



WHERE NEXT FOR CANCER SERVICES IN WALES?

AN EVALUATION OF PRIORITIES TO
IMPROVE PATIENT CARE

ACKNOWLEDGEMENTS

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

The project was produced by a working group comprising David Morrison, Gill Hubbard, Charlotte MacDonald, Richard Neal and Conan Donnelly. Annie Hendry and Tania Dawn Seale conducted all Wales stakeholder interviews. Vincent Marmara produced all graphs from data provided by the Welsh Cancer Intelligence and Surveillance Unit. Charlotte MacDonald developed the telephone questionnaire, identified the sample of stakeholders and conducted a thematic analysis of all interviews

David Morrison and Gill Hubbard designed the study and wrote the report with Charlotte MacDonald. Rob Jones provided comments on drafts of the reports.

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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 2014/15 we spent £434 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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LIST OF ACRONYMS

ACE	Accelerate, Coordinate and Evaluate Programme
AWMSG	All Wales Medicines Strategy Group
AWTTC	All Wales Therapeutics and Toxicology Centre
CaNISC	Cancer Network Information System Cymru
CDP	Cancer Delivery Plan
CIG	Cancer Implementation Group
COSC	Clinical Oncology Sub Committee
HIW	Healthcare Inspectorate Wales
HQIP	Health Quality Improvement Partnership
ICBP	International Cancer Benchmarking Partnership
IPFR	Individual Patient Funding Request
LHB	Local Health Board
MDC	Multidisciplinary Diagnostic Centres
MDT	Multidisciplinary Team
NICE	National Institute for Health and Care Excellence
NSAG	National Specialist Advisory Group
NWIS	National Wales Informatics Service
SACT	Systemic Anti-Cancer Therapy
SEA	Significant Event Analysis
WCISU	Welsh Cancer Intelligence and Surveillance Unit
WHSSC	Welsh Health Specialised Services Committee

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EXECUTIVE SUMMARY

Incidence of cancer is rising, with one in two people born after 1960 expected to be diagnosed with cancer in their lifetime.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 more² – UK cancer survival remains lower than in Australia, Canada, and several comparable European countries.^{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 ten years. Having high quality NHS cancer services across the UK is crucial if we are to reach this goal.

Cancer Research UK therefore commissioned the Institute of Health and Wellbeing at the University of Glasgow to explore the 'state' of cancer services in Wales, Scotland and Northern Ireland. This report presents findings on Wales and our ambition for the shape of cancer services going forward.

A NEW CANCER STRATEGY FOR WALES

Cancer strategies are a vital tool to improve outcomes. They set direction and make the best use of resources over a defined time period to reduce cancer incidence and mortality, and improve survival.

Since 2012, cancer services in Wales have been guided by the Welsh Government's 'Cancer Delivery Plan' (CDP). This strategy comes to an end in 2016 and a successor is being developed.

Developing a new cancer strategy provides an opportunity to deliver better outcomes for patients in Wales. As the number of cancers diagnosed rises, so does demand on the health service. It is therefore critical that the Welsh Government capitalises on this opportunity and ensures the new strategy considers all elements of cancer services and sets out ambitious goals for the coming years to ensure the NHS can meet the needs of patients.

THE CANCER LANDSCAPE

Over 19,100 people in Wales were diagnosed with cancer in 2014.⁵ This has risen from around 16,800 in 2005, representing an average annual increase in cases of 1.5%.⁶ The annual number of cancer cases diagnosed in Wales will continue to rise. It is estimated that the number of new cases diagnosed in Wales every year will soon reach 20,000 cases.⁷ An ageing population is driving this, in part, but preventable risk factors such as smoking are also contributing.⁸

Breast, prostate, lung, and bowel cancers together account for 53% of diagnoses in 2014.⁹ They are also the most common cancers worldwide.¹⁰

Cancer incidence also varies across Wales. For example, the incidence rate among the most deprived quintile of the Welsh population is 23% higher than among the least deprived.¹¹

Cancer survival in Wales is improving. Just over 70% of people diagnosed with cancer are now living for one year; five-year survival has reached 54%.¹² However, this varies significantly by cancer type – pancreatic and liver cancer, and acute myeloid leukaemia, proving the lowest with relative one-year survival rates of less than 30%.¹³

NHS STRUCTURES, POLICIES AND LEADERSHIP

In 2014-15, the Welsh Government spent around £5.8 billion on healthcare.¹⁴ Of this, approximately 7.1%, was devoted to 'cancer and tumours' equating to about £132 per head of population.

A dedicated leadership structure is in place to oversee cancer services. The Cancer Implementation Group (CIG) has strategic oversight of CDP implementation; the National Specialist Advisory Group for Cancer (NSAG) provides clinical input and Local Health Boards (LHBs) plan and deliver services at the local level. Until 2016, there were also two regional cancer networks to facilitate coordination between LHBs and Trusts.

From 2016 a new leadership structure will be in place, intended to improve coordination. The two cancer networks are becoming a single network, the Wales Cancer Network.¹⁵ This will advise the CIG on priorities, be responsible for implementation of the new cancer strategy and report annually on national progress.

Our research found support for reforming the leadership of cancer services. The new structure should support stronger national leadership and collaboration across LHBs.

RECOMMENDATIONS

- 1. The Welsh Government should develop a comprehensive strategy for cancer which sets ambitious goals and allocates sufficient resource to ensure cancer services can improve outcomes while meeting rising demand and reducing variation in care. Measurable targets should be set 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. We suggest the following targets:**
 - One-year survival should reach 75% by 2020.
 - Five-year survival should reach 58% by 2020.
- 2. The new cancer strategy must ensure that the new organisational structure for cancer services provides clear leadership and accountability mechanisms. The creation of the Wales Cancer Network is an opportunity; it should have responsibility for implementing the cancer strategy, tackling variations in care, and have authority to shape behaviour at LHB and Trust level through performance management levers.**

NHS PERFORMANCE ON CANCER

Performance data published by the Welsh Government and LHBs show that action is needed to improve cancer services.

For example, the NHS in Wales is not meeting its two cancer waiting time targets – a clear indication that the service is struggling to keep up with demand.

- The target for 95% of newly diagnosed cancer patients, referred via the urgent route, to begin treatment within **62 days** of referral has not been met since 2008.¹⁶ Performance in the last quarter of 2015 was 83.7%.
- The target for 98% of patients referred via the non-urgent route to begin treatment within **31 days** of the decision to treat was last met in 2014.¹⁷ The figures for the last quarter of 2015 show performance was 97.5%.

The 31-day wait is holding up reasonably well, but it does not capture the time it takes to diagnose patients via the non-urgent route. Poor performance in meeting the 62-day wait, compared to the 31-day wait, therefore indicates that patients are experiencing delays in being diagnosed.

The Welsh Government is piloting a 'single pathway' approach to record waiting times from the point of suspicion of cancer.¹⁸ It has committed to roll this out nationally but progress has been slow.

The stage of cancer at the point of diagnosis in Wales shows scope for improvement. Recording the stage at the point of diagnosis as improved from around 50% in 2012¹⁹ to almost 75% in 2014.²⁰ But progress on diagnosing patients earlier has been relatively limited – the proportion of cancer patients diagnosed at stage four only improved by two percentage points from 21% in 2012 to 19% in 2014.²¹

The 2013 Wales Cancer Patient Experience Survey offers a broadly positive assessment of cancer care in Wales.²² Eighty nine per cent of patients described their care as either excellent (58%) or very good (31%). But it also highlights areas for attention, for example variation in experience, based on location and cancer type, was also prevalent.

RECOMMENDATIONS

- 3. The Welsh Government should review the metrics it uses to evaluate the performance of cancer services. The new strategy should develop metrics, which provide insight into performance throughout the cancer pathway. The following measures of performance should be considered:**
 - The proportion of patients seen by a consultant within 14 days of referral from general practice.
 - The proportion of patients receiving a definitive diagnosis within 28 days of suspicion of cancer.
 - The proportion of patients commencing treatment within 14 days of a decision to treat.
- 4. The new strategy should move to consistently reporting waiting times from the point at which cancer is suspected; this would more accurately reflect patients' experience. The national roll out of the single pathway should be a priority for the new strategy.**
- 5. The strategy should introduce a target to reduce the number of cancers diagnosed late, at stages three and four, and increase the proportion diagnosed at stages one and two. Since 2012, data completeness of stage at diagnosis has improved; the new strategy should set targets to continue this improvement.**

EARLY DIAGNOSIS

Early diagnosis is critical to improving patient outcomes. For example, when bowel cancer is diagnosed at stage one around 90% of patients survive ten years compared to just 5% for those diagnosed at stage four.²³

The CDP identified early diagnosis as a priority. Our research identified several areas for improvement that should be reflected in the new strategy.

The Welsh Government has been less active in educating the public about cancer than other

UK nations. A major public awareness campaign in Wales, focused on the signs and symptoms of lung cancer, is scheduled for summer 2016. Based on the outcomes of that, further initiatives to raise public awareness should be considered.

Access to primary care can be problematic. Thirty seven per cent of respondents to the 2014-15 national survey for Wales said it was 'fairly difficult' or 'very difficult' to get a GP appointment in the previous 12 months.²⁴ Access can also be more difficult in less affluent areas, where recruitment and retention of primary care staff can be challenging. A new contract for GPs in Wales, introduced in 2014, may help to improve this situation.

Performance against waiting times targets suggest that issues with diagnostic capacity are delaying some patients receiving a definitive diagnosis and therefore starting treatment. In addition, our research suggests there is variation in GPs' direct access to diagnostic tests. Further investigation is needed to understand the workforce and equipment capacity needed to meet demand.

The rise in cancer incidence, as well as NICE's decision to lower the threshold of referral for suspected cancer²⁵ will increase demand for investigative tests in the coming years. New approaches to achieving early diagnosis being tested in other countries could support improvement. The Accelerate, Coordinate and Evaluate (ACE) programme in England, for example, may have findings relevant to the new strategy.

RECOMMENDATIONS

- 6. Public Health Wales should consider further public cancer awareness campaigns following an evaluation of the 2016 lung cancer campaign.**
- 7. The Welsh Government should conduct an urgent review of the state of direct access to diagnostic tests for GPs. It is vital that the next strategy should ensure there is sufficient resource committed to diagnostic services – both equipment and workforce – to meet rising demand and to support GPs consistently implementing NICE referral guidelines.**

ACCESS TO TREATMENTS

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

Cancer drugs, radiotherapy and surgery are the three main types of treatment. Our research gave a broadly positive assessment of them in Wales. But it also revealed areas for improvement in each category.

Concerns were raised about surgery capacity, particularly the number of surgeons and specifically related to lung cancer surgery. In radiotherapy, our research identified variation in access to cutting-edge equipment and in the time patients wait before undertaking treatment.

Long travel times and variable support to help patients' access treatment centres were thought to delay some patients from starting treatment. In addition, patients in North Wales are routinely referred to cancer services in England, which produces unique geographic differences in access to care.

Concentration of some services was recognised to support high-quality treatment. But better strategic planning and coordination to provide more equitable access is needed. A national

body to oversee and set standards for specialist cancer services would support this.

Concerns were raised that LHBs discretion over funding approved cancer drugs has led to variation in access for patients. In addition, the Individual Patient Funding Request process, which provides access to unapproved drugs for some patients, is slow; and decisions, which are made by LHBs, are not consistent across Wales.

Developments in drug policy in England demand consideration. The Cancer Drugs Fund, which provided access to non-NICE approved drugs and which Wales did not emulate, is now being incorporated into NICE's appraisal process. Given Wales generally follows NICE decisions, it is important to consider how these reforms will impact on budgets and patient access in Wales.

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

RECOMMENDATIONS

- 8. The Welsh Government should reconsider its 2014 decision and introduce a national decision-making panel for Individual Patient Funding Requests to improve consistency. The new strategy should also outline how Wales will ensure access to cutting-edge treatments is maintained as NICE processes are amended following reform of the Cancer Drugs Fund in England.**
- 9. The Welsh Government should review the existing approach to commissioning specialist treatments, such as radiotherapy, chemotherapy and low-volume surgery. The new strategy should establish a national commissioning body to better plan and coordinate these services across Wales. The new strategy should also set a clear ambition to improve access to clinical trials across Wales, and detail of how this will be supported.**
- 10. The new strategy should develop a national dataset for chemotherapy and radiotherapy activity. LHBs will need to supply the information and data completeness should be reported via the annual national cancer report.**

1: THE CANCER LANDSCAPE

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

Cancer survival in the United Kingdom (UK) has been improving over time – one in two cancer patients now survive their cancer for ten years or more compared to around one in four in the early 1970s. But while improvements have been made, UK survival in bowel, breast, lung and ovarian cancer, remains lower than in Australia, Canada, and several European countries.^{26,27}

These differences are largely due to better survival at one year after diagnosis in other countries. Researchers at the International Cancer Benchmarking Partnership (ICBP) have 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 relative survival.²⁸ Improving performance in early diagnosis and access to cancer treatment is therefore a priority evident in cancer plans for the nations of the UK.

Across the four nations of the UK, there are variations in the occurrence of cancer. Wales has poorer outcomes than other parts of the UK across a range of measures. Cancer incidence in Wales (2013) was significantly higher than in England and Northern Ireland (though similar to Scotland).²⁹ Age standardised mortality (in 2014) were also significantly higher in Wales compared with England (but significantly lower than in Scotland and similar to Northern Ireland).³⁰

Furthermore, data from ICBP show that Wales had the lowest one-year survival for breast, lung, colorectal and ovarian cancer compared with England and Northern Ireland (Scotland did not participate in this study) and lower five-year survival for breast, colorectal and ovarian cancer. Not only was survival lower in Wales than in other parts of the UK, it was among the lowest of all other participating ICBP countries – Australia, Canada, Denmark, Norway and Sweden.³¹

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

Cancer Research UK has previously published work analysing the implementation of the UK's cancer strategies³² and the performance of cancer services in England.³³ 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. The report assess four aspects of cancer policy and practice in Wales:

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

Primary prevention of cancer, screening and palliative care, while vital aspects of cancer services, have not been included in this analysis. Reports on cancer services in Scotland and

Northern Ireland will be published separately.

