



WHERE NEXT FOR CANCER SERVICES IN NORTHERN IRELAND?

AN EVALUATION OF PRIORITIES TO
IMPROVE PATIENT CARE



CANCER
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UK

ACKNOWLEDGEMENTS

Cancer Research UK commissioned the Institute of Health and Wellbeing at the University of Glasgow to carry out the study.

This 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 also developed the questionnaire, identified the sample of stakeholders and conducted a thematic analysis of the interviews.

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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 and 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

Cancer Research UK is a registered charity in England and Wales (1089464), Scotland (SC041666) and the Isle of Man (1103) www.cancerresearchuk.org

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CONTENTS

| | |
|--|----|
| LIST OF ACRONYMS | 5 |
| LIST OF FIGURES | 6 |
| EXECUTIVE SUMMARY | 7 |
| CHAPTER ONE: THE CANCER LANDSCAPE | 13 |
| CHAPTER TWO: HEALTH SERVICE STRUCTURES, POLICY AND LEADERSHIP | 22 |
| CHAPTER THREE: HEALTH SERVICE PERFORMANCE | 32 |
| CHAPTER FOUR: EARLY DIAGNOSIS | 40 |
| CHAPTER FIVE: ACCESS TO EFFECTIVE TREATMENTS | 47 |
| CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS | 55 |
| APPENDIX ONE: METHODS | 57 |
| APPENDIX TWO: INTERVIEW SCHEDULE | 59 |
| APPENDIX THREE: CANCER FRAMEWORK STANDARDS | 62 |
| REFERENCES | 65 |

LIST OF ACRONYMS

| | |
|--------|---|
| ACE | Accelerate, Coordinate and Evaluate Programme |
| CDF | Cancer Drugs Fund |
| CNS | Clinical Nurse Specialist |
| CPES | Cancer Patient Experience Survey |
| DoH | Department of Health |
| DHSSPS | Department of Health, Social Services and Public Safety |
| GAIN | Guidelines and Audit Implementation Network |
| HSCB | Health and Social Care Board |
| ICBP | International Cancer Benchmarking Partnership |
| IFR | Individual Funding Request |
| IMRT | Intensity Modulated Radiotherapy |
| LCGs | Local Commissioning Groups |
| MDT | Multidisciplinary Team |
| NICaN | Northern Ireland Cancer Network |
| NICE | National Institute for Health and Care Excellence |
| NICR | Northern Ireland Cancer Registry |
| PET | Positron Emission Tomography |
| PHA | Public Health Agency |
| RQIA | Regulation and Quality Improvement Authority |
| SACT | Systemic Anti-Cancer Therapy |

LIST OF FIGURES

| | |
|-----------|--|
| Figure 1 | Cancer cases (excluding NMSC) in NI, 1993 – 2013, with projection to 2035 |
| Figure 2 | Twenty most common cancers in NI, 2014 |
| Figure 3 | Cancer incidence rate by deprivation quintile based on average cases (excluding NMSC) 2010 – 2014 |
| Figure 4 | Percentage difference from NI average cancer incidence rate by Trust (excluding NMSC), 2010 – 2014 |
| Figure 5 | Five-year net survival (%) for men diagnosed between 2005 – 2009 by cancer site |
| Figure 6 | Five-year net survival (%) for women diagnosed between 2005 – 2009 by cancer site |
| Figure 7 | Ten most common causes of cancer deaths in NI (persons), 2014 |
| Figure 8 | Structure of health service in NI, including Northern Ireland Cancer Network |
| Figure 9 | Footprints of Health and Social Care Trusts |
| Figure 10 | Percentage of patients starting treatment within 62 days of urgent referral, Q1 2010 – Q1 2016 |
| Figure 11 | Percentage of patients starting treatment within 31 days of a cancer diagnosis, Q1 2010 – Q1 2016 |
| Figure 12 | Percentage of patients seen by a specialist within 14 days of urgent referral for suspected breast cancer, Q1 2010 – Q1 2016 |
| Figure 13 | Proportion of people diagnosed at each stage for all cancer cases (excluding NMSC) based on 2010 – 2014 average |
| Figure 14 | Stage at diagnosis in four most common cancers, based on 2010 – 2014 average |

EXECUTIVE SUMMARY

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

While valuable progress has been made in improving cancer outcomes, around half of all UK cancer patients now survive 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 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 explore the 'state' of cancer services in Wales, Scotland and Northern Ireland.

This report, which is based on publicly available data and interviews with expert stakeholders in the region, presents findings on Northern Ireland (NI), and our ambition for the shape of cancer services going forward.

We believe the recommendations below would improve outcomes for patients and should be taken forward – ideally as part of a comprehensive cancer strategy for NI.

CURRENT LANDSCAPE

In 2014, over 8,900 people were diagnosed with cancer in NI.⁵ This has risen from around 7,200 in 2004. Over the last decade incidence rates have increased by 7% from 554 cases per 100,000 people between 2003-2005 to 594 per 100,000 people between 2012-2014.

This upward trajectory is expected to continue in the coming years. By 2035, it is projected there will be over 14,000 cancer diagnoses each year – an increase of 65% among men and 63% among women.⁶ This is being driven predominantly by an ageing population; but preventable risk factors, such as smoking, also contribute.⁷ Cancer services will therefore need to cope with significant increases in demand for diagnostic and treatment services.

Breast, bowel, lung and prostate cancers are the most commonly occurring cancers. In 2013 they accounted for 54% of all cases.⁸ These are also the most common cancers worldwide.⁹

Cancer incidence varies across NI. The incidence rate among the most deprived quintile of the population, for example, is 23% higher than among the least deprived.¹⁰

But cancer survival is improving. One-year net survival has reached 70%; and five-year survival has reached 54%.¹¹ This, however, varies significantly by cancer type. Over 80% of females diagnosed with breast cancer and males diagnosed with testicular cancer between 2005-2009 survived their disease for at least five years.¹² In contrast, fewer than 6% of people diagnosed with pancreatic cancer survived their disease for at least five years.¹³

POLICY AND LEADERSHIP

In 2015-16, the NI Department of Health (formerly the Department of Health, Social Services and Public Safety) had a budget of approximately £4.7 billion – around 46% of total NI Executive spending.¹⁴ In 2016-17 healthcare spending in NI is set to rise to slightly less than £4.9 billion.¹⁵

Publicly available information does not break down healthcare spending by disease area, so it is not possible to show how much is spent on cancer services specifically. We would welcome the NI Executive making this information available. This would enable the best use of resources to deliver outcomes for patients.

The healthcare system in NI is in transition. While full details of reforms to the way health services will be commissioned have not been confirmed, we expect the Health and Social Care Board to be abolished and responsibility for commissioning to move to the Department of Health. In addition, an independent expert panel has recently conducted a review to explore options for service reconfiguration.

The impact of these changes on cancer policy and leadership is not yet clear. However, we understand clinical leadership for cancer will remain through the Northern Ireland Cancer Network; and the Public Health Agency will retain its responsibility for cancer awareness and input to commissioning. It is important that strong clinical leadership for cancer services is maintained within the new structure.

These reforms, at a time of rising cancer incidence, provide a timely opportunity to take a fresh look at how cancer services should be delivered, and set new ambitions to improve outcomes for patients in NI. Clearly identifying priority areas and funding requirements would support annual planning and investment decisions.

While other countries across the UK set out new strategies with clear ambitions for improving cancer outcomes, it is clear that NI must now do the same. NI's most recent strategy for cancer, the 'Cancer Control Programme', was published in 2008 and has not been reviewed since. While the Service Framework for Cancer was published in 2011 and is being reviewed, it is not a comprehensive strategy.

RECOMMENDATIONS

- 1. The NI Executive should develop a new comprehensive cancer strategy, which sets ambitious goals and allocates sufficient resource to ensure cancer services can improve outcomes, meet rising demand and reduce variation in care. The strategy should ensure strong clinical leadership for cancer services and clarify how these services will be commissioned within the reformed NI health service. It should also set measurable targets to reduce cancer incidence, improve survival and better support the growing number of patients living with cancer. Particular attention should be afforded to cancer types with poor outcomes and variation across demographic groups, including men. We suggest the following targets:**

- **One-year survival should reach 75% by 2020.**
- **Five-year survival should reach 58% by 2020.**

HEALTH SERVICE PERFORMANCE

Performance on cancer is measured through standards of care set out in the Service Framework, monitoring of performance data by Trusts, the Regulation and Quality Improvement Agency, waiting time standards, clinical audit, peer review and patient experience.

NI maintains three operational waiting times standards for cancer. These standards are not currently being met which suggests the service is struggling to keep up with demand.

1. 95% of newly diagnosed cancer patients should start treatment within **62 days** of an urgent referral by a GP. This has not been met nationally since it was introduced in 2009. Since 2013, performance has deteriorated from around 83% to below 75%. In the first quarter of 2016 performance was 69.9%.¹⁶
2. 98% of patients should commence treatment within **31 days** of a cancer diagnosis. Performance against this standard is higher but still below the target. It was last met between October and December 2013; in the first quarter of 2016 performance was 95.5%.¹⁷
3. Thirdly, there is an operating standard that 100% of patients referred urgently with suspected breast cancer should be seen by a specialist within **14 days**. This target was last met in July – September 2012. In the first quarter of 2016 performance was 81.8%.¹⁸

While performance against the 31-day standard is holding up reasonably well, it does not capture the time it takes to diagnose patients. Therefore, significantly lower performance against the 62-day standard suggests patients are experiencing delays in being diagnosed.

NI is unusual in applying the 14-day operating standard only to breast cancer patients. This has implications for where resources are focused.

Our research found the ongoing peer review process was having a positive impact. The commitment to extend peer review to cover all the major cancer types is welcome.

In general, measures with potential to drive quality improvement seem to be in place. It is less clear, however, why these have not necessarily led to improvements in service delivery. Further work is therefore needed to understand why key targets such as waiting times are not being met.

On a positive note, the Northern Ireland Cancer Patient Experience Survey (CPES) showed that the majority of patients are pleased with the services they receive. 92% of respondents described their overall care as ‘very good’ or ‘excellent’.¹⁹ But in some areas performance is poor and must be improved. For example, only 18% of respondents reported being asked whether they would like to participate in clinical research.

RECOMMENDATIONS

2. **The Department of Health and Trusts should undertake work to clarify why operating standards for cancer are not being met. Based on that, the Department should provide investment to ensure they are met in the future. The Department**

should also consider broadening the 14-day operating standard to cover all cancer types.

- 3. The Public Health Agency should fund and continue to undertake the CPES on a regular basis. Its findings should be used to support ongoing evaluation and improvement.**

EARLY DIAGNOSIS

Early diagnosis is crucial to improving survival in many cancer types.²⁰ For example, when bowel cancer is diagnosed at stage one around 95% of patients survive their disease for at least five years compared to less than 10% among those diagnosed at stage four.²¹ But evidence strongly suggests that barriers to early presentation are contributing to the UK's cancer outcomes being below those of some other countries.

Information on stage at diagnosis is relatively good in NI; stage was recorded in 72% of cases during 2010-2014. However, too many patients are being diagnosed late. On average across 2010-2014, around 45% of patients with known stage were diagnosed at stage three or four.²²

Public awareness campaigns are an important way to encourage people to see the doctor when they have concerns about their health. The *Be Cancer Aware* programme was adopted for NI in 2015 following a baseline study in 2014 to enable monitoring of the campaign's impact.²³ This should be continued and expanded to try and reach more disadvantaged groups.

GP direct access to diagnostic testing seems to be geographically variable – investigation is needed to understand how this can be addressed. In addition, the work being done to identify the resource implications of introducing the latest NICE referral guidelines must happen swiftly so that best practice can be implemented as soon as possible.

There are examples where new models of diagnostic services, such as a 'one-stop shop' for urology assessment, are operating in NI. It is important that these innovations are evaluated and rolled out where shown to be effective.

A clear area that is in need of further analysis is capacity in diagnostic services. The 2015/16 Commissioning Plan identified large numbers of vacant radiology posts and suggested a new regional service to ensure the service can meet demand.²⁴ Work is required to understand capacity needs in diagnostics to ensure the service can cope with increasing numbers of cancer referrals.

RECOMMENDATIONS

- 4. The Public Health Agency should continue funding the *Be Cancer Aware* programme and look to expand it. The programme should be developed to target different types of cancer and hard to reach groups.**
- 5. The Department of Health should undertake an urgent review of the state of direct access to diagnostic tests for GPs and capacity needs in diagnostic services. It should**

make the necessary investment to ensure diagnostic services can meet rising demand.

- 6. The Department of Health should explore the potential for new service models to support diagnosis, for example multi-disciplinary diagnostic centres to help diagnose cancer cases swiftly where symptoms may be vague.**

ACCESS TO TREATMENTS

Providing all patients with access to high-quality, evidence-based treatments is crucial to improve survival.

The Service Framework sets out a number of measurable standards for treatment services. However, a lack of publicly available data makes it difficult to assess whether patients are receiving the best treatments. For example, there is no data on access to modern radiotherapy techniques, like Intensity Modulated Radiotherapy, when clear access targets have been set in other countries.²⁵

Peer review data is available on a group of cancer sites.²⁶ In places, these indicate a lack of progress in improving treatment services since 2010. While there has been some progress, such as increasing resection rates for lung cancer, other areas indicate variable access to treatments and long waiting times. The roll out of peer review to all cancer types will be crucial to get a better understanding of performance across the board.

Our research identified concerns that access to new cancer drugs was poorer in NI than in England but that difference was diminishing in recent years. However, issues with swiftly adopting NICE guidance remain and must be resolved. Changes to the way NICE assesses cancer drugs following reform of the Cancer Drugs Fund in England demand attention as this will impact on drug approvals in NI.

The ongoing reforms to the Individual Funding Request (IFR) system, including the expected softening of the exceptionality criteria, are welcome.²⁷ We hope to see more data on IFR requests made available to ensure the system is working effectively.

As noted above, the CPES showed less than one-fifth of patients recall being asked to consider participating in clinical research.²⁸ Our research also identified concern about participation in clinical research going forward. This requires attention.

Shortages in oncology staff were also highlighted as an issue, exacerbated by the demands of the new acute oncology services. More work is required to understand where additional capacity is needed to ensure treatment services can cope with demand and consistently deliver the best treatments.

RECOMMENDATIONS

- 7. The Department of Health should develop national datasets for chemotherapy and radiotherapy activity to help better understand access to these types of treatments. Further data on the success of IFR requests at the local level is required.**
- 8. The Department of Health should set a clear ambition to increase the opportunities for patients to participate in clinical research. To support this, it should conduct a review to identify current barriers to setting up and running clinical trials.**
- 9. The Department of Health should review workforce capacity in treatment services to understand where there are shortfalls in staff and set out how these will be addressed.**

1: THE CANCER LANDSCAPE

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.²⁹ But while improvements have been made, UK bowel, breast, lung and ovarian cancer survivals remains lower than in Australia, Canada, and several European countries.^{30,31}

These differences are largely due to better survival at one year after diagnosis in other countries, although coding differences could also play a role. Researchers at the International Cancer Benchmarking Partnership (ICBP) have proposed that differences in individual, health-system, and clinical factors, such as diagnostic delay and access to optimal treatment, are potential explanations for the variations in survival.³² Improving performance in early diagnosis and access to cancer treatment should therefore be priorities for the nations of the UK.

Across the four nations of the UK, there are variations in the occurrence and consequences of cancer.³³ The cancer incidence rate in Northern Ireland (NI) is lower than in England, Wales and Scotland.³⁴ The mortality rate from cancer in NI is significantly higher than in England, similar to Wales, but lower than in Scotland.³⁵

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

Cancer Research UK has previously published work analysing the implementation of the UK's cancer strategies³⁶ and the performance of cancer services in England.³⁷ 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. A report on Wales was published earlier this year; a separate report on Scotland will be released in the coming months.³⁸

This report assesses four aspects of cancer policy and practice in NI:

1. Health services 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 important aspects of cancer services, have been the subject of other work and therefore are not included in this study.

