cancer types.
6. The DCE programme should publish a clear evaluation of public awareness campaigns to understand their impact. As outlined in Beating Cancer, DCE should publish plans on how they will reach deprived, harder to reach communities where early detection of cancer remains poor.
7. The Scottish Government should explore best practice pathways for referral of patients with vague or non-specific symptoms, such as the Borders model, and consider whether national guidance should be updated to ensure consistent pathways for referral.
8. The Scottish Government should ensure the NCCSG Radiotherapy Sub Group has the resources it needs to provide strong leadership in taking forward the commitments made in Beating Cancer to address inequality of access to modern radiotherapy. A national radiotherapy lead should be appointed to support this. Developing and reporting annually on a national dataset for radiotherapy should be a priority for this group.
9. The Scottish Government and SMC should ensure equal access to new drugs across the country by considering mandating that Health Boards fund them once approved. A national approach should also be taken to IPTRS to ensure consistent decisions for all patients in Scotland. A national dataset for chemotherapy should be developed to help understand outcomes and assess progress.
10. The NCCSG should work to clearly define workforce capacity shortages in radiotherapy (via the Sub Group) and chemotherapy services, and identify mechanisms to address this to ensure adequate resource is in place to provide access to the best, evidence-based treatments.

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The project was produced by a working group comprising David Morrison, Gill Hubbard, Charlotte MacDonald, Richard Neal and Conan Donnelly. David Morrison and Gill Hubbard designed the study and wrote the report with Charlotte MacDonald.

Charlotte MacDonald developed the telephone questionnaire, identified and contacted the sample of stakeholders, conducted the majority of interviews, conducted a thematic analysis of all interviews and wrote the report.

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APPENDIX 1 - METHODS

We used four principal methods to inform our work, drawing on Cancer Research UK's *Cancer Services: Reverse, Pause or Progress?*

1. Interpretation of routinely available quantitative datasets.
2. Cancer policy review. The period 1999-2014 was chosen because it encompasses the effects of major policies such as the Calman-Hine report, the Campbell report and similar others which recommended that cancer services be reorganised into managed clinical networks (MCNs). The effects of these reports continue to influence cancer service provision. The period also corresponds to the year that Scotland's government was devolved.
3. Description of structures of health and social services and cancer leadership in each country.
4. Stakeholder interviews. These comprised structured telephone interviews. Twenty-seven telephone interviews were carried out with policymakers, senior managers, clinicians and patient representatives.

INTERPRETATION OF ROUTINELY AVAILABLE QUANTITATIVE DATASETS

We obtained data on incidence, survival, mortality and prevalence of cancer, including analyses of any temporal and socio-economic patterns, and any that reflected the impact of the diverse geography of the devolved nations. We considered projections made to estimate future cancer burden. We identified routinely available data and publications on routes to diagnosis and early diagnosis.

We used these data to draw conclusions on priorities for early diagnosis and access to treatment and provide potential explanations for progress or lack of improvement in survival, and living with cancer. Where data that might be useful were limited or not available, we suggested where improvements might be made, in our conclusions and recommendations.

CANCER POLICY REVIEW

We identified and described the major cancer policy themes in this section. (Our stakeholder interviews present qualitative information on the perceived effectiveness of these policies). We considered policies in a hierarchical way starting from high-level, national policies and national clinical and management leads. This [follows] through to regional or Health Board level policy and its governance in tertiary, secondary and primary care. We recognised that policies do not flow in simple, linear ways and that national clinical guidelines, prescribing guidance and formularies, and other health policies (such as waiting times targets) have important roles that need to be described.

DESCRIPTION OF STRUCTURES OF HEALTH SERVICES AND CANCER LEADERSHIP IN EACH COUNTRY.

We described the structures of both cancer services and relevant social services in each country. We will also considered the structures and functions of the major charitable and patient-representative groups.

STAKEHOLDER INTERVIEWS

Our stakeholder interviews were the main source of reflections on how – and how well – policies and leadership to achieve early diagnosis and access to treatment were perceived to work. Telephone interviews are relatively inexpensive and facilitate access to geographically disparate participants.” An interview schedule was used (Appendix N). For the sample, we identified a wide range of individuals, some via third parties and websites, and sent email invitations with information about the study. In order to maximise diversity in the sample we employed the principle of maximum variation sampling, a purposive approach that seeks to select participants to include the widest possible range of characteristics. To encourage freedom of expression anonymity was guaranteed. Of the 38 stakeholders contacted we were able to interview 27. This sample gave us access to experiences and perspectives from a range of clinical, socio-demographic and professional contexts. The following breakdown indicates the range.

Government/national NHS role (4)

Clinicians drawn from surgery, oncology, radiology, pharmacy (11)

Nurses (3)

GPs including some with regional and national roles (6)

Other including representatives of third sector and patient organisations (3)

Clinicians, nurses and GPs were distributed geographically as follows:

West region 12

South East region 5

North region 3

We had hoped to include more stakeholders in the North region but experienced some difficulty both identifying suitable individuals and in getting responses – of the 11 people we were unable to interview 5 were in this region.