Wales's cancer strategy, *'Together for Health: Cancer Delivery Plan for the NHS to 2016'*, comes to an end in 2016. The Welsh Government has indicated it will develop a successor plan over the summer in 2016. The Welsh Government therefore has an opportunity to bring forward an ambitious strategy that accelerates improvements for cancer patients.

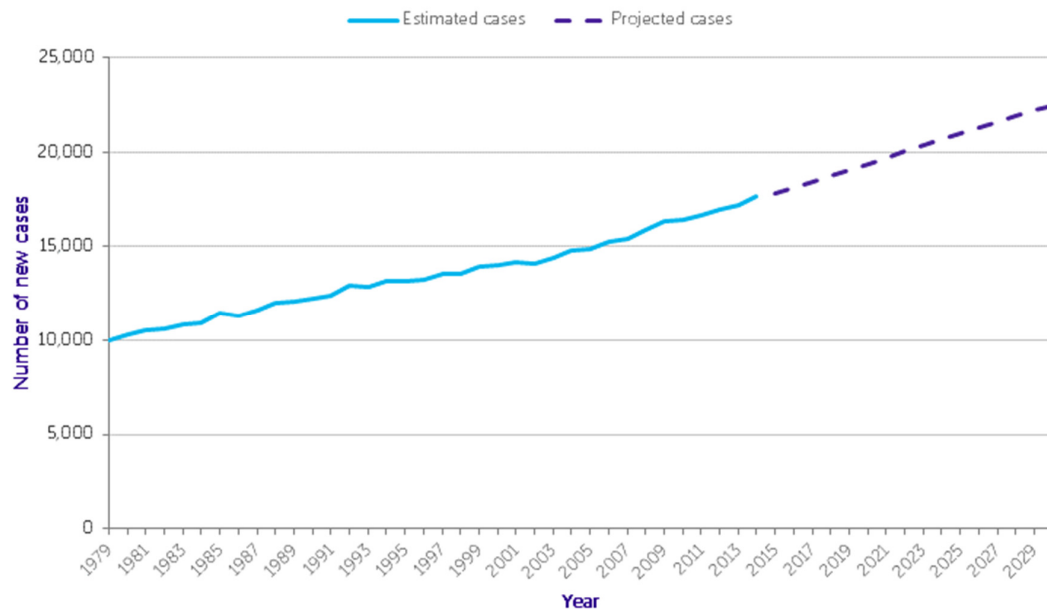
This report provides insight as to what the new cancer strategy should focus on. It brings together routine data on cancer incidence, prevalence and survival with an analysis of the existing policy architecture. An important component of the report is 15 telephone interviews with senior stakeholders – national policymakers, senior managers, clinicians and patient representatives – in Wales.¹

1.1 INCIDENCE

The incidence rate for cancer is the number of new cancers diagnosed in a specified population, usually 100,000 people, during a year. In Wales, there has been a 2% increase in cancer incidence rates over the past decade. The number of cases has also increased. In 2004 approximately 16,900 people were diagnosed with cancer and in 2014 this number was around 19,100 (Figure 1).^{34,35} Over this period, the number of cancer cases diagnosed each year has increased at approximately 1.5% per year.³⁶

It is likely this trend will continue in the years to come. It is estimated that the number of new cases diagnosed in Wales every year will soon reach 20,000 cases.³⁷

FIGURE 1: PROJECTED CANCER CASES IN WALES TO 2030²



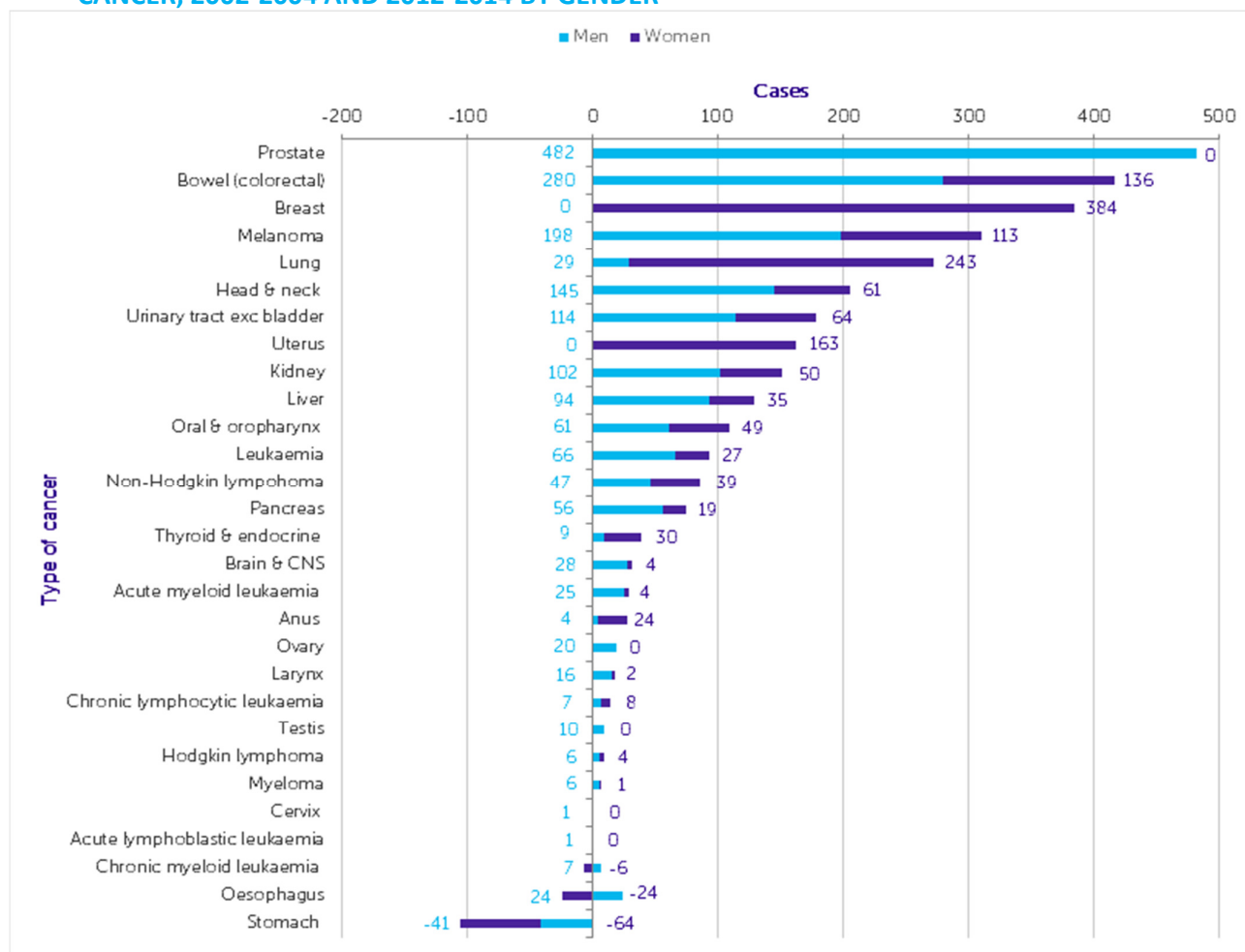
¹ Interviews were conducted between August and November 2015.

² This analysis was completed on UK level data and scaled to Wales based on the proportion of the UK population who live in Wales. The number of cases shown between 1979 and 2013 underrepresents the number diagnosed during this period, as the number of cases in Wales is higher than the UK average. Therefore the projected number of cases is likely to be an underestimate.

These increases are being driven by an ageing population and by preventable risk factors such as smoking. It is estimated around four in ten cancers are attributable to preventable risk factors.³⁸

The most commonly occurring cancers in Wales are breast, lung, prostate and bowel cancer (Figure 2). These are also the most common cancers worldwide.³⁹ In men, the most common cancers are prostate, lung and colorectal, which comprise 53% of all cancers; in women, breast, lung and colorectal cancers are most common, accounting for 54% of all malignancies.⁴⁰

FIGURE 2: CHANGE IN AVERAGE ANNUAL NUMBERS OF NEW CASES OF DIFFERENT TYPES OF CANCER, 2002-2004 AND 2012-2014 BY GENDER



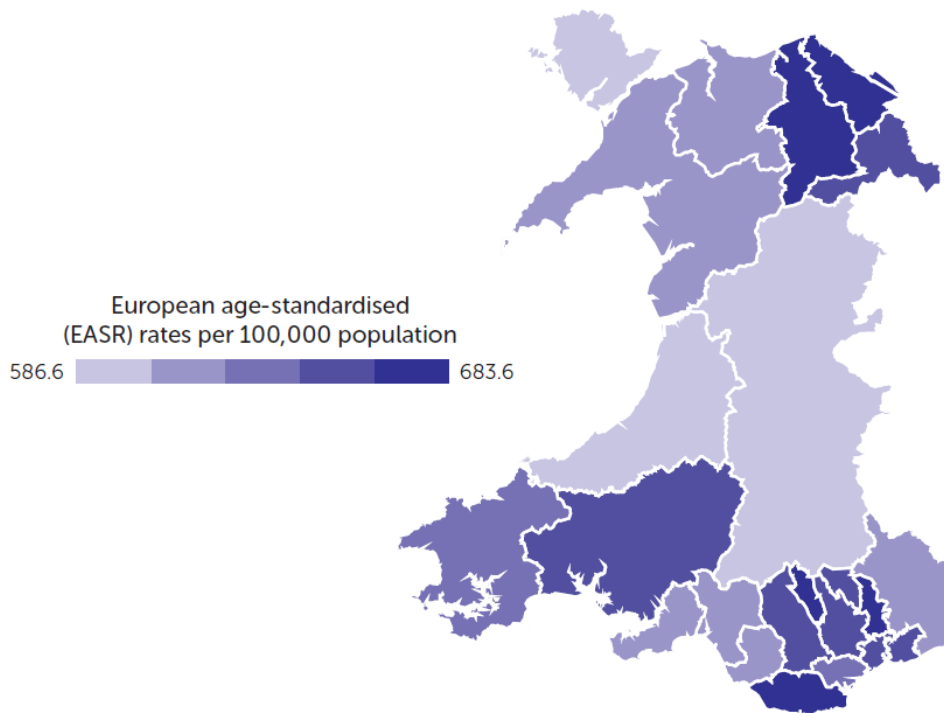
Source: Welsh Cancer Intelligence and Surveillance Unit

The total rise in new cancers between 2002-2004 and 2012-2014 comprises an increase among women but a decrease among men.⁴¹ Among men, the age-adjusted cancer incidence rate decreased by slightly more than 3% in the ten years up to and including 2014; over the same period, the rate for women increased by more than 5%. Prostate, then bowel, breast, melanoma and lung cancers had the largest average annual increases in cases over that period. In percentage terms, melanoma in men and liver cancer in women showed the largest increases. The apparent decrease in bladder cancers may be real or partly due to re-coding within this period. In women, by far the largest increase in numbers of new cancers has been

in breast cancer. Cancers of the uterus, lung and malignant melanoma of the skin have also increased.

The incidence of cancer is significantly higher among populations in socio-economically deprived areas compared to more affluent areas.⁴² There are large variations in cancer incidence between the 22 Welsh local authority areas (Figure 3), which have been partly attributed to socio-economic deprivation.⁴³

FIGURE 3: CANCER INCIDENCE, ALL TYPES EXCLUDING NON-MELANOMA SKIN CANCER, BY LOCAL AUTHORITY, 2010-2014



Source: Welsh Cancer Intelligence and Surveillance Unit

1.2 SURVIVAL

Cancer survival in Wales, as in the rest of the UK, has been improving over time but is lower than in other comparable health systems. One-year survival for across all cancers has reached just over 70% in Wales; five-year survival has reached 54%.

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.⁴⁴ Survival is frequently used as a composite indicator of health service performance. It is often expressed as relative survival – that is, the proportion of patients who survive a given length of time compared with similar people in the general population without cancer. Where relative survival is 100% this indicates that having cancer does not reduce a person's survival compared to what would be expected for an individual of the same age, sex and socio-economic group without cancer.