Effective cancer strategies are crucial to improving outcomes for people affected by cancer. The World Health Organisation notes that, “A well-conceived, well-managed national cancer control programme lowers cancer incidence and improves the life of cancer patients, no matter what resource constraints a country faces.”³⁹

The 2008 ‘Regional Cancer Framework – A Cancer Control Plan for Northern Ireland’ is the most recent strategy in NI. In 2011, the Department for Health, Social Services and Public

Safety (DHSSPS), subsequently renamed the Department of Health (DoH), published the 'Cancer Services Framework', which set specific standards for the health service to meet. However, the Service Framework is not a comprehensive strategy.

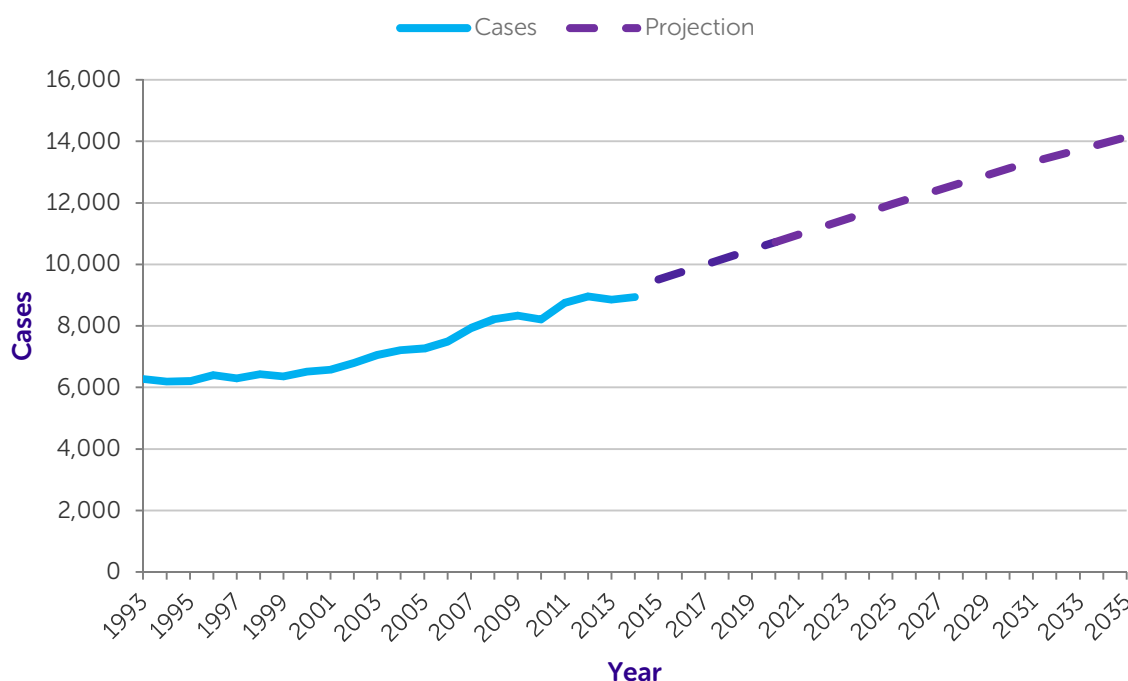
It is clear, therefore, that a new cancer strategy for NI is needed to drive improvements in survival for patients in the region.

This report provides insight as to what a new cancer strategy should focus on. It brings together routine data on cancer incidence, mortality, prevalence and survival with an analysis of the existing policy architecture. The report was informed by a number of interviews with senior stakeholders in NI, including representatives of the Public Health Agency's (PHA) cancer group, clinicians, third sector representatives and patients.ⁱ

1.1 INCIDENCE

The number of cancer cases diagnosed each year in NI is rising. In 2004 there were approximately 7,200 cases; in 2014 there were over 8,900 (excluding non-melanoma skin cancer).⁴⁰ This trend is expected to continue in the coming years. It is projected that by 2035 there will be over 14,000 cancer cases per year – an increase of 65% among men and 63% among women compared with 2009-2013 (Figure 1).⁴¹

FIGURE 1: CANCER CASES IN NI (EXCLUDING NMSC), 1993 – 2013, AND PROJECTION TO 2035



Source: Donnelly, D., Gavin, A. (2015) *Cancer Incidence Trends 1993-2013 with Projections to 2035*, Northern Ireland Cancer Registry

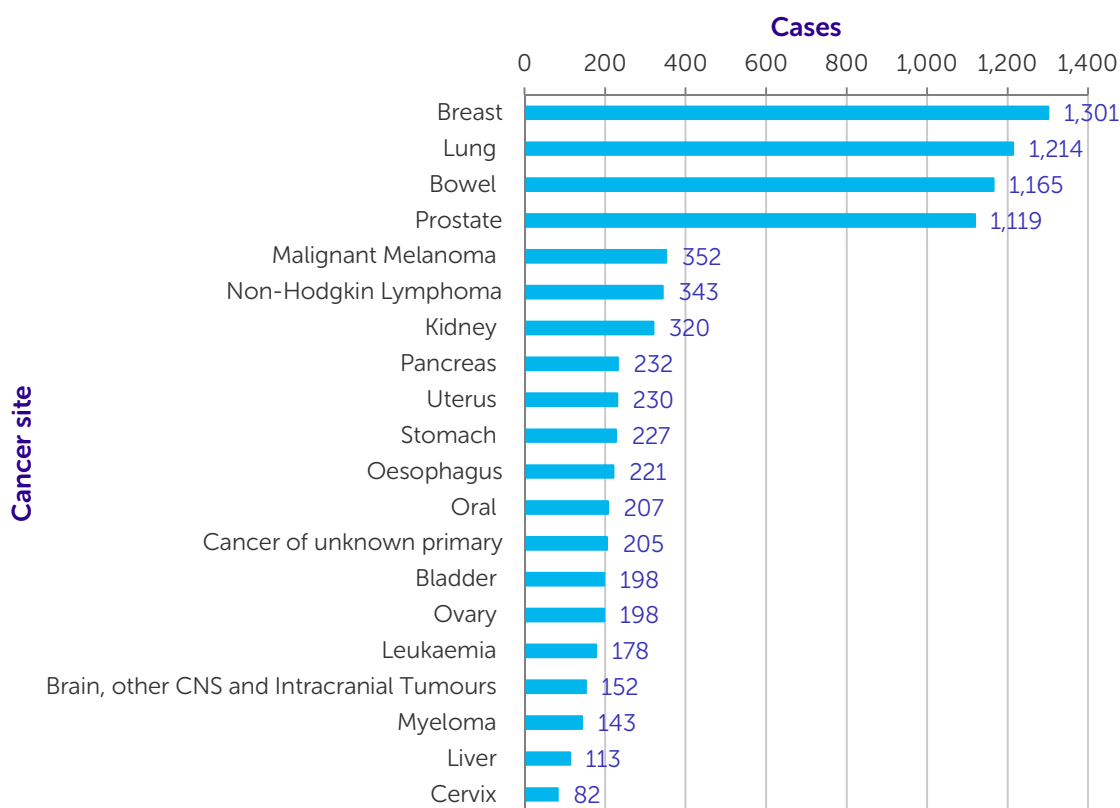
ⁱ Interviews were conducted in the second half of 2015.

These projected increases are being driven predominantly by a growing ageing population. But preventable risk factors, such as smoking and obesity also contribute. 22% of adults in NI smoke⁴² and 25% of the adult population is obese – up from 19% in 1997.⁴³

The incidence rate for cancer is the number of new cancers diagnosed in a specified population, usually per 100,000 people, during a year. In NI the cancer incidence rate has been growing since the early 2000s. Over the last decade the cancer incidence rate has increased by 7% from 554 cases per 100,000 people between 2003-2005 to 594 per 100,000 people between 2012-2014.⁴⁴

Different types of cancer occur with different frequency. As they are worldwide,⁴⁵ cancers of the breast, lung, bowel and prostate are the most common cancers in NI (Figure 2).⁴⁶ In men, the most common cancers are of the prostate, bowel and lung, which comprise 54% of diagnoses. In women, breast, bowel and lung cancers are most common, comprising 52% of cases.⁴⁷

FIGURE 2: TWENTY MOST COMMON CANCERS IN NI, 2014

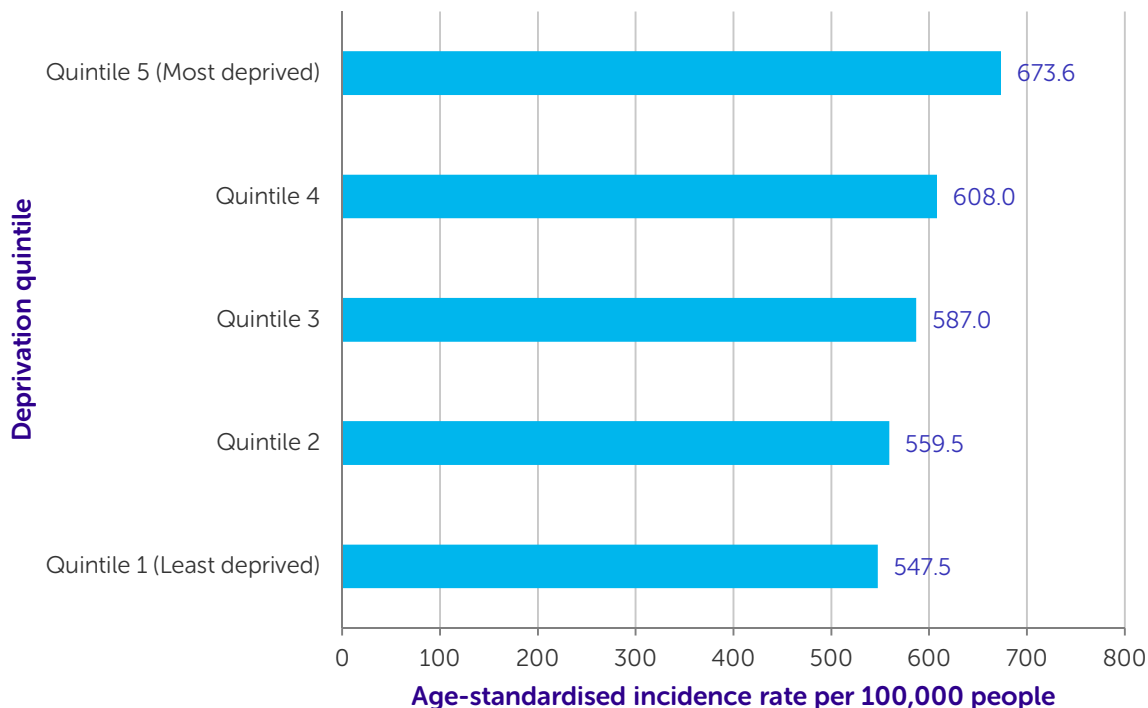


Source: Statistical Team at Cancer Research UK

The incidence of cancer in NI varies across different groups of society. For example, the overall cancer incidence rate is 23% higher among the most deprived quintile of the population than among the least deprived (Figure 3).⁴⁸ However, this pattern varies by cancer

site. Cancers of the lung, oral cavity, lip and pharynx, stomach, oesophagus, bowel (men only), head and neck, bladder and cervix are all more common in the most deprived populations. Alternatively, malignant melanoma and cancers of the prostate are more common among less deprived groups compared to NI's average.⁴⁹

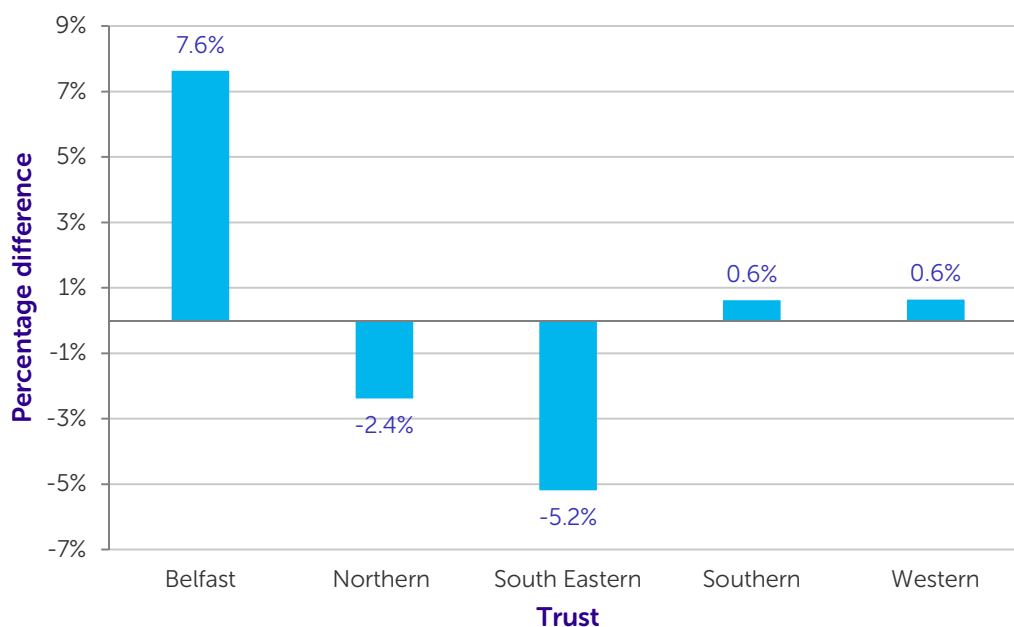
FIGURE 3: CANCER INCIDENCE RATE BY DEPRIVATION QUINTILE BASED ON AVERAGE CASES (EXCLUDING NMSC), 2010 – 2014



Source: Northern Ireland Cancer Registry (2015) All cancers (excluding NMSC): Incidence, prevalence and survival statistics: 1993-2014

Cancer incidence also varies across different geographical areas of NI. Because Trusts have regional footprints this affects their cancer burdens. For example, the Belfast Trust has the highest incidence rate, 7% above the NI average,⁵⁰ the South Eastern Trust alternatively has an incidence rate 5% below the NI average (Figure 4).

FIGURE 4: PERCENTAGE DIFFERENCE FROM NI AVERAGE CANCER INCIDENCE RATE BY TRUST (EXCLUDING NMSC), 2010 – 2014



Source: Northern Ireland Cancer Registry (2015) All cancers (excluding NMSC): Incidence, prevalence and survival statistics: 1993-2014

1.2 SURVIVAL

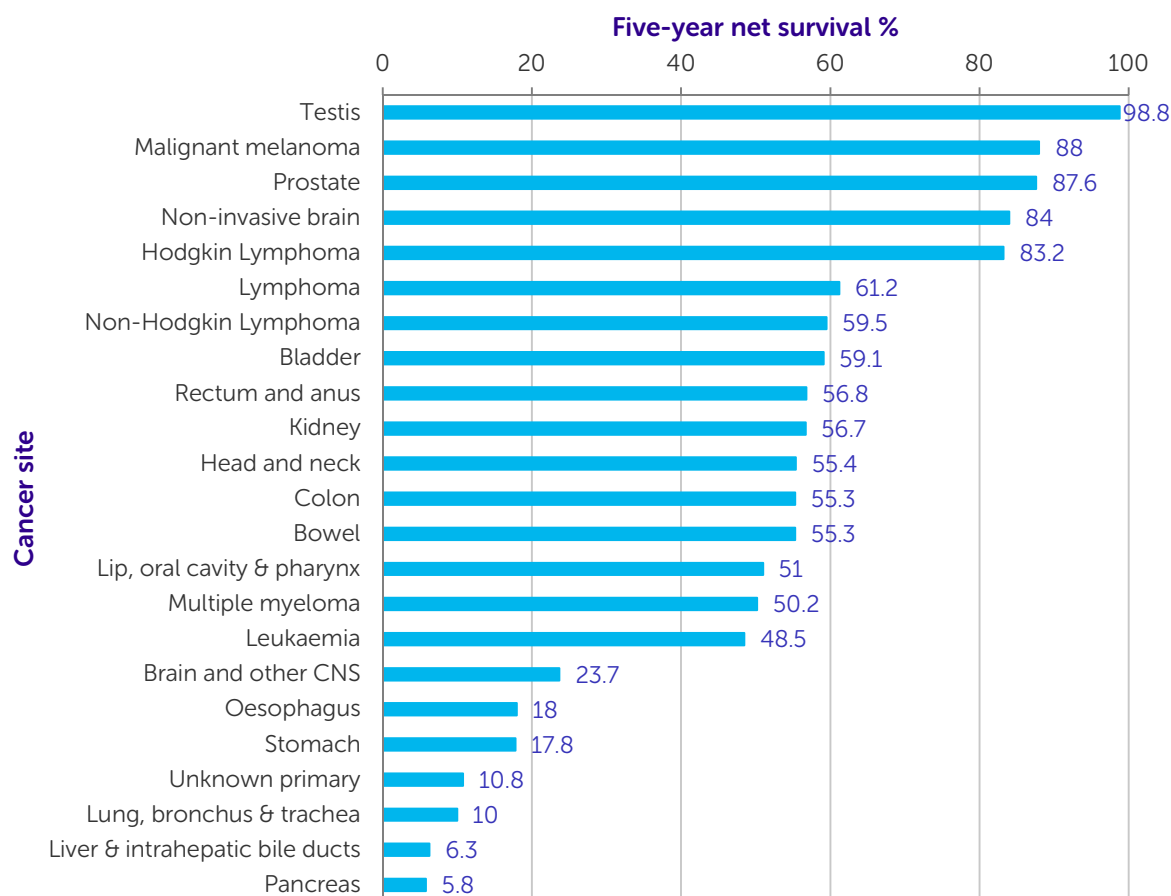
Survival from cancer can be influenced by a number of factors: stage at diagnosis, other health conditions that a patient has, and the effectiveness of treatment.⁵¹ Survival is frequently used as a composite indicator of health service performance.