Interviews were kept strictly to 30 minutes; some were shorter. To make sure that the focus was on areas where the stakeholder had most to contribute, not all questions were covered for each stakeholder. Interviews, with participants’ permission, were digitally recorded and transcribed verbatim. Transcripts were analysed thematically using the Framework approach; a rigorous method providing a structure within which qualitative data are organised, coded and themes identified. We identified key themes about early diagnosis, treatment and cancer policy and leadership and highlighted common themes for these three key areas.

ETHICAL CONSIDERATIONS

We sought advice on the requirement for ethical approval for this study from the West of Scotland Research Ethics Committee. We were advised that an application for ethical approval was clearly not necessary.

APPENDIX 2 – QUALITY PERFORMANCE INDICATORS

BOX 10: QUALITY PERFORMANCE INDICATORS

Acute Leukaemia Quality Performance Indicators
Bladder Cancer Quality Performance Indicators
Brain CNS Cancer Quality Performance Indicators
Breast Cancer Quality Performance Indicators
Cancer Patient Experience Quality Performance Indicators
Cervical Cancer Quality Performance Indicators
Clinical Trials Quality Performance Indicator
Endometrial Cancer Quality Performance Indicators
Head and Neck Cancer Quality Performance Indicators
Lymphoma Quality Performance Indicators
Melanoma Quality Performance Indicators
Ovarian Cancer Quality Performance Indicators
Overview of Development Process
Prostate Cancer Quality Performance Indicators
Renal Cancer Quality Performance Indicators
Sarcoma Quality Performance Indicators
Testicular Cancer Quality Performance Indicators
Colorectal Cancer Quality Performance Indicators
HPB Cancer Quality Performance Indicators
Lung Cancer Quality Performance Indicators
Upper GI Cancer Quality Performance Indicators

APPENDIX 3 – QPIS, COLORECTAL CANCER

BOX 11: COLORECTAL CANCER PERFORMANCE

QPI	Target	Performance
QPI 1(i): Radiological Diagnosis and Staging (Colon) - Patients with colorectal cancer should be evaluated with appropriate imaging to detect extent of disease and guide treatment decision making.	95%	91%
QPI 1(ii): Radiological Diagnosis and Staging (Rectal) - Patients with colorectal cancer should be evaluated with appropriate imaging to detect extent of disease and guide treatment decision making.	95%	90%
QPI 2: Pre-Operative Imaging of the Colon - Patients with colorectal cancer undergoing surgical resection should have the whole colon visualised pre- operatively.	95%	86.4%
QPI 3: Stoma Care - Patients with colorectal cancer who require a stoma are assessed and have their stoma site marked pre-operatively by a nurse with expertise in stoma care.	95%	89.8%
QPI 4: Lymph Node Yield - For patients undergoing resection for colorectal cancer the number of lymph nodes examined should be maximised.	80%	86%
QPI 5: Neoadjuvant Radiotherapy - Patients with locally advanced rectal cancer should receive neoadjuvant chemoradiotherapy designed to facilitate a margin-negative resection.	90%	82.7%
QPI 6(i): Surgical Margins - Rectal cancers undergoing surgical resection should be adequately excised. For patients who receive primary surgery, or surgery following neo-adjuvant short course radiotherapy.	<5%	3.8%
QPI 6(ii): Surgical Margins - Rectal cancers undergoing surgical resection should be adequately excised. For patients who receive surgery following neo-adjuvant long course radiotherapy or chemo radiotherapy.	<15%	10.2%

QPI 7: Re-operation Rates - For patients undergoing surgery for colorectal cancer, re-operation should be minimised.	<10% (Elective surgical resection) <15% (Emergency surgical resection)	- -
QPI 8(i): Anastomotic Dehiscence - For patients who undergo surgical resection for colorectal cancer anastomotic dehiscence should be minimised. For patients receiving colonic anastomosis.	<5%	3.7%
QPI 8(ii): Anastomotic Dehiscence - For patients who undergo surgical resection for colorectal cancer anastomotic dehiscence should be minimised. For patients receiving rectal anastomosis.	<10%	5.2%
QPI 8(iii): Anastomotic Dehiscence - For patients who undergo surgical resection for colorectal cancer anastomotic dehiscence should be minimised. For patients receiving anterior resection with total mesorectal excision (TME).	<20%	2.8%
QPI 9: 30 Day Mortality Following Surgical Resection - Mortality after surgical resection for colorectal cancer.	<5% (Elective surgical resection)	1.7%
	<15% (Emergency surgical resection)	8.5%
QPI 10: Adjuvant Chemotherapy - Patients with Dukes C and high risk Dukes B colorectal cancer should be considered for adjuvant chemotherapy.	70% (Patients with Dukes C colorectal cancer)	70.6%
	50% (Patients with Dukes B colorectal cancer)	52.4%
QPI 11: 30 Day Mortality Following Chemotherapy or Radiotherapy - Mortality after chemotherapy or radiotherapy with curative intent for colorectal cancer.	<2%	0.7%

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