In common with other developed countries, women in Wales have higher cancer survival than men overall.⁴⁵ This is partly because survival from female cancers, such as breast cancer, is

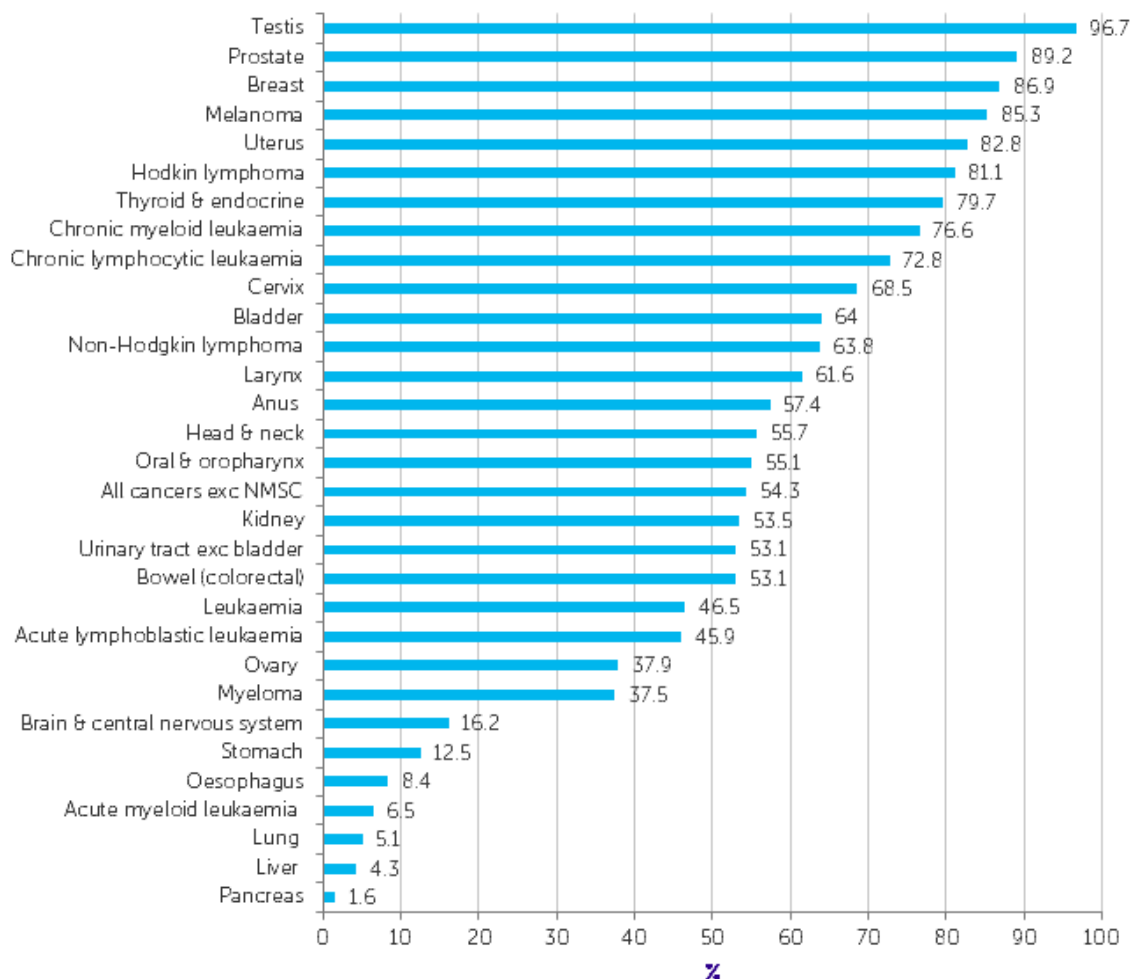
relatively good, and partly because women have better survival from cancers also experienced by men e.g. melanoma.⁴⁶ Cancer survival in Wales is poorer among patients from more socio-economically deprived areas.⁴⁷

Survival is poorest for cancers of the pancreas, liver, acute myeloid leukaemia, lung, stomach, brain and central nervous system and oesophagus. Survival is highest for cancers of the testis, prostate breast cancer, malignant melanoma, uterus and thyroid and endocrine respectively (Figure 4).

BOX ONE: EARLIER STAGE DIAGNOSIS AND SURVIVAL

Currently stage-specific survival data are not routinely published. However, where analyses have been carried out, earlier stage at diagnosis is consistently associated with better survival. The ICBP compared different methods used to classify and record stage data and recommended consistent approaches to allow better comparisons between countries.

FIGURE 4: VARIATION IN FIVE-YEAR SURVIVAL BETWEEN DIFFERENT TYPES OF CANCER 2005-2009 (%)



Source: Welsh Cancer Intelligence and Surveillance Unit

1.3 MORTALITY

In the decade to and including 2014, mortality rates in Wales have decreased overall in both sexes but the number of deaths has increased. Mortality rates from lung cancer increased in women but decreased in men, largely reflecting changes in incidence rates rather than survival. Liver cancer mortality rates increased in both sexes but the increase was larger among men.⁴⁸ Despite increases in the incidence rates for both breast⁴⁹ and bowel⁵⁰ cancer over the past decade, mortality for both fell^{51,52} because of improvements in survival.⁵³

1.4 PREVALENCE

Cancer prevalence provides a snapshot of people either living with, or surviving cancer. As the number of cancers being diagnosed increases and survival improves, the population living with cancer also grows. In 2011, 3.3% of the population of Wales had been diagnosed with a cancer within the previous 20 years.⁵⁴

Cancers with relatively high incidence and good survival are most prevalent. Among men, prostate cancer is the most prevalent, with 2,191 men in Wales in 2011 alive a year after diagnosis and 17,133 men alive up to 20 years after a diagnosis.⁵⁵ Colorectal cancers, bladder and head and neck cancers are also among the most prevalent in men. In women, breast cancer is the most common type of cancer and survival is relatively high so prevalence is high, with about 2,294 women alive up to one year after diagnosis and 26,293 alive up to 20 years after a diagnosis.⁵⁶ Colorectal, malignant melanomas and uterine cancers are also among the most prevalent in women.

1.5 SUMMARY

There has been a 2% increase in cancer incidence rates in Wales over the past decade and the number of cases has also risen. Ten years ago approximately 16,900 people were diagnosed with cancer in Wales and in 2014 this number was around 19,100. Incidence is set to increase and it is estimated that the number of new cases diagnosed in Wales every year will soon reach 20,000 cases.⁵⁷ The increase in the number of cases is largely attributable to a growing, ageing population.

Cancer incidence and survival, to some extent, both reflect socio-economic conditions. For certain cancer types, people from more deprived areas of Wales are more likely to be diagnosed with cancer and their survival outcomes are worse than those from more affluent backgrounds.

Cancer survival in Wales, as in the rest of the UK, is lower than in many comparable health systems. One-year survival has reached 70%; five-year survival is at 54%. There are variations in survival across different cancer types. Survival from cancer of the female breast, testis and prostate are among the highest. Cancers of the pancreas, lung and liver, among others, have significantly poorer survival outcomes.

2: NHS STRUCTURES, POLICIES AND LEADERSHIP

Healthcare has been a devolved policy area since 1999. The Welsh Government provides strategic leadership by setting the health outcomes it expects for the people of Wales, via an annual outcomes framework, and holding the NHS to account for delivery. The Department of Health and Social Services monitors the performance of NHS Wales against this framework. The 2015-16 outcomes framework has been presented as a new approach to doing this, focused on population outcomes rather than process measures.

The current health policy agenda in Wales is shaped by the Welsh Government's endorsement of 'Prudent Healthcare'. Prudent Healthcare aims to change the culture within the NHS, provide strong leadership, improve efficiency, reduce ineffective and inefficient care and emphasise prevention. It was first articulated in 2013 by the Bevan Commission, a group of independent experts established in 2008 to advise the minister for health.⁵⁸ The Commission consulted on its ideas in 2014 and published a final version later that year.⁵⁹ In early 2015, Mark Drakeford, the minister for health and social services at the time, publicly endorsed the approach.⁶⁰ The Welsh Government's recent primary care strategy seeks to apply these principles.⁶¹

The NHS in Wales operates through integrated health boards, planning and providing care, and makes very little use of private sector providers. There are seven Local Health Boards (LHBs) each with a regional remit, and three Trusts which provide care across Wales. Lines of accountability are via the chairs of the LHBs and Trusts to the minister for health. The chief executives of LHBs and Trusts report to the chief executive of NHS Wales who is also director general of the Department of Health and Social Services.

2.1 CANCER POLICIES AND PRIORITIES

BOX TWO: CANCER POLICY MILESTONES IN WALES SINCE 1995

- 1995** Calman-Hine Report: A Policy Framework for Commissioning Cancer Services in the UK
- 1996** The Cancer Services in Wales (Cameron) Report. Implementation of Calman-Hine
- 2005** National Cancer Standards
- 2006** *Designed to Tackle Cancer in Wales* – A Welsh Assembly Government Policy Statement
- 2012** *Together for Health, Cancer Delivery Plan for the NHS up to 2016* (the Welsh Government publishes an annual report on cancer stating its policies, priorities and achievement against performance measures – 2015 report published in January 2016)⁶²
- 2014** Report of *Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan* – Health and Social Care Committee, National Assembly for Wales

2.1.1 TOGETHER FOR HEALTH: CANCER DELIVERY PLAN

The Welsh Government's Cancer Delivery Plan (CDP) was published in 2012 and was intended to be a 'framework for action by LHBs and NHS Trusts'. It defined 'the Welsh Government's expectations of the NHS in Wales to tackle cancer' for the period 2012 to 2016.⁶³ Plans have been put in place to develop a new CDP over the summer of 2016.

The CDP focuses on person-centred care that is equitable for patients of all ages, wherever they live in Wales. The vision is for *'people of all ages to have a minimised risk of developing cancer and, where it does occur, an excellent chance of surviving, wherever they live in Wales'*, and for *'Wales to have cancer incidence, mortality and survival rates comparable with the best in Europe'*.

It focuses on a number of areas, including prevention, early detection, delivering treatment, meeting people's needs, care at the end of life, improving information and targeting research.

The CDP mandated several actions for LHBs:

- Use national profiling data of cancer prevalence, mortality and survival rates to inform targeted action on particular cancers and communities
- Raise public awareness of cancer symptoms
- Raise GP awareness of symptoms to promote rapid referrals in line with national guidance, local pathways and waiting time standards
- Work with GPs to introduce evidence-based risk assessment tools to help identify those most at risk of having cancer
- Provide GPs with direct and prompt access to diagnostic tests for cancer
- Audit the pathway for each person diagnosed with advanced cancer and act on findings to improve services for early diagnosis
- Develop acute oncology services to support the needs of people admitted as emergencies.

LHBs produced individual plans outlining how they would implement the strategy and provided updates on delivery via annual reports. The Welsh Government's annual cancer report outlined national progress.

The national reports for the CDP period, 2012 to 2015, indicate that, while cancer cases continue to rise, outcomes for cancer patients in Wales are improving. Mortality has been falling over the long term and this trend continued over the first years of the CDP period.⁶⁴ Survival is also rising: for the first time one-year survival has exceeded 70%.

More detail on the performance of cancer services is explored in chapter three. Broadly speaking, however, the evidence suggests that the CDP has supported the ongoing improvement of cancer care in Wales.

In 2014 the Welsh Assembly's Health and Social Care Committee conducted an inquiry into progress delivering the CDP.⁶⁵ While broadly supportive of the CDP's aspirations, the committee identified a number of areas for attention, including performance management, workforce and inequities in treatment. Of particular concern to the committee was the need to establish 'stronger national leadership'. The committee made a number of recommendations which the Welsh Government accepted in all but one case.

The exception was a proposal to reform the Individual Patient Funding Request (IPFR) process (discussed in chapter five). The committee requested that the Minister report back to them one year later to provide an update. The minister invited the committee to assess progress based on the annual cancer reports.⁶⁶

2.2 STRUCTURES AND LEADERSHIP FOR CANCER SERVICES

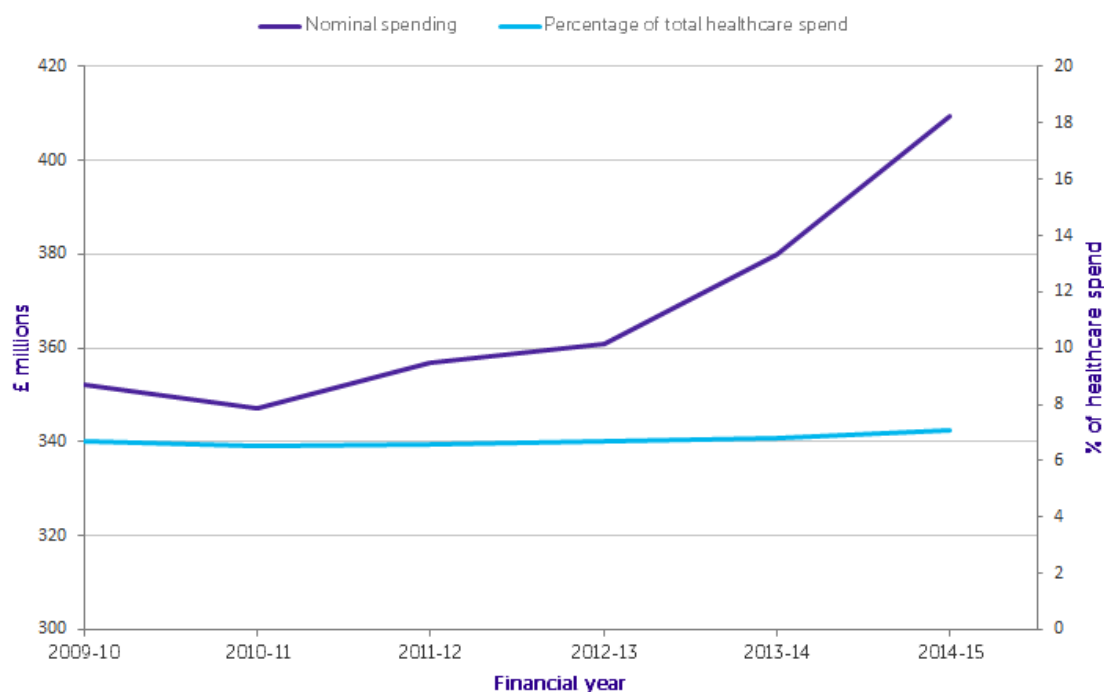
2.2.1 SPEND ON CANCER

In 2014-15 the Welsh Government spent approximately £5.8 billion on healthcare.⁶⁷ Health spending in Wales declined after 2008 but has increased since 2012-13.