Survival from cancer in NI is improving but, as in other parts of the UK, it is lower than in some comparable health systems.⁵² For people diagnosed between 2005-2009 one-year net survival from cancer has reached 70% and five-year net survival has reached 54%.⁵³ For comparison, among people diagnosed between 2000-2004, one-year net survival was below 66% and five-year net survival was less than 50%.

There are differences in survival between groups of society. In common with other developed countries, women have higher overall cancer survival than men. Among those diagnosed between 2005-2009, women have five-year net survival of over 55%; while men have five-year net survival closer to 52%.⁵⁴

Survival also varies significantly by cancer site. Among men diagnosed between 2005-2009, five-year net survival is highest – over 80% – for cancers of the testis, malignant melanoma and prostate. In contrast, the worst outcomes are achieved for men with cancer of the pancreas, liver and lung for which five-year net survival is 10% or less (Figure 5).

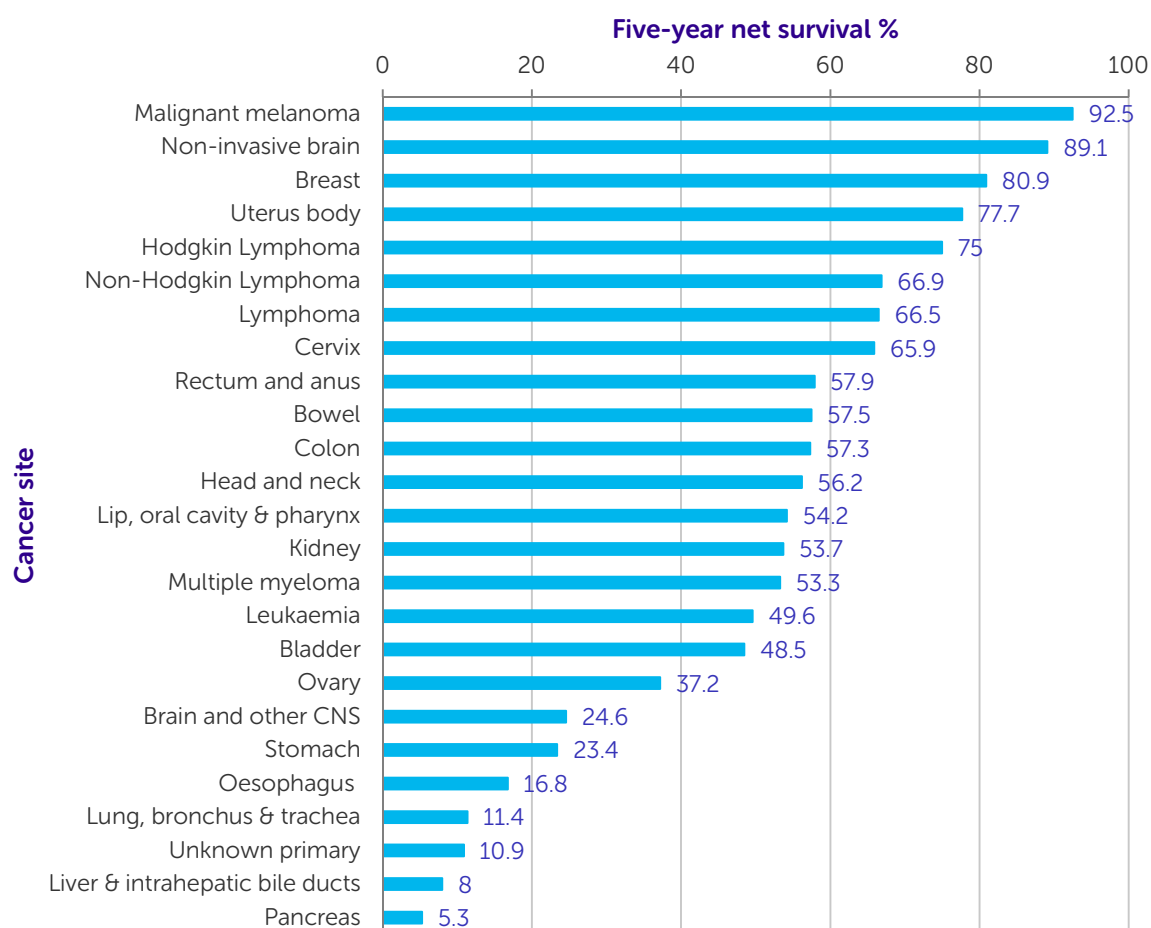
FIGURE 5: FIVE-YEAR NET SURVIVAL (%) FOR MEN DIAGNOSED BETWEEN 2005 – 2009 BY CANCER SITE



Source: Northern Ireland Cancer Registry (2015) Factsheet: All Cancer (excluding NMSC)

Women face comparable variations in survival across different types of cancer. Women diagnosed with malignant melanoma, non-invasive brain and breast cancer between 2005-2009 had five-year net survival of over 80%. In contrast, women diagnosed in the same period with cancers of the pancreas, liver and lung and of unknown primary had net five-year survival of less than 12% (Figure 6).

FIGURE 6: FIVE-YEAR NET SURVIVAL (%) FOR WOMEN DIAGNOSED BETWEEN 2005 – 2009 BY CANCER SITE



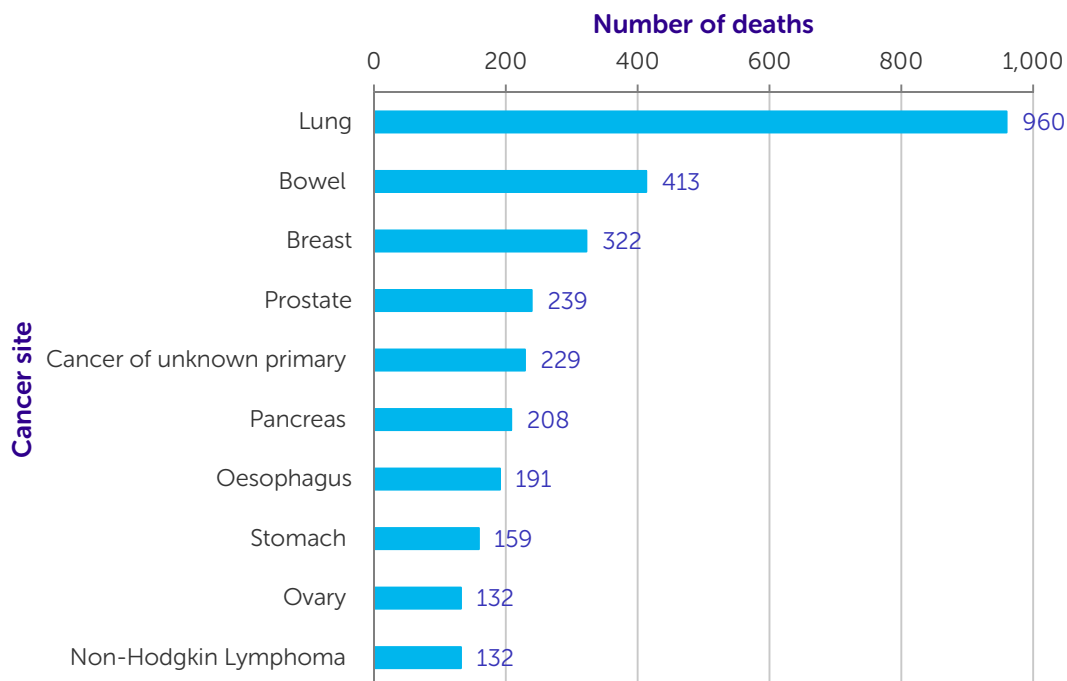
Source: Northern Ireland Cancer Registry (2015) Factsheet: All Cancer (excluding NMSC)

1.3 MORTALITY

Cancer mortality rates relate to the number of deaths from cancer in a specific population, usually per 100,000 people, within a specific period of time, usually a year. Overall cancer mortality rates in NI have fallen over the last decade – from 304 deaths per 100,000 between 2003-2005 to 288 deaths per 100,000 between 2012-2014.⁵⁵

The number of deaths from cancer, however, has risen over the same period – from around 3,700 in 2005 to around 4,300 in 2014.⁵⁶ Compared to other clinical areas, cancer is the single largest cause of death in NI.⁵⁷ Lung cancer is the largest cause of cancer deaths in NI (Figure 7).⁵⁸ In men, prostate and bowel cancers are the second and third most common causes of cancer deaths respectively. In women, breast and bowel are the second and third most common causes of cancer death.

FIGURE 7: TEN MOST COMMON CAUSES OF CANCER DEATHS IN NI (PERSONS), 2014



Source: Statistical Team at Cancer Research UK

1.4 PREVALENCE

Cancer prevalence refers to the number of people who are alive on a particular date having previously been diagnosed with cancer. It provides a 'snapshot' of people living with cancer.

At the end of 2014 there were around 55,700 people in NI who had been diagnosed with cancer in the previous 22 years.⁵⁹ Among men, cancers of the prostate, bowel, lymphoma and melanoma are the most prevalent.⁵⁸ In women, breast, bowel, uterine and melanoma cancers are the most prevalent.

1.5 SUMMARY

Around 8,900 people were diagnosed with cancer in NI in 2014. This number has been rising over recent years and is set to continue. By 2035, the number of cases diagnosed each year is predicted to reach 14,000. A growing ageing population is the main driver of this, but preventable risk factors, such as smoking and obesity, are also likely to contribute.

Breast, bowel, lung and prostate cancers are the most commonly diagnosed cancers in NI. The incidence of cancer is significantly higher among more socio-economically deprived groups compared to more affluent groups, although this pattern varies by cancer site.

Overall cancer survival is improving – five-year net survival has reached 54% – but, in common with the rest of the UK, survival is lower than in many Western countries. Survival also varies

by cancer site and sex. People diagnosed with cancers of the breast, prostate or testis have relatively strong survival prospects; alternatively survival from cancers of the pancreas, liver and lung is poor. Overall cancer survival among men is lower than among women.

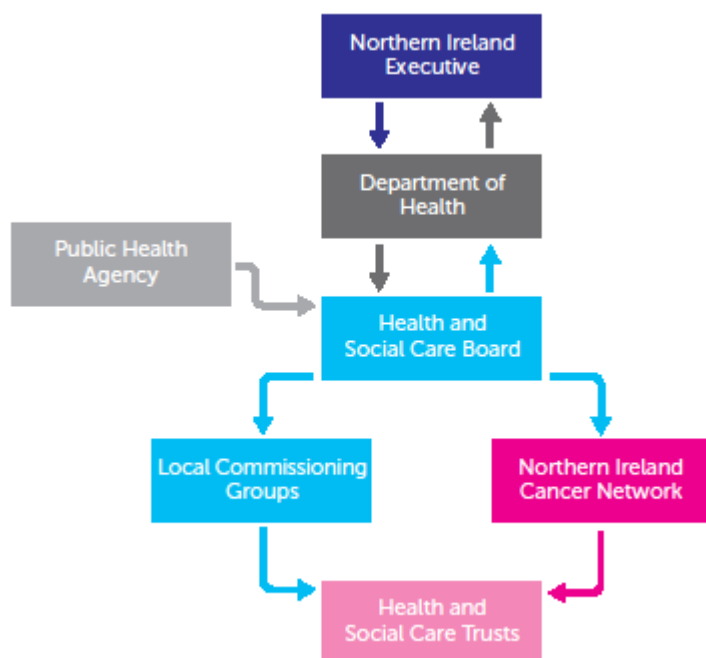
2: HEALTH SERVICE STRUCTURES, POLICY AND LEADERSHIP

This chapter briefly describes how healthcare is organised in NI. It then outlines, and attempts to assess, the cancer-specific policy and leadership structures which operate within that.

NI is distinctive within the UK in that, since 1973, it has had an integrated health and social care service.⁶⁰ From 1972 to 1999 direct rule from London was in place and consequently health policy in NI largely followed developments in England. In 1999, in line with wider devolution across the UK, the NI Executive assumed responsibility for healthcare. Since then, with the exception of subsequent periods of direct rule, the Department of Health, Social Services and Public Safety (DHSSPS) has been responsible for the health service. In 2016 the DHSSPS was renamed the Department of Health (DoH).

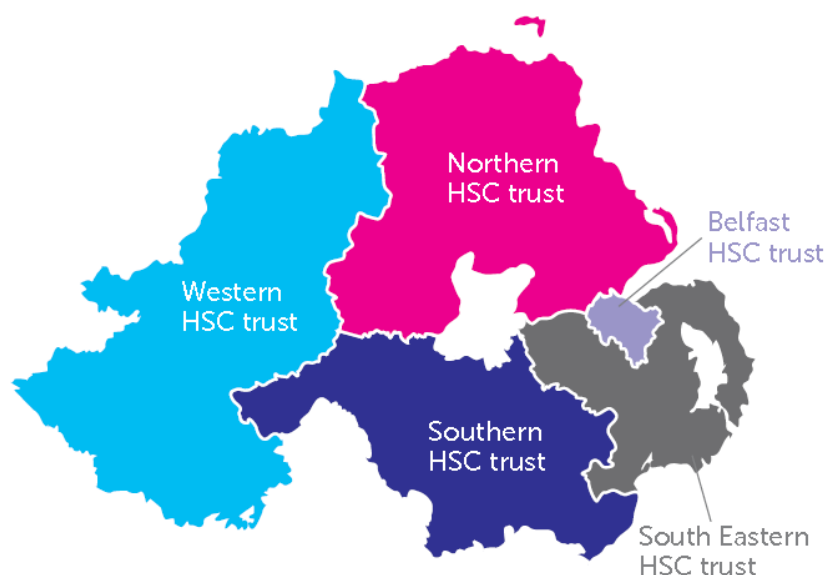
Today NI's healthcare system maintains a purchaser/provider split; while this normally entails competition, current policy emphasises cooperation between providers.⁶¹ The Health and Social Care Board (HSCB) is responsible for commissioning services across NI and is accountable to the DoH (Figure 8). The HSCB assesses the needs of NI's population, with input from the Public Health Agency (PHA), which is responsible for health improvement and equity in healthcare, and commissions activity accordingly. It sets priorities for the service via an annual commissioning plan; five Local Commissioning Groups (LCGs) commission services from regional Health and Social Care Trusts. The Regulation and Quality Improvement Authority (RQIA) is the main healthcare regulator.

FIGURE 8: STRUCTURE OF HEALTH SERVICE IN NI, INCLUDING NORTHERN IRELAND CANCER NETWORK⁶²



There are six Health and Social Care Trusts in NI. Five cover defined geographical areas which map onto the footprints of the Local Commissioning Groups (Figure 9).⁶³ Each of these Trusts, which on average provide for a population of around 360,000, is responsible for the full range of health and care: hospital care, primary care and residential homes. The sixth Trust provides ambulance services across NI.