In 2014-15, approximately £409 million was spent on 'cancers and tumours'; this equates to £132.40 per head of population. In 2009-10, £352m was spent on cancer and tumours and spending – in nominal terms – has risen each year since then, with the exception of 2010-11 when it fell to £347.1m (Figure 5). It is not entirely clear whether this spend covers all services associated with cancer, and further detail of the breakdown of costs would be welcome.

As a proportion of health spending, cancer has remained relatively steady at just under 7%, until 2014-15 when it rose to 7.1%.

FIGURE 5: SPENDING ON CANCERS AND TUMOURS IN NOMINAL TERMS AND AS A PROPORTION OF HEALTHCARE SPENDING, 2009-10 TO 2014-15

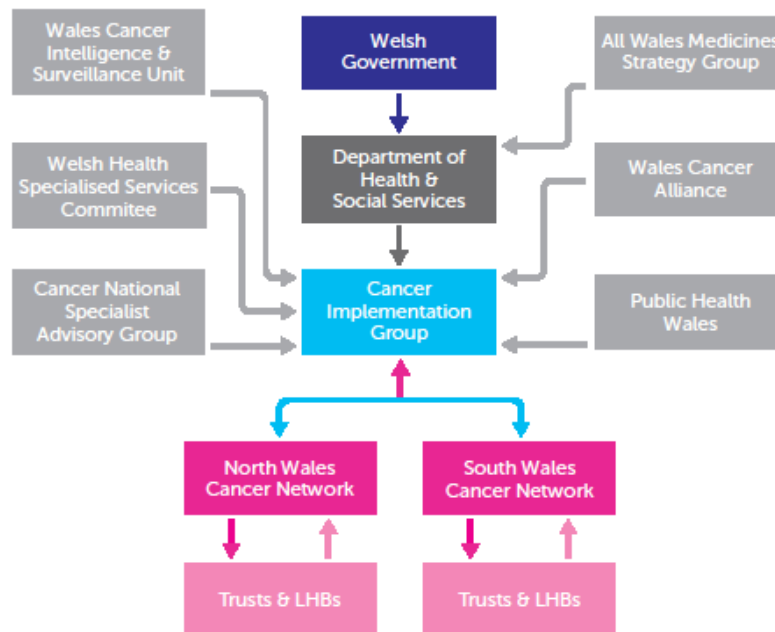


Source: Welsh Government (2016) Programme budgets 2014-15

2.2.2 NATIONAL LEADERSHIP

Since 2012 a dedicated leadership structure has existed for cancer services in Wales. A new structure for leadership was proposed in late 2015. The new structure is intended to be '*simpler and more focussed on cancer*'.⁶⁸ Below we first outline how cancer services in Wales have been organised to date (Figure 6) and incorporate interviewees' reflections on this structure. Subsequently, we provide a brief description of how the new structure will operate.

FIGURE 6: LEADERSHIP STRUCTURE FOR CANCER SERVICES IN WALES BEFORE 2016



CANCER IMPLEMENTATION GROUP (CIG)

The CIG was created to provide joined-up leadership and oversight of the CDP and to coordinate action in a strategic way. It aims to support LHBs to deliver outcomes in a consistent way across Wales, to agree how best to measure success, to facilitate the sharing of best practice, and to identify common issues and share solutions. Its membership includes the Welsh Government, representatives of the cancer networks, the LHBs and cancer charities.

The CIG agrees priorities for improving cancer services each year. For 2015-16, the priorities included:

- A lung cancer initiative – this includes a planned public awareness campaign and support for monitoring and research aiming to improve outcomes
- Delivery of a new NHS leadership structure for cancer in Wales (see below)
- Development of a new single cancer pathway for Wales, which would eventually replace current waiting time standards
- Development of a primary care oncology model

The emphasis on lung cancer was, in part, due to it being one of the types of cancer with the largest rise in cases over the last ten years (Figure 2) and there being a high proportion of late-stage presentations in lung cancer.⁶⁹

CLINICAL INPUT

The leadership structure has two key forums to facilitate clinical input. Firstly, The National Specialist Advisory Group for Cancer (NSAG) provides clinical specialist advice on cancer across Wales. It currently supports an executive group and ten cancer sub-groups³ as well as

³ Cancer Sub Groups: Breast, Colorectal, Gynaecological, Haematological, Head and Neck, Lung, Sarcoma, Skin, Upper GI, Urological cancers. <http://www.wales.nhs.uk/sites3/page.cfm?orgid=322&pid=47537>

the CIG and its sub-groups. The NSAG provides advice in response to requests from the CIG, the cancer networks and other all Wales organisations such as Welsh Health Specialised Services Committee (WHSSC) and All Wales Therapeutics and Toxicology Centre (AWTTC) for LHBs. It also attempts to keep up to date with developments in cancer treatments and initiatives in the rest of the UK. NSAG membership includes representatives of the cancer networks, charities, the royal colleges, the WHSSC and others.

Secondly, clinical guidance is developed by the Clinical Oncology Sub Committee (COSC) of the Wales Medical Scientific Committee. The COSC brings together key people from the three Wales cancer centres including medical physicists, clinical oncologists and radiographers.

SPECIALISED SERVICES

The WHSSC was set up in 2010 to replace Health Commission Wales following a highly critical review of that body.⁷⁰ The WHSSC operates as a joint committee of the seven LHBs and is responsible for planning all specialised and tertiary services for Wales. Funding is provided by the LHBs.

The WHSSC publishes protocols for the use of services it commissions including pathways for each of the regions. These currently include some cancer services, such as services for children, and certain types of radiotherapy and surgery.⁷¹ It also considers some Individual Patient Funding Requests (IPFRs) from patients with conditions that fall within its remit, while LHBs consider other IPFRs (see chapter five).

The NHS in Wales follows NICE guidance on whether a drug should be made routinely available. Wales also has its own, separate process to assess drugs, and this can sometimes reach decisions more quickly than NICE. However, once NICE has made a decision this replaces any decisions that have been made on a Wales-only basis.

The New Medicines Group (NMG), a sub-group of the All Wales Medicines Strategy Group (AWMSG), is the body that considers the clinical and cost-effectiveness of a medicine, along with written evidence from the pharmaceutical company, clinical experts in the field and relevant patient and other organisations. The NMG makes a preliminary recommendation to the AWMSG in relation to each medicine undergoing appraisal. However, decisions about whether particular treatments are funded, whether approved by NICE or AWMSG, rest with the individual LHBs.

DATA

Public Health Wales provides LHBs with information to inform service planning. It also provides the Wales cancer registry through its Welsh Cancer Intelligence and Surveillance Unit (WCISU). WCISU publishes statistics and research reports, the latest of which, published in 2016, present statistics and research on lung cancer incidence, stage at diagnosis and survival.⁷² In addition, Velindre NHS Trust hosts the National Wales Informatics Service (NWIS), which supports LHBs in the collecting and reporting of information. NWIS includes the Cancer Network Information System Cymru (CaNISC) where clinical patient information is recorded.⁷³

2.2.3 NETWORKS AND LOCAL LEADERSHIP

The seven LHBs are responsible for planning and delivering local services to help prevent cancer, to diagnose, treat and care for people affected by cancer. All seven LHBs plan and fund a limited number of specialist cancer services through their partnership work on the

WHSSC.

Treatment for cancer is provided at a number of hospitals across Wales. Three regional centres provide radiotherapy and more specialist treatment:

- Velindre Cancer Centre in Cardiff, Velindre NHS Trust, serves South and Mid Wales
- North Wales Cancer Treatment Centre at Glan Clwyd Hospital, Betsi Cadwaladr University Health Board, serves North Wales
- Singleton Hospital, Abertawe Bro Morgannwg University Health Board, near Swansea, serves South West Wales

Currently there are two regional cancer networks in Wales – North and South Wales. These bring together LHBs, Trusts, Community Health Councils (which act as patients’ ‘watchdog’ in Wales), voluntary organisations and Public Health Wales to co-ordinate the planning and delivery of cancer services within their area.

2.2.4 CLARITY ON LEADERSHIP RESPONSIBILITIES

Although there are structures in place for cancer, a common theme in interviews for this research was that cancer services in Wales lack a strong national lead. To this extent, our interviewees agreed with the assessment of the Welsh Assembly’s Health and Social Care Committee. While the minister for health and social services and the chief executive of NHS Wales are responsible for the health service overall, cancer is just one part of their respective remits. There is no clear lead within the Welsh Government or NHS Wales for cancer. The CIG plays a key strategic role in coordinating improvements for cancer for Wales, but further clarity on its role and responsibilities is needed.

Interviewees suggested there was a lack of clarity about who is responsible for policy implementation and monitoring, and there has been ‘buck passing’ between local and national levels. Joint working between LHBs was thought to be lacking and that this resulted in inefficient use of equipment and inconsistencies in services across the country. As a leading clinician put it: Wales lacks a ‘national clinically-led organisation that can deliver change’, the cancer networks lack ‘teeth’, and there was no process to get LHBs to collaborate to develop specialist services.

Third sector respondents also highlighted this issue.

“There isn’t an established body...if we’re going to see [a] major step change in Wales...then we need that driving body to drive that change”. (Third sector interviewee)

“[If someone were to] go to the health minister and say ‘This should be happening all across Wales, this is part of NICE guidance or guidelines, this should be done’, they’ll say ‘well that’s the responsibility of the health board’. Then you go to the health board and they’ll say, ‘well that’s the responsibility of the service’ or ‘this needs to be done at a regional level’. And so it feels like everyone’s passing the buck...There is probably a lot of guidance [relating to] things that are not being enforced and someone needs to be ... monitoring it and enforcing it, or at least asking the question ‘why isn’t that being followed?’” (Third sector interviewee)

OPPORTUNITY FOR BETTER COORDINATION AND EFFICIENCIES

Clinicians we interviewed advocated a more centralist approach – something they felt existed elsewhere in the UK:

“I think one of the difficulties is the reticence from government to sometimes be much more centralist...it’s very much up to the health boards. I’ve just got the feeling, talking to colleagues in Scotland and Northern Ireland, that there’s much more of a willingness from the government there to be more centralist”. (Senior clinician)

Other interviewees gave examples of where the lack of coordination created inefficiencies. For example, below, a nurse describes how decisions by local services to acquire their own diagnostic equipment led to the equipment being under-used and funds not being available to buy more expensive equipment that subsequently comes on stream. In the second quotation an interviewee compares the situation in Wales with Scotland:

“We’re not using the resources that we’ve got efficiently because we’re working it around the clinicians rather than the patient need. And I think that’s probably the same from lots of cancer sites’ perspectives. We all want to be experts in our field, which is very admirable, but we don’t have the resource to do that, so we should be looking at what it is we need and making sure we’ve got access to all of those things rather than everybody having the same bits [of equipment]”. (Clinical Nurse Specialist)

“[For] radiotherapy equipment, there are national replacement programmes in Scotland and...it’s agreed on an all Scotland basis who’s the next to have an accelerator replaced, whereas in Wales we don’t have that set-up. It’s allowed Scotland to negotiate much better prices for [equipment]”. (Senior clinician)

CLINICAL LEADERSHIP

Some GPs and nurses felt they did not have a role in policymaking at regional or national levels but commented that there is a ‘small country’ advantage of ready access to policy makers for individuals and groups.

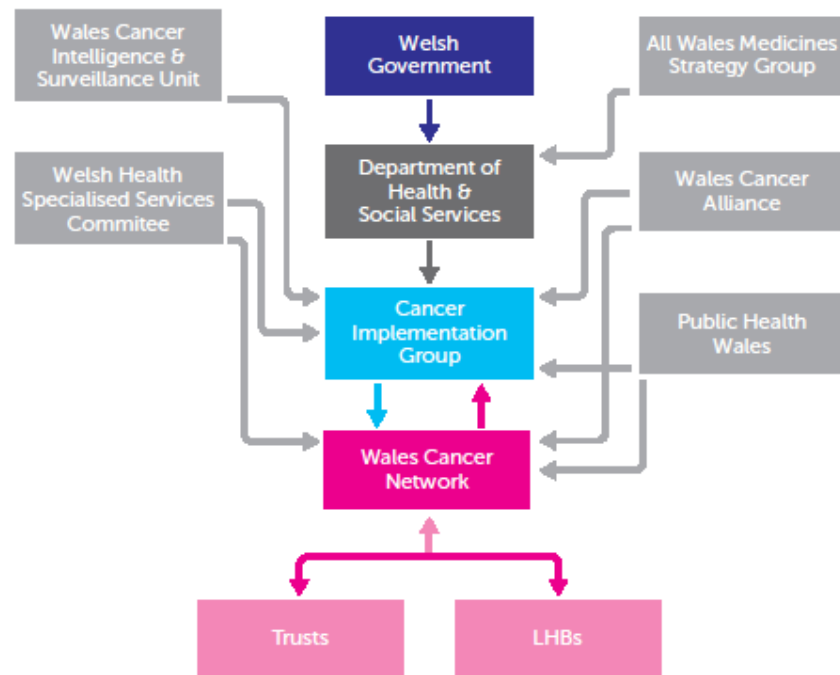
“If you want to change how you set up a particular service or change pathways then that can be done at a local level and can be done by, probably, the clinical teams looking after that patient”. (GP)

“We make sure that we cover the major specialties so for most cancers that is surgery, radiology, pathology, specialist nurse, information.... So they’re not big groups in that sense but they are democratically ... elected. When we need a new member we canvas all the MDTs for that...say we need another specialist, we go to all of the teams to say, ‘look, we have a vacancy...have you got anybody who would be interested to come forward to work on the national group?’” (National interviewee)

2.2.5 NEW LEADERSHIP STRUCTURE

As mentioned above, the national leadership for Welsh cancer services is being restructured in 2016 with the goal of simplifying arrangements. A single cancer network for all of Wales is being created. This will absorb the two existing networks and the NSAG. The Wales Cancer Network will advise the CIG on priorities and play a role in planning and coordinating LHBs and Trusts. It will also assume responsibility for producing the annual national cancer reports. Membership will include LHBs, Trusts, WHSSC, the Wales Cancer Alliance (a grouping of voluntary organisations), Public Health Wales and others. Figure 7, below, offers an interpretation of how the new leadership structure will operate.

FIGURE 7: LEADERSHIP STRUCTURE FOR CANCER SERVICES IN WALES FROM 2016



This plan was announced in the later stages of our study and where possible we asked interviewees to comment on the proposals. Most interviewees' reaction was favourable and many were optimistic that the new model would support a more collaborative approach among LHBs, which many felt was needed. Others, however, expressed a fear that the full range of cancer specialists would be under-represented at national level as a result.

Interviewees involved in designing the changes suggested the new model will enable the consolidation of specialist expertise to advice and guide policy. However, they also recognised that it wasn't enough to have clear clinical leadership: making sure plans are implemented will also be critical.

"We have a lot of clinical leadership and that's really good because we're small so you can achieve it. ...In terms of making things happen and engaging...you have to engage effectively with the health boards and the health boards themselves...need to be able to work together. Obviously that was the whole thinking about having cancer networks in the first place, across the whole of the UK in fact...cancer networks would particularly be able to help that brokering across boundaries..." (National interviewee)

"The cancer networks have a role in...changing how services are delivered...[such as] bringing about the changes so that all the rarer cancers are all treated in one unit by a small number of doctors so that you increase the skills in that skill set. They have a lot of influence on that. But it still never ceases to amaze me how if there's a resistance, against those sorts of policies, how slow it can be to change". (Senior clinician)

VOLUNTARY SECTOR

The voluntary sector plays a valuable role in informing the development of policy, acting as an advocate for patients and providing services. The Wales Cancer Alliance informs policy

through having a seat on the CIG, and provides an independent voice evaluating progress in Welsh cancer services⁷⁴. The new leadership structure for Welsh cancer services should ensure this input continues.

2.3 SUMMARY

Since 2012 cancer services in Wales have been guided by the Welsh Government's CDP. Delivery against the CDP has been monitored via national annual cancer reports. These reports indicate that the CDP has supported ongoing improvements in cancer outcomes in Wales. Cancer burden in Wales continues to grow but outcomes for patients are on a positive trajectory. That plan comes to an end this year.

During the CDP Wales has had a dedicated leadership structure for cancer services. However, this is changing and from this year there will be a new leadership structure put in place. The CIG will remain to provide strategic oversight, and a single Wales Cancer Network (WCN) – merging the two previous networks and the NSAG – is being created with the aim to simplify the structure. The WCN will assume responsibility for coordinating services across the country, will inform operational priorities and report on national progress.

Interviewees expressed mixed views about the existing leadership for cancer services in Wales. Some praised the strong clinical voice that guides cancer services. More critically, however, respondents diagnosed a lack of central leadership for cancer services in Wales. A related problem, interviewees argued, was a lack of coordination across LHBs which results in variations in care and inefficiency. Interviewees were optimistic that the new leadership structure will improve coordination.

RECOMMENDATIONS

- 1. The Welsh Government should develop a comprehensive strategy for cancer which sets ambitious goals and allocates sufficient resource to ensure cancer services can improve outcomes while meeting rising demand and reducing variation in care. Measurable targets should be set 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. We suggest the following targets:**
 - One-year survival should reach 75% by 2020.
 - Five-year survival should reach 58% by 2020.
- 2. The new cancer strategy must ensure that the new organisational structure for cancer services provides clear leadership and accountability mechanisms. The creation of the Wales Cancer Network is an opportunity; it should have responsibility for implementing the cancer strategy, tackling variations in care, and have authority to shape behaviour at LHB and Trust level through performance management levers.**

3: NHS PERFORMANCE ON CANCER

This chapter analyses the key policy levers deployed to improve the performance of cancer services in Wales. These include national performance measures, clinical guidelines, peer review, clinical audit and targets. For clinical audit, Wales is included with England in the Health Quality Improvement Partnership (HQIP) programme. Targets are set for aspects of service delivery including waiting times.

The NHS Wales Planning Framework specifies that one and five-year survival outcome measures should be reported annually. Because survival, which is a proxy for overall system performance, is used as the reporting measure it is difficult to isolate the progress made in improving elements of the pathway e.g. early diagnosis and rapid access to treatment. Progress on survival outcomes in Wales is described in chapter one.

The latest national cancer Annual Report, for example, provides little detail on progress with early diagnosis. Although, it does record that primary care is undertaking significant event analyses of gastro-intestinal and lung cancers to understand how earlier diagnosis could be achieved; outlines the aims of the new Macmillan Primary Care Oncology initiative; and highlights some patient feedback from the Wales Cancer Patient Experience Survey.

3.1 NATIONAL PERFORMANCE MEASURES

LHBs are required to publish local service delivery plans to identify action needed for all aspects of their service. Executive leads for cancer in LHBs report to their boards against milestones in the delivery plans and publish their report online annually. All Wales annual reports on cancer services have been published since 2012. The most recent report, published in January 2016, includes performance outcomes for all LHBs⁷⁵ which indicate progress against some of the measures set out in the CDP:

1. The percentage of people whose cancer is diagnosed at each stage (discussed below).
2. The percentage of patients recruited into high-quality clinical research. In 2015, 18.2% of patients participated, exceeding the target of 15% (discussed in chapter five).
3. The percentage of people diagnosed with cancer who consent to donate tissue samples to the Wales Cancer Bank. A target of 20% of patients donating samples by 2016 has been set. Following a steady increase from 4% in 2008 to just over 14% in 2013, the rate fell to just over 9% in 2014.⁷⁶
4. The percentage of patients with a key worker recorded on CaNISC. While there is no target set, outcomes are published and in 2014 the all Wales rate was 32% with very wide variation between LHBs. According to the 2015 Annual Report, the majority of patients do have a key worker but recording in CaNISC is poor.⁷⁷
5. The percentage of people starting their cancer treatment in line with the cancer waiting times target (discussed below).

3.2 CLINICAL GUIDELINES

The CDP states that LHBs are expected to deliver services through multidisciplinary teams (MDTs) in line with NICE guidelines, national cancer standards and advice from the all Wales clinical advisory structures (e.g. NSAG).

NICE guidelines for England and Wales are developed by five National Collaborating Centres for Cancer, one of which is in Wales, based at the Velindre Cancer Centre in Cardiff. The guidelines include service guidance, recommending how services should be organised, and

clinical guidelines recommending treatments. Guidelines in and of themselves are likely to be less effective at driving improvement unless converted into a standard or a target. Whether guidelines influence or simply endorse practice⁷⁸ remains unclear: further research about how influential guidance is in comparison to, for instance, pharmaceutical promotion and the work of clinical networks may be helpful for understanding drivers of change.

National cancer standards for Wales were published in 2005. They aimed to outline the key elements of care – diagnostic and treatment – that patients could expect from the NHS. Ten were published at that time covering a range of cancer types including breast, colorectal, lung and gynaecological.⁷⁹ Other non-site-specific guidelines were published subsequently covering, for example, children with cancer⁸⁰ and teenagers and young adults with cancer.⁸¹ The guidelines cover a range of different elements of care, for example, organisation; patient-centred care; and multi-disciplinary teams.⁸² Within these categories the standards outline how LHBs should organise their services with an operational focus. The breast cancer standard, for instance, lists the specialists who should be members of each LHB's breast cancer MDT.⁸³

LHBs self-report their fulfilment of national cancer standards via their annual cancer reports. The national 2014 cancer Annual Report collated this data. It showed that adherence is generally strong – ranging between 80% and 100%.⁸⁴ The 2015 national Annual Report did not report performance against national cancer standards. Although adherence is generally good, national cancer standards – unless updated – are unlikely to be an effective tool for ongoing improvement. As Betsi Cadwaladr's 2014 cancer annual report highlights, the bulk of the standards have not been updated since 2005 and therefore have not incorporated subsequent NICE guidance.⁸⁵ Aneurin Bevan LHB's 2014-15 annual cancer report comments 'it is widely viewed that these are now superseded by peer review'.⁸⁶

3.3 PEER REVIEW

The Healthcare Inspectorate Wales (HIW), the independent regulator and inspector of healthcare in Wales, leads a peer review programme of cancer services in collaboration with the cancer networks. Introduced in 2012, following an English model, it involves a group of expert practitioners visiting a health boards' cancer teams in a particular specialism, e.g. breast cancer, to review their way of working. The visiting team draws on performance data and observation to make an assessment. They submit a report to the host LHB in which they identify examples of good practice and areas of 'concern', 'serious concern', and 'immediate risks'. Review reports, and the action plans LHBs develop in response, are subsequently published on HIW's website.⁸⁷

The programme operates in waves: each year it reviews all the MDTs operating in one or two specialisms. In 2015, for instance, all urological cancer MDTs were reviewed. Drawing on the reports for individual MDTs, the relevant sub-group of the NSAG then produces an overview report summarising the national picture in that specialism.

The overview report in urological cancer showed that all LHBs possessed some examples of good practice as well as areas of concern.⁸⁸ Areas of strength included several LHBs developing 'innovative pathways' and, in addition, many LHBs utilising CNSs as patients' key worker. Three LHBs were found to have areas for 'serious concern'. These included: management problems, such as a lack of consensus on service reconfiguration; staffing, specifically, a lack of input from radiologists at MDTs and a shortage of CNSs; and poor process leading to patient delays. Lung cancer MDTs were reviewed during 2014. The

summary report identified three LHBs with areas for ‘serious concerns’ and one LHB where an ‘immediate risk’ was present.⁸⁹ Lack of MDT input from the full range of specialties was a concern in all LHBs.

The peer review programme appears to be supporting real improvement. The 2014 national Cancer Annual Report argued it has achieved ‘immediate’ impact and teams are ‘embracing service improvement initiatives’.⁹⁰ The OECD’s recent report, on the quality of healthcare in the UK, similarly argued it is contributing to quality improvement. They suggest it ‘appears to have been very effective at identifying concrete concerns in clinical practice, and appears to have been well-received by clinicians.’⁹¹

The national cancer Annual Report for 2015 indicates that MDTs working in head and neck, breast, and skin cancer were peer reviewed that year. Findings from these reviews have yet to be published. Haematological services and services for rare cancers are scheduled for peer review in 2016.

3.4 CLINICAL AUDIT

The Health Quality Improvement Partnership (HQIP) conducts clinical audits in England and Wales.⁹² In 2013-14 NHS Wales participated in audits for prostate, oesophago-gastric, lung and bowel cancers.

National level interviewees viewed the clinical audit and peer review programmes as valuable for testing consistency of services and for gathering intelligence on where staff shortages were having an impact. For example, the oesophago-gastric audit found that the choice of treatment provided to patients across different networks varied. It made a number of recommendations for the cancer networks and LHBs to work together to ensure patients receive consistently high-quality care.⁹³

“We make a lot of use of national clinical audits to assess the quality of our service, assess the quality of our pathways and assess the consistency and use of particular therapies”. (National interviewee)

“Peer review in England has been going for a number of years.... In Wales it’s relatively new... They’re still going through cancer sites for the first time but it [staff shortages] is a very recurring theme. We pick it up because the Cancer Networks produce individual health board reports. Then we...do a summary...report with our National Advisory Group. ...We are picking up shortages in MDTs and there are pressures which will require a bigger picture solution in terms of NHS Wales and how they’re going to take forward the number of secondary and tertiary care places”. (National interviewee)

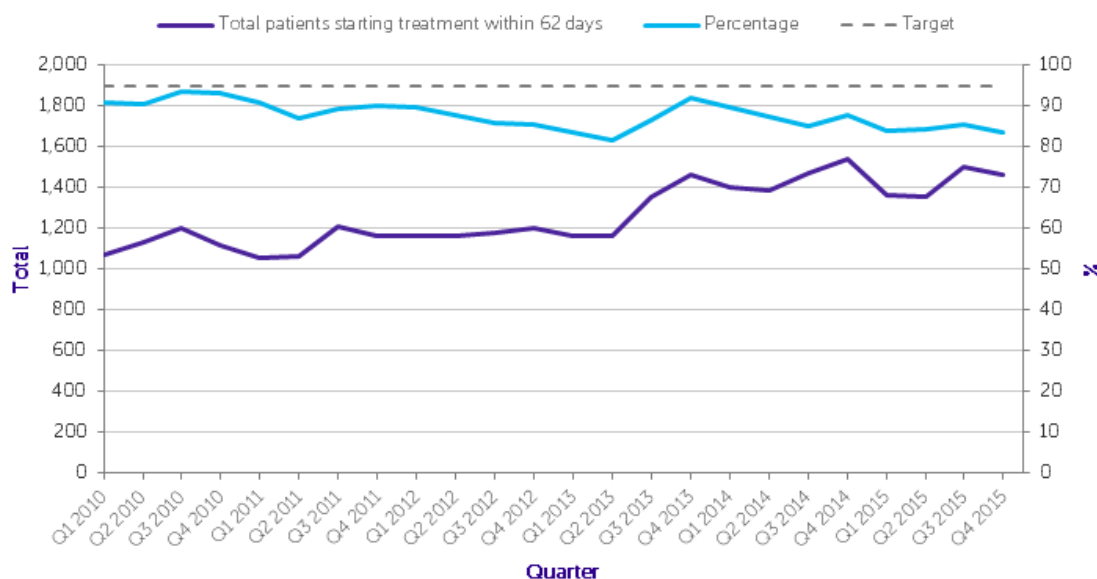
3.5 WAITING TIME TARGETS

Waiting times targets in Wales are applied to two groups of cancer patients: those who are, and those who are not, referred via the urgent suspect cancer route.⁹⁴ Information is provided below in relation to the targets for the six LHBs who provide acute services.