FIGURE 9: FOOTPRINTS OF HEALTH AND SOCIAL CARE TRUSTS



2.1 NEW COMMISSIONING LANDSCAPE

The organisational structure described above has been in place since 2009; but the health service is set for change. In 2014, the then Minister for Health, Edwin Poots, commissioned an independent report to assess the “the arrangements for assuring and improving the quality and safety of care in Northern Ireland.”⁶⁴ Liam Donaldson, England’s former Chief Medical Officer, chaired the review which published its final report in December 2014. A central recommendation was that NI’s system of commissioning should be made ‘simpler and more capable of reshaping services for the future’.⁶⁵

In 2015, Simon Hamilton, who was Minister for Health 2015-2016, brought forward reform proposals based on Donaldson’s report.⁶⁶ His measures aimed to improve the system’s efficiency and reinforce the accountability of Trusts through:

- Less complex and bureaucratic structures;
- More effective communication and collaboration across the system;
- A longer planning period than is allowed by an annual commissioning cycle;
- Greater input of clinical and professional expertise in planning and service design; and
- More effective local commissioning.

After a public consultation in early 2016, the Executive confirmed changes will go ahead.⁶⁷ This means that the HSCB will be abolished; the Department of Health will assume responsibility for strategic planning and performance managing Trusts; Trusts will have “more responsibility for the planning of care...and operational independence”; and the PHA will be retained with a greater focus on “prevention and early intervention.” It is difficult to assess the implications of these changes because the timelines for implementation, and operational

details of how the structure will operate, are not yet publicly available. However, if the new arrangements simplify the system that could be beneficial.

Further changes may take place in the coming years. Another recommendation of the Donaldson review was that an expert panel be convened to explore how frontline services could be reconfigured. This was partly because Donaldson observed that NI has a high concentration of acute hospitals relative to its population. The NI Executive appointed a six-person panel in January 2016.⁶⁸ The panel recently submitted their recommendations to Minister for Health, Michelle O'Neill; publication is expected in the autumn.⁶⁹ If the panel recommends service reconfiguration, and the Executive assents, the health service will be subject to commissioning reform and service reconfiguration simultaneously or in quick succession.

2.2 HEALTHCARE SPENDING

In 2015/16 the NI Executive spent around £4.7 billion on health and care, which equates to around 46% of the Executive's total budget.⁷⁰ In 2016/17 healthcare spending is set to increase to around £4.9 billion.⁷¹

Publicly available information does not break down healthcare spending by disease area; instead it divides expenditure into broader categories such as General Medical Services, Dental Services, and Hospital Services. It is not therefore possible to indicate how much is spent on cancer services. We would welcome the Department of Health publishing a breakdown of spending by disease area; this would enable a more strategic approach to best use limited resources to deliver patient outcomes.

2.3 CANCER LEADERSHIP

The HSCB commissions cancer services, with input from the PHA, from the five Trusts and from charitable organisations. Each Trust has one hospital designated as the main site for delivering cancer services, as follows:

| | |
|-------------------------|---------------------------|
| Western HSC Trust | Altnagelvin Area Hospital |
| Southern HSC Trust | Craigavon Area Hospital |
| Northern HSC Trust | Antrim Area Hospital |
| South Eastern HSC Trust | Ulster Hospital |
| Belfast HSC Trust | Belfast City Hospital |

The regional cancer centre is based at Belfast Trust. This provides most specialist treatments, including radiotherapy, and hosts the regional oncology service. A new radiotherapy centre is scheduled to open at Altnagelvin Hospital in autumn 2016.⁷² Chemotherapy for common tumour sites is delivered at all Trusts using a hub and spoke model with agreed regimens.⁷³ The four cancer units outside of Belfast provide care for more common cancer types such as

bowel, breast and lung.

Since 2004 clinical leadership for cancer has been provided by the Northern Ireland Cancer Network (NICaN). NICaN brings together patients, healthcare professionals and managers from Trusts to share best practice and implement national and local initiatives. It supports several sub-groups focused on particular types of cancer, for example breast, bowel and lung, and some sub-groups focused on cross-cutting subjects, such as Systemic Anti-Cancer Therapy.⁷⁴

NICaN is supported by the HSCB; we understand it will be retained under the new model but this is yet to be confirmed. The PHA also maintains a cancer group with responsibility for public awareness programmes, providing input to the commissioning process and supporting research and development.

Interviewees for this research indicated that the structure in NI has supported collaboration on cancer quite well. They noted that NI's size allows members of the cancer community to interact and build relationships:

"We tend to know one another very well. We tend to know colleagues in the Trusts and they work very closely with us. We also have [a long established] Northern Ireland Cancer Network, which is a very active forum for discussion, debate and pulling together collective views and clinical consensus. So in that regard, there is a very good collaborative approach across cancer and because of our small population, that's very beneficial to us. ...It's [also] important to highlight the collaborative approach that we have with the third sector.... We've had real collaboration in relation to the 'Be Cancer Aware' campaign. We've had real collaboration with acute oncology." (PHA interviewee)

This testimony speaks to the importance of having an established forum to bring practitioners together. It is critical that the new health service arrangements maintain strong clinical leadership of cancer services – ideally through retaining NICaN.

2.4 KEY MILESTONES IN CANCER POLICY

Cancer has been an area of significant policy activity over the last 20 years. The key milestone initiatives, at both UK and NI level, are identified in box one, below:

BOX ONE: CANCER POLICY MILESTONES IN NI SINCE 1995

| | |
|-------------|--|
| 1996 | Campbell Report (NI) 'Cancer Services - Investing for the Future' published |
| 1999 | First cancer incidence data for Northern Ireland covering 1993-1996 |
| 2004 | Northern Ireland Cancer Network (NICaN) established |
| 2006 | Belfast Cancer Centre Opened |
| 2008 | 'Regional Cancer Framework: A Cancer Control Programme for Northern Ireland' published |
| 2008 | Waiting times initiative |
| 2009 | Development of Cancer Patient Pathway System (CaPPS) |
| 2011 | 'Service Framework for Cancer Prevention, Treatment and Care' published |

2.4.1 CANCER CONTROL PROGRAMME

In 2004 the NI Regional Cancer Services Framework Group was established with a remit to consider “the ongoing development of cancer services over the next 20 years.” It was chaired by the Chief Medical Officer and included representatives from primary care, secondary care and patients; the DHSSPS provided support. The group was tasked with making detailed recommendations for cancer services up to 2008; making recommendations for development of services to 2015; and suggesting the overarching strategic direction for services to 2024.

The result was the 2008 'Regional Cancer Framework: A Cancer Control Programme for Northern Ireland', covering prevention, services and research.⁷⁵ Paul Goggins, the Minister for Health at the time, described the objective as delivering “patient centred, high quality and sustainable cancer services for all the population of Northern Ireland.” The Control Programme made 55 recommendations across six key headings:

1. Prevention, early detection and screening;
2. Improving the experience of people affected by cancer;
3. Improving access to diagnosis and treatment;
4. Research information and audit;
5. Making it happen; and
6. Equality impact assessment.

It indicated that a detailed action plan would follow the publication of the strategy. As far as we are aware, this was not made public. The Cancer Control Programme represents the last time NI developed a comprehensive cancer strategy covering prevention and all elements of the cancer pathway and research.

2.4.2 SERVICE FRAMEWORK

In 2011, the DHSSPS published the 'Service Framework for Cancer Prevention, Treatment and Care'.⁷⁶ Developed by NICaN, in consultation with stakeholders and drawing on the work of NICE, the objective was to define clear, evidence-based standards in the delivery of cancer care that could be measured. It largely focuses on treatment for people who have been

diagnosed with cancer, although it also touches on prevention. It formed one part of a wider project to develop frameworks covering the major clinical areas including cancer, cardiovascular disease, respiratory disease and mental health.

The Service Framework set out 27 standards of care within three cross-cutting categories:

1. Improving the patient experience of care;
2. Prevention, awareness and early detection;
3. Effective treatment and care.

Standards under these themes are intended to be applicable to all cancer sites. For example, standard 1, which sits under improving the patient experience of care category, stipulates that “all patients should receive good face to face communication.” Standard 5, under prevention, awareness and early detection, requires that health and social care work in cooperation with voluntary and education sectors to prevent young people taking up smoking. Standard 20, under effective treatment and care, specifies that all patients should be managed by an “appropriately constituted and effective multidisciplinary team (MDT)”.

In addition to these generic categories, the Framework included a range of standards which apply to specific sub-categories of cancer patients. These cover brain, breast, children and young people, bowel, gynaecological, haematological, lung, skin, upper gastrointestinal and urological cancers. Lastly, the Framework includes standards applicable to the provision of care for people living with and beyond cancer and for palliative care.

The Framework is currently under review by the DoH.⁷⁷ However, as this document is a set of measures, it is unlikely that the outcome of this will be a new comprehensive strategy for cancer.

2.4.3 IMPACT OF THE CONTROL PROGRAMME AND SERVICE FRAMEWORK

In our judgement the Cancer Control Programme and Service Framework have broadly supported improvements in cancer services in NI. While it is not possible to offer a comprehensive evaluation of the extent to which their commitments have been met, we can identify several areas of change.

As seen in chapter one, cancer survival in NI has improved; 54% of patients diagnosed between 2005-2009 survived their cancer for five years compared to below 45% between 1993-1999.⁷⁸ While more recent data are not available to assess changes in survival since the Control Programme was produced in 2008, mortality rates from cancer have fallen since that time which is a positive sign of progress.

In addition, the development of clear standards of care, defined by the Framework, established the platform for ongoing scrutiny of service quality via clinical audits and peer review (discussed below). For example, it is now established practice that cancer patients are managed by multidisciplinary teams (MDTs). While peer review reports identify areas for improvement in relation to having all skills consistently represented at MDT meetings, this is an important step.

There has also been a process of rationalisation whereby some specialist treatments are delivered in a smaller number of centres where teams develop their expertise through managing a greater volume of patients. Again, while peer review has highlighted that some of these pathways require further refinement, the trajectory is positive.

However, we also see a number of areas where opportunities for improvement have yet to be realised. Firstly, the Control Programme committed to establishing standards for accessing first treatment. NI's waiting time operational standards were introduced the following year in 2009 and, as shown in chapter three, performance against these standards has deteriorated over time and is now significantly below target. This suggests the system is struggling to manage demand for cancer care.

Similarly, the Cancer Control Programme committed to establishing better cost and performance information; yet it remains the case that cancer services in NI are hampered by data issues. The Control Programme also aspired to deliver equitable access to clinical trials; we have reason to believe that this is yet to be achieved (discussed in chapter five). Lastly, the peer review programme has shown that in places there is further work to be done in consistently applying the Service Framework's standards.

Therefore, ongoing increases to cancer incidence, missed and deteriorating waiting times, and the coming changes to NI's health service leads us to the conclusion that the Cancer Control Programme and Service Framework are not meeting the needs of patients in the current cancer landscape.

We believe it is time for the NI Executive to develop a new comprehensive cancer strategy. The planned reforms create an opportunity to reassess how cancer services are delivered and define a vision for the coming years to further improve outcomes for patients.

2.5 CURRENT PRIORITIES IN CANCER CARE

Although NI's overarching cancer policy documents have not been updated recently, there are ongoing initiatives to improve care. The HSCB's 2015/16 Commissioning Plan refers to the following activities:⁷⁹

- The introduction of acute oncology teams at each of the five cancer treatment centres/units;
- The extension of peer review to all MDTs providing cancer care in NI;
- The introduction of 'skills mix' in the delivery of chemotherapy (in response to an ongoing regional chemotherapy review);
- The development of a plan for specialised nursing support for people with cancer, in response to the findings of peer review and Cancer Patient Experience Survey;
- The introduction of a Regional Information System for Oncology and Haematology (RISOH) to replace an older clinical oncology information system (COIS).

However, the Commissioning Plan also makes clear that funding limitations are impeding service development. It lists a concerning number of areas that will be delayed in 2015/16 due to financial limits:⁸⁰

- Centralisation of Upper Gastro-Intestinal cancer surgery at Belfast Trust;
- The development of a skills mix approach in the prescribing and delivery of chemotherapy;
- Access to a clinical nurse specialist for patients across NI;
- Access to a fully constituted MDT for discussion of diagnosis and treatment options for cancer patients;
- The ability to provide timely access to molecular pathology tests;
- The ability to ensure a resilient and sustainable radiotherapy medical physics service;
- The ability to respond to the findings of the peer review programme.

While the proposed improvements are welcome, the list of delayed initiatives suggest NI's annual planning cycle is struggling to balance ambition for cancer services with available resource. This reinforces the need for a longer-term approach.

A new cancer strategy would be beneficial in establishing priorities over several years and making best use of resources over that period.

2.6 SUMMARY

The healthcare system in NI is in transition. The Executive has committed to ambitious reform of commissioning structures and front-line service reconfiguration may follow. The impact of these changes on cancer services is difficult to assess at this point.

Since 2004, clinical leadership for cancer has been provided by the Northern Ireland Cancer Network. NICA is expected to remain in place under the new model but this is not certain. It is important that strong clinical leadership for cancer services is maintained.

The most recent strategy for cancer, the 'Cancer Control Programme', was published in 2008 and has not been reviewed by the NI Executive since. While the Service Framework for Cancer was published in 2011 and is currently being reviewed, it is not a comprehensive strategy for cancer. In our assessment these initiatives have supported important improvement in NI's cancer services. However, developments since then mean these documents are no longer meeting the needs of patients or cancer services.

While other countries across the UK set out new ambitions for improving cancer outcomes, it is clear that NI must do the same and develop a new strategy as soon as possible. Rising incidence of cancer and reform to the health service provide a timely opportunity to reassess how cancer services should be delivered, and set new targets to improve cancer outcomes for patients.

RECOMMENDATIONS

1. **The NI Executive should develop a new comprehensive cancer strategy, which sets ambitious goals and allocates sufficient resource to ensure cancer services can improve outcomes, meet rising demand and reduce variation in care. The strategy should ensure strong clinical leadership for cancer services and clarify how these services will be commissioned within the reformed NI health service. It should also set measurable targets to reduce cancer incidence, improve survival and better support the growing number of patients living with cancer. Particular attention should be afforded to cancer types with poor outcomes and variation across demographic groups, including men. We suggest the following targets:**
 - **One-year survival should reach 75% by 2020.**
 - **Five-year survival should reach 58% by 2020.**

3: HEALTH SERVICE PERFORMANCE

This chapter provides an overview of how the health service in NI is performing for cancer patients. We draw on a number of data sources: clinical audits, NICA's peer review of cancer services, cancer waiting times, and the Cancer Patient Experience Survey.

3.1 CLINICAL GUIDELINES

The National Institute of Health and Care Excellence (NICE) develops clinical guidelines across the full range of healthcare conditions. These define best practice for treatment and are regularly updated to account for medical developments. Since 2006 the DoH (previously DHSSPS) has maintained a formal link with NICE. However, guidance is not automatically adopted in NI; there is a regular process to assess whether new guidelines are applicable.⁸¹ This involves the DoH evaluating the legal, policy and financial consequences of implementing new guidance.

The fact that NICE guidance is in principle applicable in NI facilitates assessment of how services are performing.⁸² The RQIA draws on NICE guidelines when inspecting health and social care providers. RQIA's draft 2015-18 review programme indicated that it has been commissioned by the DHSSPS to carry out a review of the implementation of the Cancer Services Framework.⁸³ However, RQIA's final review programme for 2015-18 does not specifically mention the review of cancer services.⁸⁴

3.2 CLINICAL AUDIT

Clinical audit, which is overseen by the Northern Ireland Cancer Registry (NICR) provides a snapshot of how cancer patients are being treated; by revisiting specialisms several years later it is possible to assess how services are changing over time. Between 1996 and 2006 NICR conducted a series of clinical audits, at five yearly intervals. Since 2006, a second phase of audits has been undertaken, funded by the PHA and the Guidelines and Audit Implementation Network (GAIN), which in 2015 became a unit of the RQIA. This has covered ten cancer sites with breast and bladder the most recent; a report on lung cancer is scheduled for publication in 2016.⁸⁵

The most recent audit of breast cancer care compared patients diagnosed in 2012 with those diagnosed in 1996, 2001 and 2006.⁸⁶ Broadly speaking, it showed progress. For example, it found an estimated 9.6% improvement in five-year relative survival between those people diagnosed with between 1993 – 1997 and those in 2008 – 2013.