1. AT LEAST 95% OF PATIENTS DIAGNOSED WITH CANCER, VIA THE URGENT SUSPECTED CANCER ROUTE TO START DEFINITIVE TREATMENT WITHIN 62 DAYS OF RECEIPT OF REFERRAL.

The 62-day target for urgent suspected cases has not been achieved across Wales in any quarter since April-June 2008 (Figure 8), meaning thousands of patients have waited too long to access cancer treatment.⁹⁵ Between October and December 2015 performance was 83.7% for all cancers combined. During that period there was significant variation in performance across different types of cancer. Performance ranged from 100% of sarcoma patients starting treatment within 62 days to 69.2% of lower gastrointestinal cancer patients starting treatment within the same period. For comparison, 88.1% of newly diagnosed breast cancer patients, and 85.8% of lung cancer patients, started treatment within 62 days.⁹⁶

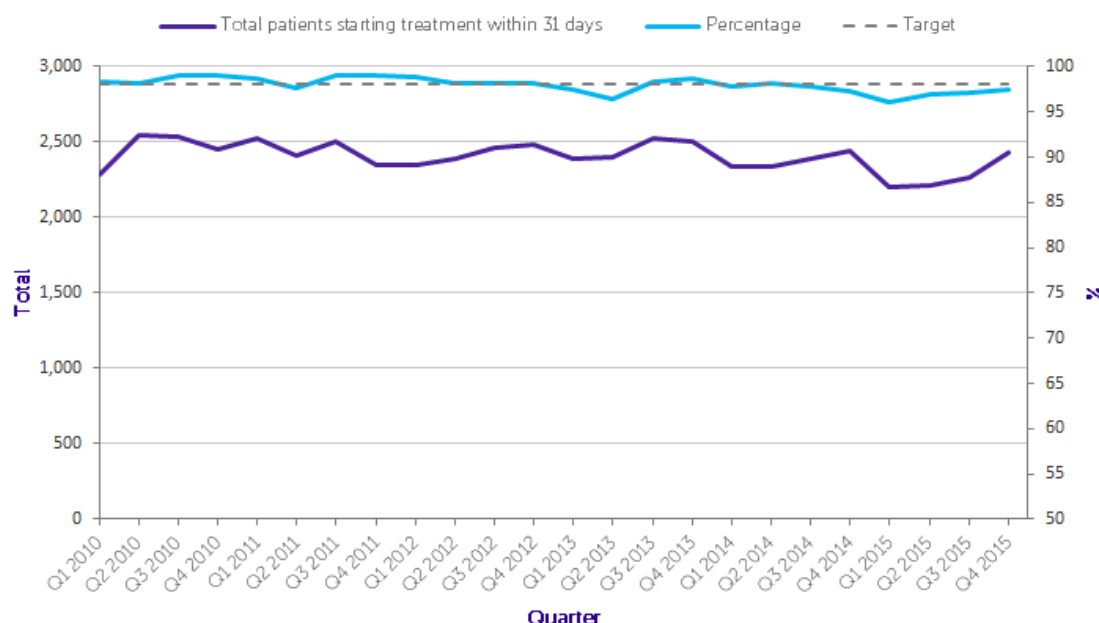
FIGURE 8: PATIENTS (TOTAL AND %) NEWLY DIAGNOSED WITH CANCER VIA THE URGENT ROUTE STARTING TREATMENT WITHIN 62 DAYS BY QUARTER, 2010-2015



2. AT LEAST 98% OF PATIENTS NEWLY DIAGNOSED WITH CANCER, NOT VIA THE URGENT ROUTE WILL START DEFINITIVE TREATMENT WITHIN 31 DAYS OF DECISION TO TREAT.

Between October and December 2015, 97.5% of patients not diagnosed via the urgent route began treatment within 31 days, narrowly missing the 98% target.⁹⁷ This was a slight improvement on the previous quarter by 0.3 percentage points. However, four out of six LHBs failed to meet the target, with performance varying from 95.7% to 99.3%.⁹⁸ Overall, the 31-day wait target was last met in April-June 2014 (Figure 9).

FIGURE 9: PATIENTS (TOTAL AND %) NEWLY DIAGNOSED NOT VIA URGENT ROUTE STARTING TREATMENT WITHIN 31 DAYS BY QUARTER, 2010-2015



It is difficult to see from this data where the real issues lie in achieving these targets, as the 62-day wait is for urgent referrals and the 31-day wait for non-urgent referrals. Importantly, the 31-day target is measured from the point of decision to treat and therefore does not capture the duration of the diagnostic phase. Given performance against the 31-day wait target remains significantly higher than the 62-day wait, this suggests delays in the diagnostic phase may be contributing to poor performance.

It is hoped that the 'single cancer pathway' (see below) will provide a more streamlined approach and the ability to understand better where there are challenges in the health system.

Stakeholder views were mixed as to whether waiting time targets helped focus minds, and more than one person felt that they were 'not clinically relevant'. A senior clinician referred to a review underway which might produce more relevant waiting time targets by including the whole diagnostic pathway in the non-urgent waiting time target rather than only the time from 'decision to treat'.

3.6 SINGLE CANCER PATHWAY

A pilot to test a 'single cancer pathway' to eventually replace the urgent and non-urgent pathways was announced in May 2014. The proposal is that in all cases the waiting time is calculated from the date of suspicion of cancer, with a target of first treatment taking place within 62 days.⁴ Key milestones are set within that period depending on the cancer site and this will enable monitoring of where the bottlenecks are. This would overcome one of the

⁴ Latest statistics do not reflect this change: urgent and non-urgent waiting times are included in quarterly reports. There are two separate sites publishing the same waiting time statistics. They are: <https://stats.wales.gov.uk/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Cancer-Waiting-Times>; and <http://gov.wales/statistics-and-research/nhs-cancer-waiting-times/?lang=en>.

limitations of the 31-day target, namely, that it does not capture delays in diagnosis.

Commenting on this initiative, a senior clinician said that the aim was to take a more patient-centred approach and acknowledged that progress had been slow:

“We’re making...slower progress in that than I would...like. We’re trying to measure waiting time for treatments...in a way that reflects patients’ experience. So the two aspects of that are not just measuring first definitive therapy but also waiting time routinely for radiotherapy and for surgery separately...whether it’s for primary treatment or for recurrence. ...Also we’re trying to measure non-urgent secondary cancer for those with certain cancers on a single pathway. ...We think there are hidden waits in the diagnostic pathway because the clock starts from the time a patient’s given a treatment plan and treatment decision”. (Senior clinician)

The single pathway pilot was scheduled to run from May to September 2014 and results have not yet been made available. Both the 2014 and 2015 CDP annual reports identify implementation of the single pathway as a priority. It is important that this work continues and is swiftly rolled out nationally once the pilots show it works. This will provide the NHS with a better barometer of cancer service performance and where improvements and resource should be focused.

3.7 STAGE AT DIAGNOSIS

The stage of cancer at diagnosis provides a crucial measure of performance in relation to early diagnosis. Use of this measure has been hampered in the past by a low level of recording in Wales. This was a concern identified by the ICBP and addressed in the CDP. The CDP noted that 50% of all cancers had stage recorded in CaNISC in September 2012 and a target of 70% was set for 2013-14.⁹⁹ Subsequently progress has been made: the Cancer Annual Report for 2015 states that almost 75% of cancers diagnosed in 2015 had a stage recorded.¹⁰⁰ A new target of 90% was set for 2016.

One interviewee commented on the ICBP findings about stage data in the UK generally and how they had concentrated attention of clinicians working in the four ICBP cancer sites (breast, colorectal, lung and ovarian) on the need to improve stage reporting:

“...Staged reporting has got better because, as I say, it’s part of a national metric... I don’t think we can say that we’ve seen a shift in stage yet. ...We do look at the data at our national groups...they don’t have it by team but they have it by health board. So it’s on a population basis. I think it would be good to move the information to get it by team for the patients they actually manage...” (National interviewee)

The recent WCISU report on lung cancer in Wales, referred to earlier, highlights stage at diagnosis as playing a critical role in lung cancer survival with 44% of cases being diagnosed at stage four in 2012.¹⁰¹ Research in England shows that the proportion of late stage presentations is much higher for lung cancer compared with other major cancer types.¹⁰² Although stage reporting improved significantly between 2010 and 2012, there remained 13% of new lung cancer cases with stage not recorded in 2012.¹⁰³

Having improved the completeness of stage data, the next CDP should go further in utilising stage at diagnosis as an indicator of performance. It should set targets to increase the proportion of cancer cases diagnosed early, stages one and two, and reduce the number of late diagnoses.

3.8 CANCER PATIENT EXPERIENCE SURVEY

In 2013 the NHS in Wales surveyed cancer patients to understand their experience. Approximately 7,350 responded (a response rate of 69%).¹⁰⁴ In general the results provided a positive picture of patients' experience: 89% of respondents described their overall care as 'excellent' or 'very good'. 86% of patients indicated that they were provided with the right amount of information and 81% felt that they were treated as a whole person rather than as a 'set of symptoms'.

Responses to more specific questions raised some areas of concern. Current policy in Wales stipulates that every cancer patient should be provided with a key worker yet only 66% of respondents said they were given the name and contact details of a key worker. 65% of patients reported that the different people involved in their treatment worked well together. Only 22% of patients reported being offered a written assessment or care plan.

The results also showed variation in patients' experience. This variation was present across different types of cancer and different treatment locations. Breast cancer patients, for example, were more likely to report a positive experience. Conversely, patients with sarcoma, lung or urological cancer were most likely to report a poor experience. Patients receiving treatment at Velindre NHS Trust, a specialist cancer centre, were more likely to report a positive experience.

3.9 OTHER MEASURES OF PERFORMANCE

There are some other measures of performance noted. This includes that 100% of new patients diagnosed with cancer should be discussed at an MDT. Performance against this target is not reported in the 2014 or 2015 CDP annual reports.

In addition, an informal target exists that patients should have their first meeting with a consultant within ten days of an urgent GP referral for suspected cancer. Performance against this target fell between October 2013 and June 2015 and the 2015 Annual Report states that *'health boards will need to focus their performance against this guideline...'*

3.10 SUMMARY

The Welsh Government utilises a number of performance management levers to shape cancer services. LHBs are required to report annually on their performance against key targets from the CDP. The Welsh Government publishes an annual report on the performance of cancer services across Wales.

A peer review programme was introduced in 2012 and is led by the HIW in collaboration with the cancer networks. Wales is part of the Health Quality Improvement Partnership clinical audits that are also conducted in England. Both of these initiatives are viewed as valuable in driving improvements in cancer services.

Performance against waiting time targets show serious cause for concern. Services are struggling to meet the two key targets and improvements are needed. The 62-day wait standard between a patient being referred via the urgent route and starting treatment has not been met since 2008. In addition, April-June 2014 was the last time 98% of patients diagnosed not by the urgent route commenced treatment within 31 days of a decision to treat.

Given these waiting time targets look at different patient populations – those referred via the

urgent and non-urgent routes – analysis of where improvements within the patient pathway are needed is difficult. However, the poor performance of the 62-day wait in comparison to the 31-day wait suggests that delays in diagnosis may be a key factor.

Interviewees expressed mixed views regarding the value of targets. Some acknowledged that they help to improve service performance; others questioned their clinical relevance. The move towards a single pathway approach should give a more accurate reflection of cancer service performance, patient experience and where resource should be focused to drive improvements. The development of this pathway should continue and its swift introduction a priority across Wales.

RECOMMENDATIONS

- 3. The Welsh Government should review the metrics it uses to evaluate the performance of cancer services. The new strategy should develop metrics, which provide insight into performance throughout the cancer pathway. The following measures of performance should be considered:**
 - The proportion of patients seen by a consultant within 14 days of referral from general practice.
 - The proportion of patients receiving a definitive diagnosis within 28 days of suspicion of cancer.
 - The proportion of patients commencing treatment within 14 days of a decision to treat.
- 4. The new strategy should move to consistently reporting waiting times from the point at which cancer is suspected; this would more accurately reflect patients' experience. The national roll out of the single pathway should be a priority for the new strategy.**
- 5. The strategy should introduce a target to reduce the number of cancers diagnosed late, at stages three and four, and increase the proportion diagnosed at stages one and two. Since 2012, data completeness of stage at diagnosis has improved; the new strategy should set targets to continue this improvement.**

4: EARLY DIAGNOSIS

There is evidence that barriers to symptomatic presentation in the UK may partly explain poorer outcomes relative to some other comparable health systems. The ICBP found that people in the UK were less likely to be aware that increasing age was a risk factor for developing cancer, and they also reported more barriers to seeking a doctor's opinion. However, awareness of cancer symptoms in the UK was similar to other countries (e.g. Australia, Canada, countries in Scandinavia).¹⁰⁵

It is clear earlier diagnosis is crucial to improving survival in many cancer types.¹⁰⁶ Some cancer types are more amenable to this, for example breast and skin cancers that have specific symptoms. But particular challenges are present in cancers where symptoms are vague.¹⁰⁷ Pancreatic cancers, for example, are among those with the poorest survival but symptoms are non-specific and so hard to detect. Denmark has pioneered multidisciplinary diagnostic centres (MDC) to facilitate early diagnosis in cases with non-specific symptoms (see box three). In England, the ACE Programme is testing similar centres.¹⁰⁸ The 2015 Cancer Annual Report indicates there will be a review of diagnostics in 2016 and this will include 'an awareness of international developments notably in Denmark'.¹⁰⁹

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

The Accelerate, Coordinate, Evaluate (ACE) Programme, which was launched in June 2014, is a unique initiative funded by Cancer Research UK and Macmillan Cancer Support. ACE is an early diagnosis programme, scheduled to run for three years, to support NHS England's Domain 1 objective of 'preventing people from dying prematurely'.¹¹⁰

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

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

The CDP recognises that rapid diagnosis improves survival and quality of life for patients in the long term. As such, a clear priority for the CDP was that '*cancer is detected quickly where it does occur or recur*'. It goes on to list ten things it wanted to see from NHS cancer care by 2016:

- Easier access to GPs, pharmacists, dentists and opticians
- More information and support services and easier to find such as through local pharmacies
- More doctors and nurses available 24 hours a day, 365 days a year
- More direct access to diagnostic tests for GPs
- A greater range of local services meaning less need to travel, particularly for diagnosis and care after treatment

- Reduced travel costs for patients
- Better take up of population screening
- Prompt and appropriate access to assessment and treatment known to work to increase the chance of cure and reduce side effects
- More information on reducing the risk of developing cancer, recognising symptoms suggestive of early cancer and what services to expect available by telephone and online
- More men going sooner to their GP or other health services.

Progress in delivering these aspirations has been mixed. On the positive side, GPs are referring more people for diagnostic tests due to suspected cancer: over 72,000 in 2014, up more than 50% over the last five years.¹¹¹ The Welsh Government has committed £1 million to support the implementation of the CIG's early diagnosis priorities in 2016. In other respects, however, progress has been limited. For example, the proportion of patients diagnosed late, with stage three or four cancer, has remained relatively stable over the CDP period at approximately 35% (although it varies significantly by cancer type).¹¹²

4.1 PUBLIC AWARENESS

The CDP's target outcomes recognise the importance of public information and education in relation to cancer prevention, symptom recognition and willingness to seek medical advice. Interviewees suggested this was an important priority in Wales and more work was needed.

4.1.1 CULTURAL BARRIERS

Many of the people interviewed for this report emphasised that patients' reluctance to recognise symptoms or to visit their GP is a factor contributing to poor survival outcomes. Interviewees offered various explanations for this:

"...Some of it will be fear, and some of it is not wanting to make a fuss and not wanting to bother about either primary care or secondary care with something that might be trivial". (Senior clinician)

"One of my big worries...certainly in the poorer areas is the high level of fatalism about certain symptoms..." (Third sector interviewee)

"Men aren't very good at going to the GP". (Clinical Nurse Specialist)

The cultural factor was frequently associated with poorer communities but also with Wales generally:

"...As a nation we are not very good at going to the GP. ...Until we change that, we are always going to have a challenge around cancer survival". (Senior clinician)

"...We would love to see a much more bottom up approach to highlighting cancer signs or symptoms that is really effective and sympathetic to the target audience". (Third sector interviewee)

Others, however, suggested that these attitudes might be influenced by people's experience of seeking medical care:

"I think culturally within Wales you don't go to a doctor unless you're really sick, and I think when you do feel really sick you can't get seen quickly which is what your expectation is, and that expectation isn't met as readily as you would want it to be".

(Clinical Nurse Specialist)

Some spoke about low levels of bowel screening take-up in 'hard to reach' groups and how this was being tackled:

"I think there is quite a drive to try and educate people, I know Public Health are trying to pitch more at local community champions...rather than big, national campaigns that might not be as relevant to the local population". (GP)

4.1.2 AWARENESS CAMPAIGNS

The interviewees felt that Wales has been slow to respond to the public education challenge compared with other parts of the UK. Although one GP commented on the effect of UK wide television campaigns available in Wales, there have not been the same kinds of high-profile campaigns originating in Wales.

"I think that one of the things that we've found a little bit...frustrating in Wales, and I think there might be some moves to change this, is that we haven't had the level of symptom awareness raising campaigns that you see in England and Scotland". (Third sector interviewee)

"...Projects with Public Health in England, and I think a similar project in Scotland as well, have shown quite favourable results in that a public awareness campaign can seem to increase people coming forward [sic]... I think in Wales we have been much slower in taking that work forward and implementing it". (Senior clinician)

A public awareness campaign for lung cancer signs and symptoms is planned for summer 2016 (co-funded by the Welsh Government and cancer charities). It is hoped that this campaign will be followed by others:

"...We've got a new project and that's one of the things that we're working for lung, but it is only lung. Our public health seems to be more reticent in investing in awareness campaigns". (Senior clinician)

"...It's an area [where] we really do need to do quite a lot more, and we'd really need for it to tie in much better with Public Health Wales about how these campaigns are going to be undertaken in the future". (Senior clinician)

A new challenge identified by some was how to ensure that GPs and diagnostic services are prepared for the impact of such campaigns to allow them to plan for an influx of patients.

An extension of public awareness campaigns would also align with the philosophy of Prudent Healthcare, a central pillar of which is co-production based on patient empowerment.

BOX FOUR: ENGLAND'S LUNG CANCER SYMPTOM AWARENESS CAMPAIGN

The Be Clear on Cancer brand has been used to promote awareness and early diagnosis of lung cancer in England since 2010. It was piloted regionally from October to November 2011 and used nationally for the first time in May 2012. Since then there have been a number of 'reminder' campaigns.

Results from previous campaigns, including those from the first national campaign (May-June 2012) show there were an estimated 700 additional cancers diagnosed in the months surrounding the campaign, compared to the same period the previous year.¹¹³ During this time, approximately 400 more people had their cancers diagnosed at an earlier stage and around 300 additional patients had surgery as a first treatment for diagnosed lung cancer.

4.2 THE ROLE OF PRIMARY CARE

Primary care plays an essential role in early diagnosis as most cancer patients are diagnosed following a referral from their GP.¹¹⁴ The CDP recognises this and identifies easier access to GPs as a key objective. In 2014 the Welsh Government introduced a new GP contract which is intended to support the formation of GP clusters and thereby improve patient access.

The Welsh Government publishes information annually on opening hours and appointment times of GP practices. An annual survey of GP patients, focused on satisfaction and ease of access, was conducted for three years, finishing in 2011.

4.2.1 ACCESS TO GENERAL PRACTICE

The difficulty of obtaining GP appointments was a common theme in interviews. There was a widespread perception that patients have problems getting to see their GP or have to wait several weeks. Some felt it was a major issue preventing people from coming forward with their symptoms and one which potentially reinforces 'fatalism' or 'stoicism' with regard to symptoms felt to be prevalent in Wales (as discussed earlier).

"Some patients report, and this is anecdotal, that they had problems booking appointments [with] GPs... They might want an appointment but they're told 'you're going to have to wait two or three weeks'...". (Senior clinician)

"Getting to see a doctor when you're ill is increasingly difficult and I think people just give up and wait until things are really bad. And we've got a particularly high number of people that present at A&E here in Wales and I think that's possibly why: because their access to primary care is limited or difficult...". (Clinical Nurse Specialist)

"We're quite rural here, and getting access to a GP is a nightmare sometimes, and if you've got a problem you've got to make an appointment for two or three weeks' time...". (Nurse)

The 2014-15 National Survey for Wales found 37% of respondents who had used a GP appointment in the last 12 months found it 'fairly difficult' (19%) or 'very difficult' (18%) to get a convenient appointment.¹¹⁵ This is similar to the 2013-14 figure of 38%.¹¹⁶

4.2.2 GP WORKFORCE ISSUES

Recruitment and retention of GPs was identified as one reason for poor access:

“We know there are huge problems...particularly in some areas with recruitment of primary care professionals and high calibre ones, if I’m being frank, into some of the poorer [and more remote] areas of Wales. We do hear quite often about patients who have delayed presentation because, either rightly or wrongly, there is [a] perception that they wouldn’t be able to get to see their GP. I don’t know if that’s really the case...but certainly that is the perception [among patients]”. (Third sector interviewee)

“...If you live in a nice posh area you are more likely to access a GP service. ...I think you’re more likely to have a regular GP and not a locum”. (Clinical Nurse Specialist)

Statistics for 2015 show GP numbers vary across LHBs. Cwm Taf LHB had the fewest, with 6.0 GPs per 10,000 of population, and Powys LHB had most with 7.4 per 10,000. The average for Wales was 6.5 GPs per 10,000.¹¹⁷

4.2.3 WAYS OF WORKING

As mentioned, a new GP contract for Wales was agreed in 2014 which focuses (among other things) on the development of GP clusters to improve coordination of care and patient access. It gives priority to early diagnosis of cancer by requiring GPs to participate in a national care pathway. GPs are now required to carry out Significant Event Analysis (SEA) for the care of all patients newly diagnosed with lung or digestive system cancer and review the care of patients diagnosed with these cancers in 2014. The learning derived from SEAs should feed into the achievement of the CDP’s outcomes for prevention (increasing patient awareness of healthy lifestyle choices) and early diagnosis.

However, there appeared to be some uncertainty among interviewees regarding how it will operate.

“At the moment the Welsh Government is setting the Significant Event Audit that all GPs are meant to do, and it’s looking at the number of cancers that they’ve had. ...One of the difficulties is I’m not sure how easy it’s going to be for us to get the results of the Significant Event Audit data back. ...We need a way in which we collect [and analyse] the data...” (Senior clinician)

4.2.4 NICE REFERRAL GUIDELINES

NICE released new referral guidelines in June 2015.¹¹⁸ As well as offering detailed guidance on assessment of symptoms, the guidelines advocate discussion with a specialist if the GP is uncertain about the interpretation of symptoms and signs, and whether a referral is needed.

Our interviewees’ views about the willingness of GPs to investigate symptoms and refer were mixed.

“There does seem to be some issue about the gatekeeper role within the GPs as to how ready they are to actually refer on”. (Senior clinician)

“...Some GPs will do nothing at all...we see quite a few patients who if only they’d had a blood test six months earlier you would have known six months earlier what was wrong with them. ...I think there’s a general reluctance to investigate. [Although] you have others [who behave differently], there’s one particular GP who retired about two

years ago and my workload dropped by about four new patients a week". (Senior clinician)

This aligns with evidence from analysis of patients' comments when responding to the most recent Wales Cancer Patient Experience Survey (see box five).

BOX FIVE: GP DECISION-MAKING

An analysis of free text comments made in the 2013 Wales Cancer Patient Experience Survey showed that 'Concerns were raised by a number of participants in relation to GP care in the pre-diagnostic phase of the cancer journey, particularly around speed of GP reaction to presenting symptoms.'¹¹⁹ This was the main factor in GPs being the only staff area in this investigation for which negative comments outnumbered positives. Speed of action was the most common area of comment relating to this phase of the cancer journey, and the majority of responses in this section were negative.

Many respondents felt that their GP was slow to act in relation to their presenting symptoms, and linked this to delays in diagnosis and beginning treatment. These comments link with responses in the Wales Cancer Patient Experience Survey where over a fifth (22%) of respondents indicated they felt they should have been seen by a hospital doctor a bit sooner (12%) or a lot sooner (10%).¹²⁰

However, awareness of cancer in one GP's practice has been improving in recent years and this has shown up in more blood tests for ovarian cancer and more chest x-rays.

"I think that some messages, [such as] we need to do more chest x-rays [and earlier]..., I think those messages are definitely getting through. I see it in my practice where the practice nurse, who runs the COPD clinic, will now come and say, 'they're getting worse and I'm wondering...if they need a new chest x-ray doing'. ...That lowering of your threshold for doing that very simple investigation...that's a real change. And that's come about in the last five years..." (GP)

The new NICE guidelines are seen as helpful in promoting this kind of change. They support primary care clinicians, who have to walk a 'tightrope' of potentially failing to refer cases of cancer promptly enough or feeling that they may overwhelm stretched diagnostic services.

"...The NICE guidelines coming out were very much on the side of referring early and I think those, hopefully, will back us up as GPs and will take some criticism away from us". (GP)

Other interviewees suggested greater clarity was required regarding the role of GPs in identifying new cases of cancer. One suggested that the funding formula for GPs should reflect this role while the other advocated a new system to get 'primary and secondary care engaged to work together' [sic].

"There's a lot of time spent working out whether that should be done in General Practice, or whether it should be done in a hospital, and a lot of to-ing and fro-ing. ...If we could find a way to get secondary care and primary care working together, on projects like early diagnosis ...that would make a massive difference". (GP)

To assist GPs in following the new guidance, Cancer Research UK has published visual summaries of the referral guidelines. Developed in collaboration with the Royal College of General Practitioners, these identify symptoms which might suggest cancer, the appropriate investigative tests and recommended timelines.¹²¹

4.3 ACCESS TO DIAGNOSTICS

The following extract from the 2015 CDP Annual Report indicates current priorities in Wales for diagnostic capacity.

“As part of the ongoing planning process within Cardiff and Vale Health Board, work is ongoing to ensure sustainable 10 day turnaround times for diagnostics. This includes MRI, CT scanning and ultrasound scans as well as collaborative working with Cardiff University on positron emission tomography. There is a developing plan to strengthen cancer diagnostic tracking to ensure that sustainable improvements are in place”.¹²²

The NICE referral guidelines set out the criteria for when direct access to diagnostic tests should be offered or considered e.g. endoscopy in cases of suspected oesophageal cancer, urgent chest x-ray in where lung cancer is suspected. The new guidelines are in the process of being introduced by LHBs.