Stage at diagnosis has also improved: in 2006 68.3% of women were diagnosed at stage one or two; by 2012 this proportion had reached 75.7%. It also showed significant improvements in clinical processes. For example, in 2006 around 55% of breast cancer patients were discussed at an MDT; in 2012 the figure was 99.8%. Recorded CNS involvement had risen from 39% in 1996 to around 78% in 2012.

Another recent clinical audit explored the care provided to patients diagnosed with bladder cancer in 2010 and 2011.⁸⁷ This work also showed some positive developments; for example

90% of patients were discussed at an MDT. But it also identified areas for improvement. Only 37% of patients were recorded as having received assistance from a CNS. In addition, it showed a high proportion of emergency presentations and a survival gap which is not explained by differences in stage at diagnosis.

Other initiatives are exploring how clinical decision-making is affecting patient care in NI. An audit of the delays from first symptoms to start of treatment for breast, colorectal, lung and ovarian cancer is underway as Module 4 of the International Cancer Benchmarking Programme, which Cancer Research UK supports.⁸⁸ The Northern Ireland Cancer Registry, which produces official statistics on cancer in NI, is also undertaking a research project, funded by Cancer Research UK, to investigate methods for improving the early detection of bowel and lung cancers.⁸⁹

3.3 PEER REVIEW

NI is currently undertaking a three-year programme of work peer reviewing cancer services.⁹⁰ This involves a group of expert practitioners visiting cancer teams in a particular specialism, for example lung cancer, to review their way of working. In 2014, bowel, breast, gynaecological, lung, services were reviewed; in 2015 services for brain and central nervous system, head and neck, hepatobiliary, skin and urological cancers were visited. Services for haematology, sarcoma, endocrine-thyroid and upper gastrointestinal cancers are scheduled for peer review in 2016.

Review teams are made up of practising clinicians working in the same specialism, healthcare managers and a patient representative. Reviewers draw on NICE research and the Service Framework to assess the team's work. They are asked to assess the extent to which services are compliant with a collection of indicators and identify areas of good practice, 'serious concern' and 'immediate risk'. They submit a report of their findings after their visit; NICaN draws together findings into overview reports each year.

The services reviewed in 2014 had also been visited in 2010 during a previous programme of peer review in NI. The 2014 findings suggest a lack of progress in the intervening years. No specialism was found to be consistently implementing best practice.⁹¹ The highest performing specialism was lung cancer in which MDTs across NI were on average complying with 65% of the indicators. In bowel, cancer, however, national compliance was 48%. In addition, in breast and bowel treatment, significant variation between MDTs was identified. In breast cancer, Trusts' MDTs ranged from 44% compliant to 78%; and in bowel cancer, MDTs' compliance varied from 38% to 64%.

More positively, a relatively small number of immediate risks were identified in 2014. However, there were some recurring themes in need of improvement. All Trusts had at least one service with inadequate provision of CNSs; likewise all Trusts had a service where some investigations or treatments were not available when reviewers felt they would make a difference to patients.

The findings from services reviewed in 2015 were more concerning.⁹² The overview report found: "overall compliance [with the indicators] was low, with the majority below 50%." A greater number of serious concerns and immediate risks were also identified. Reviewers

identified particular concerns in relation to services where specialist treatment has been centralised, for example brain and central nervous system cancer. In these specialisms reviewers highlighted that some patients are being treated outside established pathways.

Trusts are required to develop action plans in response to peer review reports. Stakeholders interviewed for this project indicated that this process is having a positive impact on services. They suggested it is strengthening transparency by improving the performance data available to providers and commissioners:

“When you have an external standard that’s common to the rest of the UK it’s very good to benchmark your services and be open, honest and transparent about what we do. I think we all [have] a tendency to think we’re slightly better than we are. I think that [peer review] puts a bit of structure and it gives a bit of clout to the Network... It’s not just an improvement tool for Trusts. It’s an improvement tool for those that commission the service and those that deliver the service.” (Lead clinician)

“I think the peer review, plus the Cancer Standards Framework go very much hand-in-hand, in trying to make sure that the progress of cancer treatment and care continues on a positive [trajectory].” (Patient representative)

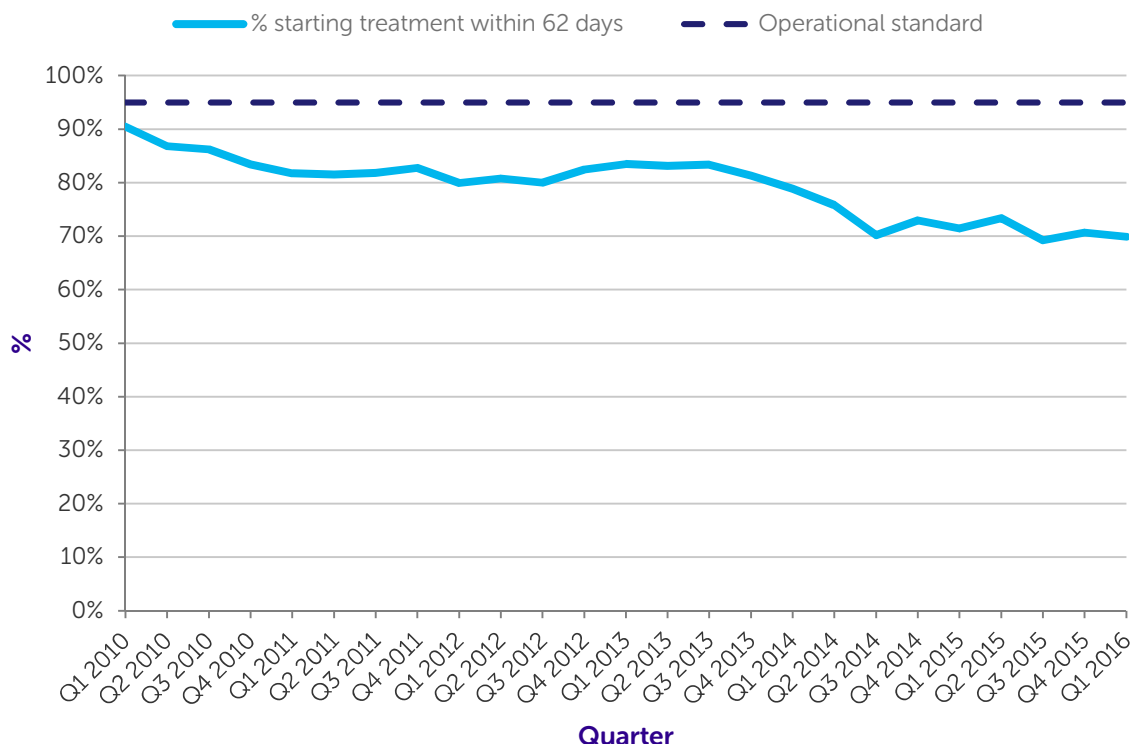
3.4 WAITING TIME STANDARDS

Waiting time targets for cancer exist to ensure patients are diagnosed rapidly and, where necessary, they progress to treatment as quickly as possible. Performance against these gives a useful insight into the state of cancer services. NI maintains three operational standards that relate to different elements of the cancer pathway and, in one case, a specific sub-group of cancer patients. Below we outline performance against each standard since 2010.

1. 95% of patients newly diagnosed with cancer should start treatment within 62 days of an urgent referral by a GP.

The 62-day operational standard has not been achieved across NI since it was introduced in 2009. Between the second quarter of 2010 and the first quarter of 2013 performance ranged between 80% and 87%. Since the first quarter of 2013, national performance has deteriorated. In the first quarter of 2016 69.9% of patients began treatment within 62 days (Figure 10).

FIGURE 10: PERCENTAGE OF PATIENTS STARTING TREATMENT WITHIN 62 DAYS OF URGENT REFERRAL, Q1 2010 – Q1 2016



Source: NI Department of Health and authors' calculationsⁱⁱ

Today all five Trusts are struggling to meet the 95% standard. Only one Trust met the 95% target in one month during the first quarter of 2016.⁹³ There is variation, however, across the Trusts. In the first quarter of 2016, the Belfast Trust's performance averaged 56% while the Western Trust averaged 94%.

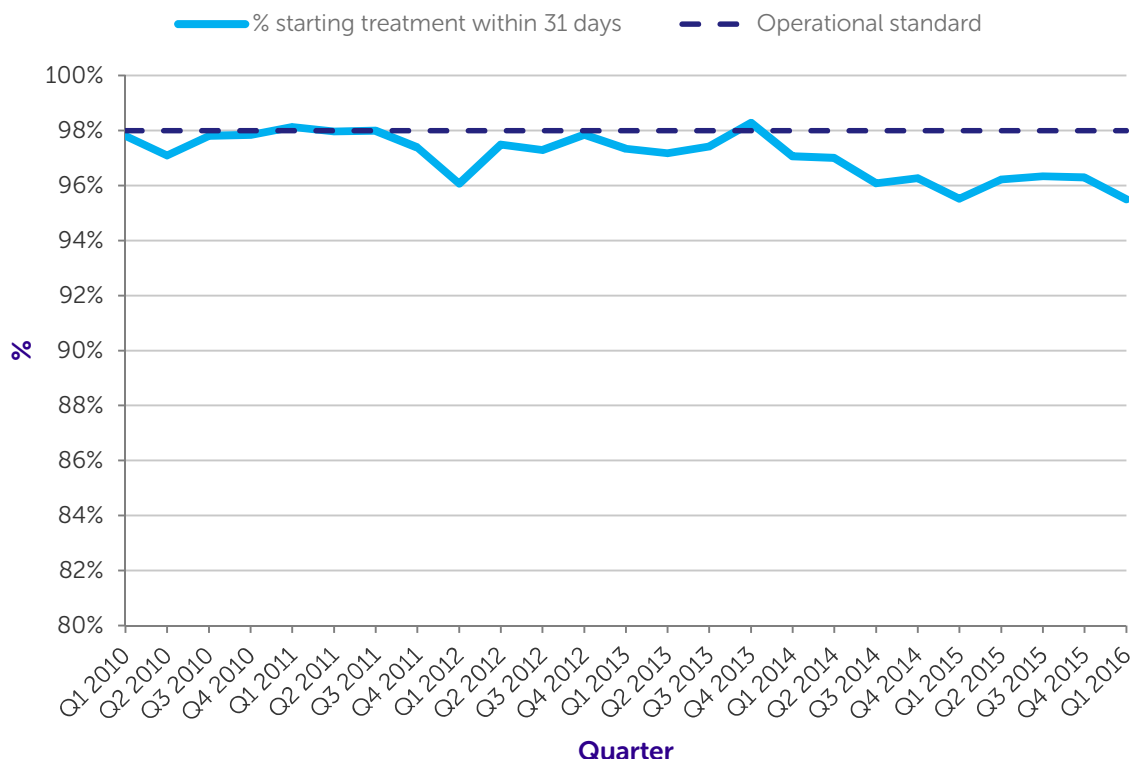
Performance against the 62-day standard also varies across cancer sites. Across NI 94% of breast cancer patients began treatment within 62 days during the first quarter of 2016; in contrast, over the same period, 68% of lung cancer patients started treatment within 62 days.

2. 98% of patients should begin treatment within 31 days of a cancer diagnosis.

Performance against the 31-day operational standard is higher than against the 62-day standard but still below target. The 31-day standard was last met in October – December 2013. Since then, there has been a slight deterioration in performance. For the last three quarters of 2015 performance stabilised at 96%. In the first quarter of 2016 performance was 95.5% (Figure 11).

ⁱⁱ The NI Department of Health publishes monthly performance data; we have calculated quarterly averages.

FIGURE 11: PERCENTAGE OF PATIENTS STARTING TREATMENT WITHIN 31 DAYS OF A CANCER DIAGNOSIS, Q1 2010 – Q1 2016



Source: NI Department of Health and authors' calculations

Against this operational standard there is variation between Trusts, with some managing to meet it. On average in the first quarter of 2016 three Trusts – Northern, Southern and Western – met the standard of seeing 98% of patients within 31 days.⁹⁴ The South Eastern Trust fell slightly below standard at 96% across the quarter and the Belfast Trust averaged 92%.

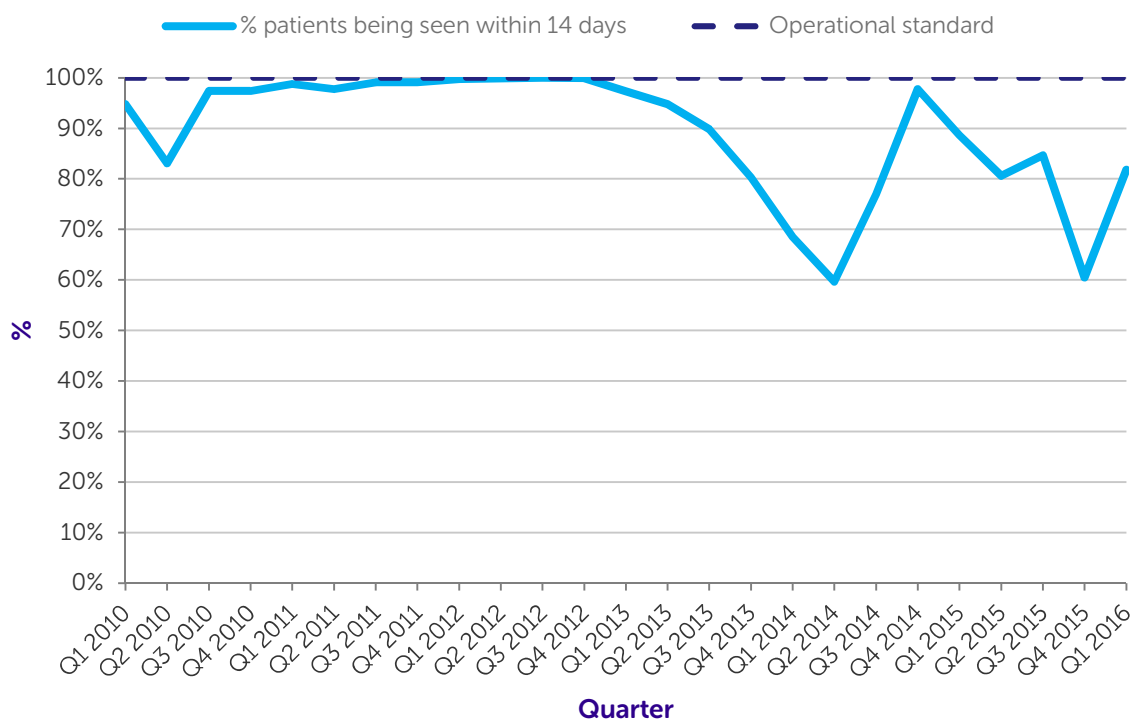
The discrepancy in performance between the 62-day target and 31-day target suggests there is a problem with diagnostic capacity. The 62-day target measures from the point at which cancer is suspected; whereas the 31-day target measures from the point at which cancer is confirmed so does not capture diagnostic delay.

3. 100% of patients urgently referred with suspected breast cancer should see a specialist within 14 days.

NI is unusual in applying a 14-day operational standard only to patients with suspected breast cancer. Performance against this standard last reached the target in the last quarter of 2012; prior to that performance had been near target with the exception of the first two quarters of 2010. Over the last three years, however, performance has been erratic. During 2013 and the first two quarters of 2014 there was a deterioration in performance, reaching 60% in the second quarter of 2014. Performance then improved sharply, reaching 98% in October –

December 2014. Since then, the proportion of patients seen within 14 days has fallen and risen again. In the first quarter of 2016 81.8% of patients saw a specialist within 14 days (Figure 12).

FIGURE 12: PERCENTAGE OF PATIENTS SEEN BY A SPECIALIST WITHIN 14 DAYS OF URGENT REFERRALS FOR SUSPECTED BREAST CANCER, Q1 2010 – Q1 2016



Source: NI Department of Health and authors' calculations

Performance against the 14-day operation standard varies markedly between Trusts. In the first quarter of 2016, Western Trust averaged 100% performance; in contrast, Belfast Trust's average performance was 48.5%.⁹⁵ In addition, several Trusts' performance varies considerably from month-to-month. For example, in the first quarter of 2016 Belfast Trust's performance improved from 37% in January to 67% in March. Northern Trust improved similarly from 58% in January to 94% in March.

Interviewees offered some possible explanations for NI's poor waiting time performance. One, below, contrasted demand for care which is dynamic with supply of cancer services which is much slower to adapt:

"Nobody is achieving the 62-day target....It's really a service under stress....I'm sure it's not just lack of funding. The targets seem to have gone off over the last year or two. There is obviously an increased demand and a static resource....There is an issue with access to complex cancer care in the cancer centre in Belfast and that might be frontline radiotherapy as first treatment, or access to complex surgery....The [waiting times] would not be deemed acceptable compared to the [rest of the] UK...especially the 62-day target for first treatment." (Lead clinician)

A lead clinician highlighted the implications of having a 14-day operational standard that only applies to patients with suspected breast cancer:

“We only have a 14-day target for breast cancer, which means that becomes a political target and enormous resources go towards breast cancer services; whereas less prominent...issues are not receiving the same resource. Many people with upper GI symptoms or lower GI symptoms wait a lot longer. Trusts try and trumpet the quality of the service by achieving the breast cancer target, which is only a proportion of patients.” (Lead clinician)

3.5 CANCER PATIENT EXPERIENCE SURVEY

In 2014, NI conducted its first Cancer Patient Experience Survey (CPES). Macmillan Cancer Support provided the funding and the results were published in autumn 2015. The survey received around 3,200 responses (a response rate of 62%) from patients who had undertaken treatment between December 2013 and May 2014.

Respondents generally gave a positive assessment of their treatment. 92% described their overall care as ‘very good’ or ‘excellent’.⁹⁶ Areas that were considered particularly strong included communication about tests and diagnoses, privacy and trust, pain control, good management of side effects and GPs being given appropriate information to help them care for patients.

Responses also suggested areas for potential improvement. The provision of information to patients could be strengthened. In particular, 66% of patients reported being given easy to understand written information in advance of an operation and the same proportion recalled being advised about financial help they might be entitled to. The factor found to have the strongest association with high patient experience scores was the assignment of a Clinical Nurse Specialist (CNS). 72% of respondents said they had been given the name of a CNS. Only 18% of patients reported that they had had a discussion with staff about taking part in research.

We welcome the introduction of a CPES in NI. Patient experience provides valuable insight into how services are performing. We think it would be a positive step to allocate budget to the CPES and thereby place it on a sustainable financial footing.

3.6 SUMMARY

It is difficult to offer a complete assessment of cancer service performance in NI due to data limitations. Nevertheless by looking across a number of indicators it is possible to get a sense of how the service is performing for patients. Our analysis suggests a mixed picture.

It is noteworthy that the recent CPES showed very high levels of patient satisfaction. This is valuable insight and we think the CPES should be continued in the future.

Other important benchmarks of cancer care quality are not being met. In particular, the health service is struggling to meet waiting time targets for cancer. None of the three standards have been met in the last two years. Performance against both the 62-day and 14-day standard was significantly below standard in the first quarter of 2016. This is a clear

indication that the service is struggling to keep up with demand. It is critical that the NI Executive undertake analysis to understand the factors driving to this.

Stakeholders regarded the peer review process positively. However, this process has revealed in places a lack of progress since 2010, variation between MDTs, and that some MDTs are not consistently following best practice. As such, there is room for improvement in cancer services in NI. It is less clear, however, why the performance measures that are in place have not necessarily led to improvements in service delivery.

RECOMMENDATIONS

- 2. The Department of Health and Trusts should undertake work to clarify why operating standards for cancer are not being met. Based on that, the Department should provide investment to ensure they are met in the future. The Department should also consider broadening the 14-day operating standard to cover all cancer types.**
- 3. The Public Health Agency should fund and continue to undertake the CPES on a regular basis. Its findings should be used to support ongoing evaluation and improvement.**

4: EARLY DIAGNOSIS

Early diagnosis is crucial to improving survival in many cancer types.⁹⁷ In bowel cancer, for example, around 95% of patients diagnosed at stage one live another five years; in contrast less than 10% of those diagnosed at stage four do likewise.⁹⁸ In this chapter we assess the initiatives undertaken in NI to diagnose cancers early and consider what measures would support improvement.

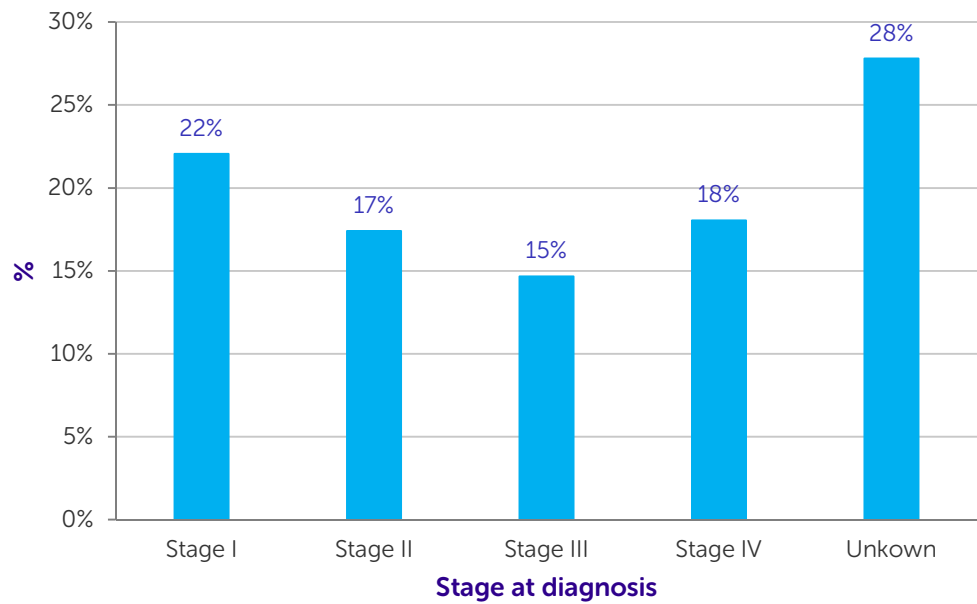
In the UK there is evidence that barriers to early presentation are contributing to our outcomes being less good than in comparable countries. The ICBP found that people in the UK, including NI, were less likely to be aware that increasing age was a risk factor for developing cancer and that they reported more barriers to seeking a doctor's opinion. Although their awareness of cancer symptoms was comparable to other countries (Australia, Canada, and Scandinavia).⁹⁹

The challenge of early diagnosis is variable across cancer types. Some types, such as breast and skin cancers, have specific symptoms; others, such as pancreatic cancer, present with non-specific symptoms. There are some international innovations which may be relevant to NI improving early diagnosis of these harder-to-detect cancers. In Denmark, for instance, multidisciplinary diagnostic centres are being tested; and in England the Accelerate, Coordinate and Evaluate (ACE) Programme, co-funded by Cancer Research UK, is piloting similar approaches.¹⁰⁰

4.1 STAGE AT DIAGNOSIS

Information on stage at diagnosis is relatively good in NI: on average between 2010 and 2014, 72% of cancer cases had a stage recorded at point of diagnosis (Figure 13). However, there is scope to detect and diagnose many cases earlier. Among patients diagnosed during this period and with a recorded date, around 45% were found to have stage three or four cancer. This limits their treatment options and negatively affects their prognoses.

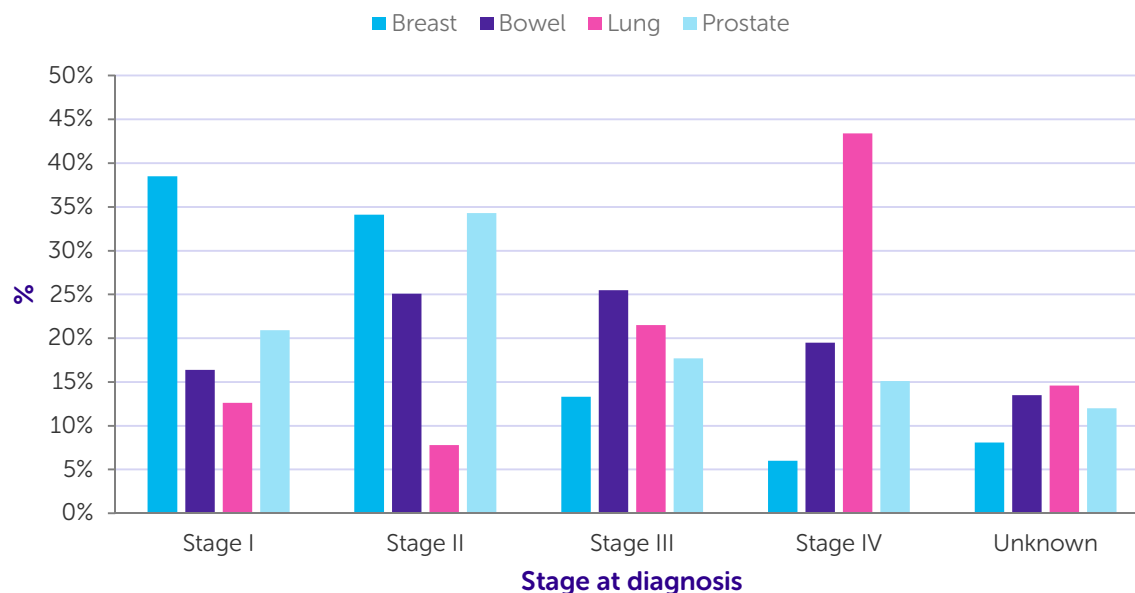
FIGURE 13: PROPORTION OF PEOPLE DIAGNOSED AT EACH STAGE FOR ALL CANCER CASES (EXCLUDING NMSC), BASED ON 2010 – 2014 AVERAGE



Source: Northern Ireland Cancer Registry (2015) All cancers (excluding NMSC): Incidence, prevalence and survival statistics: 1993-2014

Looking at the four most common cancers – breast, bowel, lung and prostate – shows variation in relation to early diagnosis. Between 2010 and 2014, over 70% of breast cancer cases and 50% of prostate cancer cases were diagnosed at stage one and two. In contrast, around 65% of lung cancer cases were diagnosed at stage three or four (Figure 14). It is noteworthy that five-year survival for breast (around 80%) and prostate cancer (approximately 88%) are significantly higher than for lung cancer (10% among men and 11% among women).¹⁰¹

FIGURE 14: STAGE AT DIAGNOSIS IN FOUR MOST COMMON CANCERS, BASED ON 2010 – 2014 AVERAGE



Sources: Northern Ireland Cancer Registry (2015) Factsheet: Breast cancer; Factsheet: Colorectal (bowel) cancer; Factsheet: Lung cancer; Factsheet: Prostate cancer.

4.2 PUBLIC AWARENESS

Consistently diagnosing cancer early relies, in part, on public behaviour. It is important that people are able to recognise symptoms that might be cancer and are willing and able to seek medical advice.

The NI Executive has taken steps to increase public awareness of cancer. In 2014 the PHA undertook a survey, which got around 1,400 responses, to understand the extent to which the public are aware of the signs and symptoms of cancer.¹⁰² This showed many people are aware of key preventable risk factors. Unprompted, 80% of respondents mentioned smoking, 35% mentioned alcohol and 25% exposure to sun. Regarding symptoms, when prompted, 86% of all respondents mentioned an unexplained lump or swelling as a warning sign. However, it also showed awareness is unevenly distributed across social groups. Cluster analysis found that limited awareness and understanding of cancer signs and symptoms is likely to be twinned with lower socio-economic status and a reluctance to consult a doctor about symptoms. These results will be used to assess the impact of subsequent public awareness campaigns.

The Executive has supported *Be Cancer Aware*, a public awareness programme which started in 2015 covering all of NI using online, television, radio and print advertising. The first phase was a 'primer campaign' which encouraged people to know the signs and symptoms of cancer and to go to their GP with concerns. Subsequently more specific campaigns, focused on lung and breast cancer, were launched. A further campaign, on bowel cancer, was scheduled for early 2016, but was postponed until autumn 2016.

Interviewees for this project expressed mixed views on the work to date. Some were positive about the *Be Cancer Aware* programme and the effect it has on the public. For example:

"I think this public campaign is good because it's creating awareness in the public so that hopefully then the public will have the courage to say to the GP... 'It was on the TV last week and I think I have those symptoms and I would like [to be] referred'." (Third sector representative)

Others, however, pointed to the need for further activity targeted at more disadvantaged groups and less well known cancer types:

"How you [reach] the most disadvantaged, [given] they're likely to have the most cancers, is harder to ascertain. I'm not sure how effective some of the awareness campaigns are. Certain groups like breast cancer is very good, and some men's cancers now are coming up a bit stronger. But bowel cancer lags greatly behind." (Lead clinician)

Previous research has illustrated the positive impact public awareness campaigns can have.¹⁰³ We therefore recommend the NI Executive continues to invest in this area. A focus on a wider range of cancer types and how to communicate with harder-to-reach groups of society would be beneficial.

4.3 THE ROLE OF PRIMARY CARE

Primary care is critical to consistently diagnosing cancer early because most cancer patients are diagnosed following a referral from their GP.¹⁰⁴ This relies on patients seeking advice and on GPs being alert to signs and symptoms and being willing and able to refer patients promptly.

Between 2007 and 2012 GPs in NI were expected to adhere to Regional Suspected Cancer Referral Guidelines, which had been developed by NICaN.¹⁰⁵ These were superseded in 2012 by NICE referral guidelines. Based on those, patients with a 'high suspicion of cancer' are referred by GPs using the 'red flag' pathway, which aims to ensure they see a specialist within 14 days of referral. According to one interviewee, however, both NICE and NICaN guidance are still in use among GPs.

"There were guidelines agreed with Northern Ireland Cancer Network and the various secondary care commissioners and so GPs would have referred to those. There are also the NICE guidelines. Both of them are available on our referral system. The referral system has improved in as much as we do it online now. It's done electronically and the guidelines are attached to that so GPs can check against that." (GP)

One interviewee highlighted that the existing system and performance issues create problematic incentives which lead to inappropriate use of the 'red flag' referral pathway.

"[GPs] try and put people into an urgent category when they possibly don't meet the criteria. And they do that because they know if they put somebody into a non-urgent category the backstop waiting times are inordinately long... So they're using the system for understandable reasons. The system is not fit for purpose currently." (Lead clinician)

Other interviewees suggested action was needed to raise awareness among GPs and combat 'complacency'. We understand that the PHA is currently undertaking work to analyse referrals from primary care with a view to identifying any additional education GPs would benefit from. The results of this analysis are not yet publicly available.

NICE issued revised guidelines in June 2015 which included a lower threshold for referral in cases of suspected cancer.¹⁰⁶ We understand that the resource implications of implementing this guidance are currently under consideration in NI. It is important that this work is conducted swiftly so that best practice can be rolled out at the earliest opportunity.

4.4 DIAGNOSTIC CAPACITY

Cancer diagnosis relies on a number of diagnostic modalities, including pathology, imaging and blood tests. As mentioned in chapter two, performance against the 62-day operational standard, which fell below 70% in the first quarter of 2016, suggests these services are struggling to meet demand. Other indicators support this analysis.

The number of people waiting to undertake a diagnostic test has risen sharply over the last two years. The total number of people waiting for a test has risen from around 69,000 in March 2014¹⁰⁷ to approximately 93,500 in March 2016.¹⁰⁸ The number of patients waiting more than nine weeks for a test is also rising. In March 2014 there were around 10,500 people who had waited nine weeks or more¹⁰⁹; by March 2016 this had reached 29,000.¹¹⁰ While not all of these people will have been referred with suspected cancer it can have knock on consequences for people who have been.

Data from the NI CPES also suggests some cancer patients are experiencing delays in progressing through treatment. Overall, 84% of respondents indicated they saw a hospital doctor as soon as they felt was necessary.¹¹¹ However, 10% felt it could have been a 'bit sooner' and 6% felt it should have happened 'a lot sooner'. In addition, there was variation between Trusts. At the highest performing Trust 89% of patients indicated they saw a specialist as soon as necessary. The lowest performing Trust had 82% of patients saying likewise.

4.4.1 IMAGING SERVICES

Imaging services in NI have historically been locally run, with each hospital managing its own service and employing the staff. The HSCB's 2015/16 Commissioning Plan recognises that this is contributing to variation in provision. It suggests that 'reporting capacity', rather than 'capacity for image acquisition', is the limiting factor.¹¹² Workforce shortfalls, including 21 vacant radiologist posts, are also highlighted. Overtime working and outsourcing of reporting to the independent sector have been used increasingly to manage these shortfalls.

The HSCB's 2015/16 Commissioning Plan proposes to take action across the region on imaging services. It suggests the development of a 'regional reporting network'. This builds on recent work by the Royal College of Radiologists.¹¹³ Radiology staff would collaborate to provide a regional service with the capacity to provide 24-hour cover and thereby save the costs of outsourcing. The out-of-hours teleradiology service operating in Belfast since 2012 is cited as a successful example. Local Commissioning Groups' (LCGs) plans for 2015/16 also recognise a

shortfall in endoscopy and imaging capacity. Belfast, Northern, Southern and South Eastern LCGs intend to increase the volume of MRI, CT scans and ultrasounds in response. In addition, Belfast and Southern LCGs plan to promote the use of nurse-led endoscopy and improve utilisation.¹¹⁴

A positive side effect of local autonomy is the scope for innovation. During our research we heard of places exploring new ways of working in diagnostics. For example, an interviewee highlighted a 'one-stop urology assessment' clinic at a Trust, intended to accelerate the diagnostic process. This is in line with the latest developments in diagnostics which involve bringing together a range of expertise. It is important that the NI Executive evaluates innovations such as this and supports roll out where they are shown to be effective.

4.4.2 DIRECT ACCESS TO DIAGNOSTICS FOR GPs

When GPs suspect cancer they generally refer patients to a specialist who then directs the patient for investigative testing. In some circumstances, however, GPs refer patients directly for tests. This relies on there being processes in place to allow this and capacity in the system.

Our interviewees suggested direct access to diagnostic tests in NI is variable. According to one stakeholder direct access to endoscopy was available to some extent and in general access to radiology was easier in smaller, less busy units.

"We can request ultrasound, chest x-ray but that's about all in our area. We can get plain x-rays; we can get MRIs of spine but we can't get any other MRIs. If something [of concern] shows on an ultrasound or an x-ray we can request CT if there's obviously a good indication....I think it could certainly be improved...If I'm referring inappropriately then some educational feedback could be provided. Certainly when we know our patients it would be good for us to be able to access those investigations."
(GP)

In the perception of GPs we spoke to, direct access to diagnostics has not been given priority because of resource pressures. As the NI Executive looks to the future, this should be a priority. We recommend an urgent review of the state of direct access to diagnostics; this should assess the extent of variations and outline actions to standardise direct access across NI.

4.5 SUMMARY

Information on stage at diagnosis is available for around 72% of patients diagnosed between 2010 and 2014 in NI. However, there is room for improvement in diagnosing more cancers earlier: 44% of patients with a known stage in that period were found to have stage three or four cancer.

The NI Executive has made efforts to improve public awareness of cancer. The *Be Cancer Aware* programme was adopted for NI as a whole in 2015 following a baseline study in 2014 to enable monitoring of the impact of the campaign. This should be continued and expanded to try and reach more disadvantaged groups.

There is evidence that diagnostic capacity is under pressure. While some innovation is taking

place, the number of patients waiting for tests is rising and this appears to be affecting some cancer patients. In addition, GPs' direct access to investigative tests seem to be geographically variable. Work is urgently needed to understand current capacity and place it on a sustainable footing to meet rising demand.

RECOMMENDATIONS

- 4. The Public Health Agency should continue funding the *Be Cancer Aware* programme and look to expand it. The programme should be developed to target different types of cancer and hard to reach groups.**
- 5. The Department of Health should undertake an urgent review of the state of direct access to diagnostic tests for GPs and capacity needs in diagnostic services. It should make the necessary investment to ensure diagnostic services can meet rising demand.**
- 6. The Department of Health should explore the potential for new service models to support diagnosis, for example multi-disciplinary diagnostic centres to help diagnose cancer cases swiftly where symptoms may be vague.**

5: ACCESS TO EFFECTIVE TREATMENTS

Once a cancer diagnosis is made, offering patients timely access to high-quality, evidence-based treatments is crucial to improve survival. ICBP data imply that poorer survival in the UK is in part due to sub-optimal access to treatments.

Cancer treatments fall into three categories: surgery, radiotherapy and drugs (including chemotherapy, targeted drugs, biological agents and hormone therapies). This chapter considers the provision of each treatment category before exploring cross-cutting issues such as the location of services, access to clinical trials, the workforce and how pathways are coordinated.

The geographical provision of treatments varies in NI. Specialist and low-volume surgery is provided at the Belfast Cancer Centre. Radiotherapy is currently only provided at the Belfast Cancer Centre; from late 2016 it will also be provided at Altnagelvin Hospital in the Western Trust. Cancer drugs may be provided at specialist cancer centres, at local hospitals or taken at home, depending on how the treatment is administered and the potential side effects.

Our ability to assess the quality of treatments is hampered by a lack of data on patients' access to treatment. Data on access to radiotherapy and chemotherapy are of particular concern. For example, it is not clear how many patients undergo Intensity Modulated Radiotherapy (IMRT), which it is thought could benefit around 50% of patients.¹¹⁵ It is important that the NI Executive makes collecting and publishing data on treatment activity a priority.

5.1 SURGERY

General surgery is conducted at all five cancer units in NI. Oncologists are all based at Belfast and conduct outreach clinics in the cancer units. Specialist surgery, for example gynaecological surgery, takes place in Belfast. In addition, for certain procedures patients travel to England for NHS-funded or private treatment. Interviewees cited examples such as robotic surgery for testicular cancer and stereotactic radiosurgery for brain metastases.

Generally interviewees consulted for this research did not express concern about the availability or quality of cancer surgery in NI. However, as will be discussed below (section 5.7), some interviewees suggested some surgery may be taking place in units which do not have beneficial critical mass in the number of cases they manage.

5.2 RADIOTHERAPY

Radiotherapy is currently provided exclusively at the Belfast Cancer Centre, which opened in 2006. Their information estimates they treat around 4,000 new patients each year using radiotherapy.¹¹⁶ IMRT is provided at Belfast and is described as 'well established' in the 2014 peer review report.¹¹⁷ However, a lack of data on access makes it difficult to understand what proportions of patients are accessing optimum treatments.

From 2016 radiotherapy will also be available at Altnagelvin Hospital in the Western Trust. This service has been jointly funded with the Republic of Ireland and will serve patients from

both NI and the Republic. One interviewee outlined the impact as follows:

“It will bring additional capacity [so] that people won’t be travelling for four hours a day for a relatively short routine therapy. It’s done cross-border to get an appropriate cohort of population and therefore it’s funded by two governments and it’s an interesting way of doing healthcare and it will lead to other changes. It certainly will change [the Western Trust] and it should reduce the demand at the Belfast centre.”
(Lead clinician)

According to the PHA, there are no waiting lists for radiotherapy treatment. It is not possible to confirm this because, as far as we are aware, the data are not made available publicly. We understand that in some cases patients are sent to England for specialist radiotherapy services. Others have also shown that previously a small number of patients have attended hospitals in the Republic of Ireland for radiotherapy.¹¹⁸

5.3 CANCER DRUGS

Cancer drugs and chemotherapy are administered at all five cancer units. There is also some provision for district nurses to manage patients at home if the treatment is provided orally; more exceptionally, some patients receive chemotherapy at home.

“There are a small number of patients who have their chemotherapy at home privately or very, very occasionally on the NHS. We had one patient who was quite debilitated by profound anticipatory nausea and vomiting following previous chemotherapy and just couldn’t go near the hospital so [s/he] had it at home. ...The Trust on this occasion funded it but it was quite protracted to get that. It would be a one-off case.” (GP)

A third sector stakeholder we interviewed commented that chemotherapy services are struggling to meet demand and staff did not have time to give patients the support they need. This type of analysis would be supported by the development of a regional dataset on chemotherapy activity. This would show the volume of patients the service is managing and the proportion of patients undertaking chemotherapy.

The 2015/16 NI Commissioning Plan references an ongoing regional chemotherapy review. It explains that recommendations expected from the review will create an opportunity to improve skills mix and consequently improve quality and timeliness of treatment. Subject to consultation, HSCB anticipate introduction of skills mix in late 2015.¹¹⁹ As far as we are aware, details of the regional chemotherapy review have not been published.

5.3.1 ACCESS TO NEW DRUG TREATMENTS

As discussed in chapter three, NICE guidance is in principle applicable in NI. But NI maintains a process to assess the impact of guidance before endorsing it. An official we interviewed described the process for authorising new NICE-approved drugs as follows:

“...If NICE recommend a drug for use in the health service we immediately make that drug available in the first instance on a cost per case basis until we have a sense of how much we need and whether there’s any infrastructure. And we go through a process of identifying what’s actually needed associated with the drug, drug

procurement costs and any infrastructure and we formally commission it. It can take a few months to get to the formal commissioning, but in the meantime the drug is made available on a cost per case basis.”

While this process may ensure approved drugs are appropriate for NI, it also introduces an additional stage into the process and, therefore, potential delays. Some interviewees highlighted that delays in access to new drugs have been a historical problem, but suggested there has been improvement recently:

“The system is better than it was: up until 18 months ago even NICE approved drugs were in some ways difficult to get because when a drug was approved by NICE it was maybe six to nine months delay before it was available in Northern Ireland. Now that has changed.” (Third sector interviewee)

However, some stakeholders we interviewed believed that new cancer drugs are more readily available ‘on the mainland’. This was linked to the existence of the Cancer Drugs Fund (CDF) in England since 2011; a move the NI Executive has not emulated.

Recent changes to the CDF in England will require a policy response in NI. From July 2016 new cancer drugs will be appraised by NICE with the CDF operating as a ‘managed access scheme’.¹²⁰ NICE will therefore have the option to conditionally approve a new drug for a specified period. During that time, additional evidence about its effectiveness will be gathered before a definitive decision on whether it should be routinely commissioned. NI does not currently have a ‘managed access’ approach for drugs, so it is unclear how the Department of Health will manage drugs which are conditionally approved by NICE. It is important that the NI Executive outlines how its process will adapt in response.

The NI Executive has found it difficult to manage the budget impact of new NICE approved treatments. This led to access to new treatments being curtailed for a period. The Executive’s 2015-16 budget explained “The Department [of Health]’s budget does not allow the funding of new service developments in 2015-16 across a number of areas...including National Institute of Clinical Excellence (NICE) drugs and specialist services.”¹²¹ This has led to NI patients missing out on the latest available treatments – clearly impeding delivering the best possible outcomes for patients.

5.3.2 INDIVIDUAL FUNDING REQUESTS

Individual Funding Requests (IFRs) are the mechanism by which patients apply to access drugs which have not been approved by NICE and therefore are not routinely commissioned. IFRs are not limited to cancer treatments but are an important avenue for people suffering from rarer cancers. The criteria to assess IFRs are as follows:¹²²

- The patient’s clinical condition represents an unusual or rare circumstance and one likely to occur very infrequently;
- The treatment requested is a new or developing treatment not normally commissioned by the HSCB;
- The treatment is commissioned or funded in NI in certain circumstances but not applicable to the circumstances that apply to the IFR;

- For any other reason, the treatment may not be commissioned or funded in NI.

According to an official, the process does allow for the use of discretion:

“...If NICE are looking at something, but it is some way off before we would expect a recommendation either to use or not to use, the commissioners have the discretion to look at other sources of information across the UK. And in that regard we might look at what the [Scottish Medicines Consortium] are doing or the All Wales group, or others. But that is much more discretionary rather than a formal relationship.”

The DHSSPS undertook an evaluation of the IFR process in late 2014 in response to “concerns that [it] was not meeting its objective of providing access to unapproved specialist drugs where there is an agreed clinical need.”¹²³ The evaluation identified a number of concerns.

Firstly, in the previous three years nearly 98% of IFRs were approved at the HSCB level. However, applications first have to be approved by Trusts and there is no data on applications and approvals at Trust level. Secondly, it noted a lack transparency over the process by which Trusts make IFR decisions: only the Belfast Trust has a formal scrutiny process. Thirdly, NI’s definition of exceptionality, that a patient’s clinical circumstances are different to at least 95% of patients with the same condition, was found to be “significantly more stringent than that used in England, Wales or Scotland.”¹²⁴

The evaluation made a number of recommendations for how the system should be improved. This included the introduction of a Specialist Medicines Fund financed by the reintroduction of prescriptions charges in NI (which were abolished in 2010). This recommendation was rejected but in December 2015, Simon Hamilton, then the Minister for Health, announced that three of the report’s recommendations, below, would be taken forward:¹²⁵

1. The existing exceptionality criteria should be amended to remove the reference to 95%.
2. The establishment of regional scrutiny committees should be considered to ensure all IFR applications are subject to consistent clinical input and peer review.
3. The existing IFR guidance should be revised to include greater transparency.

The Minister announced the establishment of a task and finish group to implement the changes. We also think it would be valuable to improve the data available on IFR applications at Trust level.

5.4 ACCESS TO CLINICAL TRIALS

Medical research, of which clinical trials are an integral part, is critical to improving cancer outcomes. It has been shown that patients who receive treatment in research active environments achieve better results than others who do not.¹²⁶ In NI, however, there is evidence to suggest that patients are not being offered the opportunity to participate in clinical research as frequently as in other places. The 2014 peer review report highlighted this concern;¹²⁷ and stakeholders we interviewed suggested it was variable across NI:

“...Part of the issue...[is] the cancer units are staffed by peripatetic oncologists... And

while they would have a good cancer trial infrastructure within the cancer centre, the infrastructure's not quite the same within the cancer units. And we need to do a major piece of work with triage nurses [about] just having the concept of recruitment [to] trials across the network in Northern Ireland, as opposed to just in the cancer centre."
(Lead clinician)

Another interviewee raised concern that patients' future participation in clinical trials may be hampered. This is because some trials require that participants have previously taken a particular drug. If that drug is not available, or there is delay in patients accessing it, this may hamper NI patients' eligibility for trials:

"...We are told by people in our clinical trials department that it is going to impact even on clinical trials being available in Northern Ireland because a lot of the clinical trials before you're eligible, you have to have tried drug A, B and C but if drug C isn't available in Northern Ireland then you'll not get on to the trial." (Third sector interview)

In light of these findings, we think it is important that the NI Executive sets a clear ambition to increase opportunities for patients to participate in clinical trials. A review to understand barriers to establishing and running clinical trials in NI would be a beneficial first step.

5.5 LOCATION OF SERVICES

The practicalities of undertaking cancer treatment can be difficult for patients. Because some treatments have to be administered in instalments patients are often required to frequently attend a centre over a period of several weeks. This can lead to long travel times.

Interviewees for this project did not identify travel and transport issues as a major barrier for patients in NI. Radiotherapy, where provision is centralised in Belfast, was recognised to be an exception. One interviewee, for example, conceded that some patients will face more difficulty than others but argued that generally geography was not a significant impediment in NI:

"There will always be an issue about elderly, or people with multiple comorbidities, travelling to any unit. But we have a wide geographic spread of five cancer units across Northern Ireland now. I don't think people are particularly disadvantaged, apart from access to radiotherapy." (Lead clinician)

The opening of a radiotherapy centre at Altnagelvin, in the West of NI, in autumn 2016 should help to reduce travel times for patients who live outside Belfast. It would be beneficial for the NI Executive to undertake work to understand patients' views on the location of services.

5.6 WORKFORCE ISSUES

Workforce planning is the responsibility of the NI Department of Health but Trusts have autonomy over local staffing arrangements. Interviewees for this project suggested that there is a general difficulty in attracting medical staff to NI. Beyond that, they suggested different Trusts face distinctive workforce challenges:

"The Belfast area tends to be protected as that's where people go to university, to

settle and live. Other Trusts have different challenges around recruitment. Regionally in Northern Ireland we seem to have shortages of oncologists, shortages of haematologists and shortages of radiologists. We seem to have a lot of surgeons. But radiologists, oncologists and haematologists would be our main concern.” (Lead clinician)

Workforce statistics confirm a varied picture across NI: at the end of March 2015, Trusts’ medical vacancy rates varied from 2% to 13%.¹²⁸ Interviewees suggested that Trusts should have greater input into the workforce planning process. They reasoned that it is difficult for a regional body to be sufficiently conversant with local complexities.

Several categories of medical staff, including CNSs and oncologists, were identified as problematic. NI’s 2014 census of hospital-based CNSs found that numbers had not kept pace with growth in cancer patient numbers, having risen only 2% (from 56 to 57) since 2011.¹²⁹ Consequently, staffing gaps identified in 2011 had increased. The HSCB’s 2015/16 Commissioning Plan states that “work is currently underway to develop a robust and sustainable plan for specialising nursing expertise to support people with cancer.”¹³⁰

During 2015 the HSCB worked to roll out an Acute Oncology Service across all cancer units, with the goal of improving the management of cancer patients and reducing unplanned admissions. Interviewees, however, suggested the introduction of this service did not account for a shortage of oncologists:

“...We don’t have enough oncologists, but they’ve commissioned acute oncology in six different sites in Northern Ireland. So it’s single handed practitioners and it just goes against the grain. If somebody’s going to arrive at a unit for acute oncology reasons, they need to be in a unit that is capable of delivering the totality of care.” (Lead clinician)

Workforce is critical to the provision of high quality cancer treatments. We heard concerns about a number of categories of workforce. On that basis, we recommend the NI Executive review the current state of the cancer workforce. This work should identify areas of shortfall and lay out options to fill these in the coming years.

5.7 TREATMENT PATHWAYS

Interviewees explained that NICaN has played a positive role in bringing practitioners together to shape treatment pathways and achieve greater consistency across NI. However, we heard that some specialisms have made greater progress than others:

“...The Northern Ireland Cancer Network has the various tumour site-specific groups and that has been bringing uniformity to the treatments and follow-up as well. The breast group are well organised, the upper GI are getting more organised. Some of the other ones are... further behind.” (GP)

Another explained that standardisation can require concentration of services in fewer sites and this sometimes meets resistance:

“...We only deliver breast cancer treatment where there is a screening unit which is the ideal situation. But that’s not the situation as I say for colon cancer or for prostate

cancer, and for a range of other cancers where small more generalist...units are still dabbling in care, so that probably needs to stop. The difficult thing is we're stopping something in the NHS. It's very easy to increase things and it's very difficult to stop things." (Lead clinician)

This was attributed to some surgeons wishing to retain their involvement in cancer surgery despite there being relatively low volume in some areas. Another interviewee, involved in pathway development since the late 2000s, however, was more positive. They argued that there had been 'inherent resistance to change' but that this had dissipated over time.

Arrangements to centralise specialist surgery at Belfast were made "before we had cemented pathways for patients." One interviewee highlighted the consequence of this is some pathways remain quite fragmented:

"That has improved over the years, but people have to go up to Belfast. They may be diagnosed locally then have local staging. But then they have to go up to Belfast for PET scanning. There's only one PET scanner in Northern Ireland and that would determine whether they're fit for surgery by and large. And then they have to go back up again for surgery in a regional unit and capacity is limited. So some of these cancer centres' pathways are a bit disjointed and slow." (Lead clinician)

5.8 SUMMARY

There are three key categories of cancer treatment: surgery, radiotherapy and drugs. A lack of publicly available data means it is difficult to reach an accurate assessment of whether patients in NI are receiving the best possible treatments. This should be a priority for the NI Executive.

The people we interviewed for this research highlighted issues in accessing cutting-edge medicines in NI. Respondents believed that access to new cancer drugs was poorer in NI than in England but that the difference was diminishing more recently. Changes to the way NICE assesses cancer drugs following reform of the Cancer Drugs Fund require attention as this will impact on drug approvals in NI.

A review of the IFR system made welcome recommendations to improve transparency and consistency between Trusts. We hope that more data on IFR requests will be made available to ensure the system is working effectively.

Patients' access to clinical research was identified as inconsistent.

In relation to workforce, NI faces a general challenge in attracting medical staff. More specifically, shortages in clinical nurse specialists and oncology were highlighted. Further work is required to understand where additional capacity is needed to ensure treatment services can cope with rising demand.

RECOMMENDATIONS

- 7. The Department of Health should develop national datasets for chemotherapy and radiotherapy activity to help better understand access to these types of treatments. Further data on the success of IFR requests at the local level is required.**
- 8. The Department of Health should set a clear ambition to increase the opportunities for patients to participate in clinical research. To support this, it should conduct a review to identify current barriers to setting up and running clinical trials.**
- 9. The Department of Health should review workforce capacity in treatment services to understand where there are shortfalls in staff and set out how these will be addressed.**

6: CONCLUSION AND RECOMMENDATIONS

In 2014, around 8,900 people were diagnosed with cancer in NI. That number is set to rise over the coming years. Projections suggest there will be over 14,000 cases a year by 2035. Cancer services will need to cope with significant increases in demand for diagnostic and treatment services.

Outcomes for cancer patients have been improving over time. Today more than 70% of patients will survive their cancer for one year; around 54% will survive for five years. Cancer Research UK believes these outcomes can be improved significantly. Within 20 years three in four cancer patients can be living ten years after a diagnosis. Achieving this type of improvement will require concerted action.

NI's most recent cancer strategy dates from 2008; while it was followed by the 2011 Services Framework, it has not been updated since. Much has changed in the intervening period, including refinements to how the health service operates. In the coming months further changes to NI's healthcare system are expected. Commissioning will be reorganised and frontline provision may follow.

These changes present an opportunity for NI to reassess how it provides for cancer patients. We recommend the Executive uses this moment to reassess and develop a new comprehensive cancer strategy. The challenge is to continue improving outcomes for patients while meeting rising demand for cancer care.

This report has explored a range of sources to understand the current performance of cancer services. It offers a mixed picture. The patient experience survey shows very strong results. However, other indicators, including performance against waiting time standards, suggest the health service is struggling to effectively meet demand. This is leading to patients waiting longer for treatment and negatively impacting on their prospects.

A new cancer strategy for NI should take action across the breadth of the patient pathway – and before. Further investment in awareness raising should be made. Diagnostic capacity will need to be assessed with a view to diagnosing cancers early and reducing patients' waiting times. In relation to treatments, performance would benefit from improved data collection; and a review of the workforce required to deliver truly effective services.

The development of a new strategy would allow each of these areas to be explored, resource to be committed and change instigated. We make recommendations below outlining the measures we believe would be beneficial.

RECOMMENDATIONS

1. The NI Executive should develop a new comprehensive cancer strategy, which sets ambitious goals and allocates sufficient resource to ensure cancer services can improve outcomes, meet rising demand and reduce variation in care. The strategy should ensure strong clinical leadership for cancer services and clarify how these services will be commissioned within the reformed NI health service. It should also set measurable targets to reduce cancer incidence, improve survival and better support the growing number of patients living with cancer. Particular attention should be afforded to cancer types with poor outcomes and variation across demographic groups, including men. We suggest the following targets:
 - One-year survival should reach 75% by 2020.
 - Five-year survival should reach 58% by 2020.
2. The Department of Health and Trusts should undertake work to clarify why operating standards for cancer are not being met. Based on that, the Department should provide investment to ensure they are met in the future. The Department should also consider broadening the 14-day operating standard to cover all cancer types.
3. The Public Health Agency should fund and continue to undertake the Cancer Patient Experience Survey on a regular basis. Its findings should be used to support ongoing evaluation and improvement.
4. The Public Health Agency should continue funding the *Be Cancer Aware* programme and look to expand it. The programme should be developed to target different types of cancer and hard to reach groups.
5. The Department of Health should undertake an urgent review of the state of direct access to diagnostic tests for GPs and capacity needs in diagnostic services. It should make the necessary investment to ensure diagnostic services can meet rising demand.
6. The Department of Health should explore the potential for new service models to support diagnosis, for example multi-disciplinary diagnostic centres to help diagnose cancer cases swiftly where symptoms may be vague.
7. The Department of Health should develop national datasets for chemotherapy and radiotherapy activity to help better understand access to these types of treatments. Further data on the success of IFR requests at the local level is required.
8. The Department of Health should set a clear ambition to increase the opportunities for patients to participate in clinical research. To support this, it should conduct a review to identify current barriers to setting up and running clinical trials.
9. The Department of Health should review workforce capacity in treatment services to understand where there are shortfalls in staff and set out how these will be addressed.

APPENDIX ONE: METHODS

We used four principal methods to inform our work, drawing on Cancer Research UK's 2012 publication, *'Cancer Services: Reverse, Pause or Progress?'*¹³¹

1. Interpretation of publicly available quantitative datasets.
2. Cancer policy review. The period 1999-2014 was chosen because it encompasses the effects of major policies and coincides with the period of devolution.
3. Description of structures of health and social services and cancer leadership in each country.
4. Stakeholder interviews. These were structured telephone interviews.

INTERPRETATION OF DATASETS

We obtained data on cancer incidence, survival, mortality and prevalence, 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 of 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 treatments 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 time targets) have important roles that need to be described.

DESCRIPTION OF STRUCTURES AND LEADERSHIP

We described the structures of cancer services and considered the role of major charitable and patient-representative groups.

STAKEHOLDER INTERVIEWS

Our stakeholder interviews were the main source of reflections on how effectively policies to achieve early diagnosis and access to treatment are operating. Telephone interviews are relatively inexpensive and facilitate access to geographically disparate participants.

An interview schedule was used (appendix two). For the sample, we identified a wide range of individuals, 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 23 stakeholders contacted in NI we were able to interview eight; four individually and the remaining four in a group. The response was disappointing and we are unable to present the range of perspectives for which we had hoped.

Interviews were kept 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.

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 not necessary.

APPENDIX TWO: INTERVIEW SCHEDULE

The schedule is based on five key questions. Alongside each question is a list of possible prompts which may be used. These will also serve as a checklist following the interview to ensure that we are getting adequate information.

Introduction

- ☐ *Introduce myself*
- ☐ *Check that information note received*
- ☐ *Policy evaluation in three countries*
- ☐ *Focus is on early diagnosis, access to treatment and leadership*
- ☐ *Interview responses will be confidential – quotes used in the report will not be attributed*
- ☐ *OK to use voice recorder?*

Please tell me a bit about yourself:

- 1. What is your current role and what are your main responsibilities?**
- 2. How long have you been in post?**
- 3. What have you done previously? (other relevant experience)**

Early diagnosis

| | |
|---|---|
| 4. What progress do you think is being made, what problems can you identify and how widespread do you think they are? | In your experience how is this problem being dealt with on the ground? |
| Areas of interest: <i>Public awareness re. symptom recognition</i> <i>Access to primary care</i> <i>GP willingness to investigate and refer</i> <i>Primary care direct access to diagnostic tests</i> <i>Waiting times for diagnostic tests and for reporting of diagnostic test results</i> <i>Diagnostic capacity</i> | Are improvements being made in this area of practice? If so, what are they and is the pace of change appropriate? |
| | Other improvements that could be made (in this area of practice) |
| | Barriers to improvements being made |
| | Changes such as reorganisation or introduction of a new system that have had an impact on this problem (positive or negative) |
| | Part played by regional and local policies, targets, guidelines and standards |

Access to treatments

| | |
|---|--|
| 5. What particular issues are there around access to the range of cancer treatments such as radiotherapy, chemotherapy, surgery? Can you identify any problems and indicate how widespread you think they are? | In your experience how is this problem currently dealt with on the ground? Are improvements being made in this area? If so, what are they? |
| Areas of interest: <i>Standard vs advanced radiotherapy</i> <i>Funding</i> <i>Formulary</i> <i>Location of services</i> <i>Staffing and skills</i> <i>Access (having to apply to Trust for approval/requiring an IFR application etc)</i> <i>Capacity (eg in RT services, surgery etc)</i> | Other improvements that could be made (in this area of practice) |
| | Barriers to improvements being made (individual or structural) |
| | Changes such as reorganisation or introduction of a new system that have had an impact on this problem (positive or negative) |
| | Part played by regional and local policies, targets, guidelines and standards |

6. Does access to high-quality treatment vary across the country? If so, what variations are you aware of? What might be the underlying causes?

Areas of interest

Remote and rural areas – transport issues

Access to clinical trials – policy and practice

Policy and leadership

We're interested in your view of how cancer services in general are influenced by policy and leadership at regional; and local levels.

| | |
|---|---|
| 7. What or who has the greatest influence on cancer services in your view and why? | Effectiveness of coordination at Northern Ireland level |
| PROMPTS <i>Do you think you are well informed about new plans, policies etc?</i> <i>Are you able to offer comments on any new plans/policies etc and have your input be heard?</i> | Effectiveness of local coordination |
| 8. What do you see as the main issues and challenges facing cancer services in Northern Ireland at present? | |

END

THANK YOU – IF YOU WANT TO ADD ANYTHING LATER FEEL FREE TO EMAIL ME

APPENDIX THREE: CANCER SERVICE FRAMEWORK STANDARDS APPLICABLE TO ALL CANCER TYPES

| Standard | Key Performance Indicators | Anticipated Performance Level |
|---|--|--|
| Standard 20: All patients who have high clinical suspicion or have a diagnosis of cancer should have their care managed by an appropriately constituted and effective multidisciplinary team (MDT) which meets weekly or fortnightly (in accordance with the manual of Cancer Services Standards) | <p>Percentage of people with high clinical suspicion of / diagnosed with cancer who are discussed at an MDM</p> <p>Percentage attendance by individual core members or their agreed cover at the multidisciplinary meetings</p> <p>MDT performance against MDT measures outlined in the Manual for Cancer Services Standards</p> | <p>March 2011 – 95%</p> <p>March 2012 – 98%</p> <p>March 2011 – 66%</p> <p>Baseline to be established Implementation to be phased commencing with breast, lung, gynaecological and colorectal teams in 2010. Trusts to evidence action against peer review recommendations</p> |
| Standard 21 All patients should be assessed by a clinical nurse specialist (CNS) at the time of diagnosis, at the end of each treatment episode and as required throughout their cancer journey | Percentage of patients having a comprehensive assessment by a clinical nurse specialist at diagnosis | <p>March 2011 – Establish baseline</p> <p>March 2013 – Provisional target of 90%, dependent on baseline</p> |
| Standard 22 All patients being offered treatment should be given a realistic and meaningful explanation of the aim of their proposed treatment by appropriately skilled specialist health professionals. This will also be communicated to other | Percentage of patients whose treatment intent is recorded in the CaPPs system | March 2012 – 90% |

| | | |
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| professionals involved in their care | | |
| Standard 23 All patients who need systemic cancer therapy (i.e. chemotherapy and hormone therapy) should have aspects of their therapy provided closer to home in line with regional chemotherapy standards, where their treatment and disease allows this | <p>Development of CMGs and care pathways for systemic treatments</p> <p>Activity figures</p> | <p>March 2011 – CMGs and care pathways developed for breast, lung, upper gastro intestinal, colorectal, urological, gynaecological, skin & haematological cancers</p> <p>March 2012 – Annual improvement from zero baseline</p> |
| Standard 24 All patients with cancer who require radiotherapy should have equitable and timely access to complex radiotherapy techniques in line with tumour group specific recommended best practice | <p>Development of cervical brachytherapy service</p> <p>Percentage of eligible patients for radical treatment for cervical cancer who choose to receive high dose rate brachytherapy and who have access to it</p> <p>Development of prostate brachytherapy service</p> <p>Percentage of eligible patients with localised prostate cancer who want to have high dose rate brachytherapy and who have access to it</p> <p>Development of IMRT service</p> | <p>March 2010 – Establish service</p> <p>March 2011 – 100%</p> <p>March 2010 – Establish service</p> <p>March 2011 – 100%</p> <p>March 2011 – Establish baseline</p> |
| Standard 25 As a safety measure, all radiotherapy treatment plans should be checked for accuracy by a second person from an | Percentage of radical and adjuvant radiotherapy plans that are checked for accuracy by a second member of the team before | <p>March 2011 – 66%</p> <p>March 2012 – 75%</p> <p>March 2013 – 85%</p> |

| | | |
|---|---|---|
| agreed list of staff before treatment begins | treatment begins | |
| Standard 26 All patients who are eligible for an existing clinical trial should be offered the opportunity to take part in a clinical trial by the multidisciplinary team | Percentage of patients entered into clinical trials | <p>March 2011 – 10% of patients entered into trials with at least 5% of patients entered into randomised controlled trials for 2010/11</p> <p>March 2012 – At least 10% of patients entered into trials with at least 6.75% entered into randomised controlled trials for 2011/12</p> <p>March 2013 – At least 10% of patients entered into trials with at least 7.5% into randomised controlled trials for 2012/13</p> |

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