The experience of our interviewees in accessing diagnostic testing was variable, depending on geographic area and the type of investigation required. A national level interviewee suggested that there was no problem. Most of the frontline interviewees, however, highlighted long waits and poor access.

Some GPs we spoke to describe a very positive situation, although they did point out that GPs are not always aware of, or willing to use, the pathways:

“There's a very clear pathway that we don't have to involve referral to a consultant, we can refer directly for an ultrasound for a neck lump.... We've got good access to x-ray, we can access other imaging, like CT and ultrasound, we can access that routinely. But we can also, by speaking to a radiologist...access things more urgently. ...The availability of diagnostics is actually good in our Health Board, but GPs didn't feel that it was. ...There was a survey done of some of the GPs and they were saying that things weren't available, when they were”. (GP)

Other GPs presented a contrasting experience, highlighting limited direct access to tests.

“It's very limited where we are.... ...If you don't fulfil the criteria, for example, for an urgent gastroscopy [the patient has] to be seen in clinic and that's a massive delay, even if you ask for urgent you're looking at many weeks. ...I think if we can have easier access to investigations...we will probably use it wisely and take some of the strain off secondary care...” (GP)

“...In some cases we've added an extra layer of processing which could delay the speed at which diagnosis happens. But we're getting around that and we're seeing improvements and the new NICE guidelines are very helpful in saying what should be a direct referral and what things you need to ask for expert opinion on”. (National interviewee)

Secondary care clinicians were more likely to express fears that the service would be unable to cope with more direct access for GPs. They themselves felt that they had to wait too long for tests. Some were concerned about inappropriate referrals, and wanted to see NICE guidelines that set stricter criteria taking account of whether open access was:

“A, desirable, B, affordable and, C, if we're clear on the first two how to use it most appropriately...” (Senior clinician)

Easier access for GPs does not guarantee that the test will be carried out quickly. A clinician

who reported that there was no problem for GPs requesting x-rays or CT scans in their health board also said that it could take two to three weeks for the GPs to get the x-ray report:

“Similarly with CT scans and I think when you have those delays in getting results back then it detracts from the message that we’ll get these tests done quickly...” (Senior clinician)

4.3.1 DIAGNOSTIC CAPACITY

A common issue identified in interviews was the pressure of demand on diagnostic capacity. Respondents recognised that the increased incidence of cancer and the lower threshold for referrals implicit in new NICE referral guidelines were both adding to that pressure.

The most commonly heard explanation for the waiting time problem was lack of capacity both in staff and equipment.

“I think we have major problems...with both radiology and pathology diagnostics in secondary care in terms of retraining and recruiting adequate resource. I think there’s a recognition [of this] certainly among the, somewhat fragmented, leadership we have. ...We have a national imaging policy board talking about changing the way we train our radiology colleagues but there’s been very little...in terms of us ensuring that we have adequate diagnostic capabilities”. (Senior clinician)

Some interviewees also thought existing capacity is not used in the right way and should be opened up for wider use while at the same time recognising that diagnosticians would object to testing more patients who are found not to have cancer. Workforce issues included the difficulty of recruiting staff, especially in the more rural parts of Wales, and the high proportion of staff about to retire.

It was also argued that restructuring was needed to make diagnostic services work better and that might mean fewer but more ‘comprehensive’ centres:

“We need to be able to recruit radiologists and pathologists. These are national shortage areas because they will affect [early diagnosis].... I know the health boards...are looking at how they can restructure the diagnostic element of the health service”. (National interviewee)

Historical under-investment in laboratory services was attributed to a political preference for funding ‘patient facing’ specialties. ‘Back room’ services such as pathology, in contrast, were not receiving the investment they need. Recruitment of pathologists in North Wales was said by one respondent to be hampered by the fact that they were not allowed study leave.

The view from GPs was that the solution to the delays lay with secondary care capacity and organisation rather than with GPs. Some proposed a one-stop shop model (as in Denmark):

“A more general assessment clinic, rather than...having to choose a speciality, might help. ...If you can have your tests done, and [get] the results on the same day, or the next day, and not have to wait weeks and weeks for your results.... That is going to free up clinic time...” (GP)

Interviewees highlighted the challenges that arise from the length of time it takes to get a patient to the decision to treat. This view was echoed by GPs referring patients to the ‘rapid access clinic’ who then had to wait too long for the investigations and their results, a six week waiting list in some cases.

"I had a lady with a very abnormal liver, I rang the department, three hours on a phone, finally got through to ask for an urgent scan, it took two weeks for the scan to be done then it took a month for the result to come back, despite ringing most days to try and get the result, and when the result came back it was metastatic liver cancer. It's a big issue...because obviously I then had to refer her into the hospital... [and] there was another two or three weeks' wait for that; its delays all the way down the line really". (GP)

"I think the big problem is we are seeing people and saying, 'you need to go and have a test or you need to see the GP'... They go to their GP and are then told they can't use specialists for a number of months...or can't go for a scan or can't go for a biopsy or can't go for an endoscopy, for months.... Maybe presentation of symptoms isn't the issue, maybe it's the length of time it takes them to actually have the definitive cancer tests". (Third sector interviewee)

Overall, in spite of some negative views, there was a certain amount of optimism that early diagnosis was being taken seriously at strategic level:

"I think there's a lot of progress been made. There's been an increasing recognition at a political and policy level that early diagnosis is the thing which will have the biggest impact on survival and mortality. I think it's a common consensus now and you can see it in policy documents, you can see it in the way politicians speak..." (National interviewee)

A separate study by Cancer Research UK is assessing the current level of pathology capacity, demand and variation in Wales.⁵

4.4 SUMMARY

Early diagnosis is crucial to improving patient outcomes and has been a key target outcome of the Welsh Government's CDP. However, there remain a range of areas where improvements could be made – particularly in access to primary care, public awareness of signs and symptoms, and diagnostic capacity.

Access to primary care can be problematic. Thirty seven per cent of respondents to the 2014-15 national survey for Wales said it was 'fairly difficult' or 'very difficult' to get a GP appointment in the previous 12 months.¹²³ Access can also be more difficult in less affluent areas, where recruitment and retention of primary care staff can be challenging. A new contract for GPs in Wales, introduced in 2014, may help to improve this situation.

The Welsh Government has been less active in educating the public about cancer than other UK nations. A major public awareness campaign in Wales, focused on the signs and symptoms of lung cancer, is scheduled for summer 2016. Based on the outcomes of that, further initiatives to raise public awareness should be considered.

Performance against waiting time targets and responses from interviewees suggest that issues with diagnostic capacity are delaying some patients receiving a definitive diagnosis and therefore starting treatment. In addition, our research suggests there is variation in GPs direct access to diagnostic tests. Further investigation is needed to understand the workforce and

⁵ This will be available in Autumn 2016 from www.cancerresearchuk.org

equipment capacity needed to meet demand.

The rise in cancer incidence, as well as NICE's decision to lower the threshold of referral for suspected cancer¹²⁴ will increase demand for investigative tests in the coming years. New approaches to achieving early diagnosis being tested in other countries could support improvement. The Accelerate, Coordinate and Evaluate (ACE) programme in England, for example, may have findings relevant to the new strategy.

RECOMMENDATIONS

- 6. Public Health Wales should consider further public cancer awareness campaigns following an evaluation of the 2016 lung cancer campaign.**
- 7. The Welsh Government should conduct an urgent review of the state of direct access to diagnostic tests for GPs. It is vital that the next strategy should ensure there is sufficient resource committed to diagnostic services – both equipment and workforce – to meet rising demand and to support GPs consistently implementing NICE referral guidelines.**

5: ACCESS TO TREATMENTS

Once a diagnosis is made, offering all 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 less than optimal treatment access.

The type of cancer treatments a patient may need vary according to the site and stage of the disease and other clinical factors. However, they broadly fall into three categories: surgery, radiotherapy and cancer drugs (including chemotherapy, targeted drugs, biological agents and hormone therapies).

The geographical provision of each of these treatments differs across Wales. The majority of surgery for breast and colorectal cancers, for example, is provided at local hospitals throughout Wales. Smaller volume and specialist surgery is limited to fewer centres of excellence. Cancer drugs are provided either at specialist cancer centres, at local hospitals or taken at home, depending on the type of drug that is needed. Radiotherapy, which requires specialist equipment, is provided at three hospitals in Wales.

While comments from interviewees were generally positive about access to treatment in Wales, concerns were raised around variation in access to specialist services and a lack of national coordination for some services.

However, what is evident from our research is that there is very little data to tell us more about access to treatments. The clinical audits described in chapter two provide some information for specific cancer types. However, lack of data on access to radiotherapy and chemotherapy treatments in particular hold back the ability to assess the service and understand where improvements are needed. For example, it is not clear what proportion of patients in Wales receive Intensity Modulated Radiotherapy – a modern type of treatment that around 50% of patients receiving curative radiotherapy should have access to. The Welsh Government must make collecting and publishing data on treatment access to priority for the new cancer strategy.

5.1 SURGERY

Interviewees were broadly positive about the quality of surgery available to cancer patients in Wales:

“In most places surgery is being completed appropriately. There are one or two examples that I’m aware of, such as eye cancer, where we’re still not very good in Wales for surgical services according to the NICE guidelines that were issued in 2001. But those are small examples”. (Senior clinician)

The availability of surgery was identified as more problematic. Specifically several interviewees expressed concern about surgical capacity for treating lung cancer. The most recent workforce statistics reported that, in 2014, Wales had 12 full time equivalent consultant cardio-thoracic surgeons and four associate specialists.¹²⁵ It was suggested that ‘a significant increase in capacity’ was needed to bring the volume of patients undergoing thoracic surgery up to European standards.

Interviewees noted that pressure to provide access to new surgical techniques arises from comparison with the NHS in England. Robotic surgery for urology was introduced in September 2014.

“There was the robot that they used for prostatectomies in England, we’ve only just got one in Wales, so we had a period of strife where people [were] wanting one in Wales and we didn’t have one” . (Clinical Nurse Specialist)

“I think for the surgeons to keep up to date with the latest developments is not easy. They’re another specialty under pressure” . (Senior clinician)

5.2 RADIOTHERAPY

There are three radiotherapy centres in Wales: Velindre in Cardiff, Singleton Hospital in Swansea and North Wales Cancer Treatment Centre in Rhyl.

Future demand for radiotherapy and the associated implications for equipment and workforce needs was the subject of a 2006 report by the Welsh Government, which was updated in 2014.¹²⁶ This does not appear to have the status of a national plan: the report is subtitled ‘*Guidance to inform Local Health Boards (LHBs) in their future planning of radiotherapy service*’.

The 2014 update indicates that uptake of radiotherapy in 2011-12 was about 40% less than was predicted in the 2006 report.¹²⁷ The reasons for this were considered to be unclear but LHBs were urged to examine access rates in their areas to identify service and patient related factors that might be behind this. The report also states that the commissioning of linear accelerators had fallen short of the requirements projected in 2006, suggesting LHBs had not been investing where necessary.

Radiotherapy procurement is an area where several respondents felt better national leadership and joint working across LHBs were needed. Currently each of the three radiotherapy centres commissions its own equipment. The Velindre Centre has recently upgraded its radiotherapy facilities to include a new stereotactic machine. This is welcomed but a few expressed concern about whether the same level of service would be available in other parts of the country.

“... IMRT [Intensity-modulated radiation therapy] has been rolling out in Wales which has been good. ...The question is to make sure that developments that might happen initially in Cardiff...are then made available across the three centres” . (National interviewee)

Some believe that waiting times to access to radiotherapy has improved significantly in the past five to seven years.

“The waiting times are not huge and in some ways, in some areas we have amazing returns The head and neck radiotherapy pathway is down to two weeks instead of four weeks” . (Senior clinician)

However, interviewees also highlighted variation in the time patients have to wait for treatment in different areas (ascribed to different funding policies of LHBs). One respondent from a rural part of Wales said that patients have to wait four or five weeks following a scan for treatment to start.

“I know in some areas that they [a patient] would start radiotherapy treatment in two or three weeks’ time. So that does cause an impact sometimes...and if they need another scan, patients won’t start treatment for about six weeks, so that is a bit of a

problem with capacity really, but we cover a huge rural area so that as well impacts on our local radiotherapy department.... It all comes down to funding in the end..."
(Nurse)

More efficient use of equipment was advocated by one clinician who felt that the potential for extending the operating hours of equipment should be investigated. However several respondents felt the capacity of the service was limited by staffing rather than equipment. A national level respondent was concerned that with equipment becoming increasingly specialised it was necessary to make sure that NICE guidance was followed in deciding the most effective treatments to offer.

However, technology is constantly improving and it was suggested a replacement programme is needed to maintain a high standard of treatment:

"I think there does need to be continued investment...to make sure that we have equipment that's available and is capable of providing these radiotherapy treatments at the top level.... If we just take the radiotherapy side, I think we need an agreed equipment replacement programme...trying to keep capital [expenditure] down doesn't help". (Senior clinician)

The impact of location of these services and data on treatment access is explored below.

5.3 ACCESS TO DRUGS

As described in chapter two, the NHS in Wales follows NICE guidance on whether a drug should be made routinely available. Wales also has its own, separate process, to assess drugs through the All Wales Medicines Strategy Group (AWMSG). This process can reach decisions more quickly than NICE, but is superseded once NICE has made a final decision. However, decisions about whether particular treatments are funded, whether approved by NICE or AWMSG, rest with the individual LHBs.

For access to drugs not approved for routine use by AWMSG or NICE, an all Wales Individual Patient Funding Request (IPFR) policy dates from 2011. This allows doctors to apply for drugs which are not routinely available where they believe it could benefit a patient.¹²⁸ Each LHB and the WHSSC has its own panel to decide on IPFR applications.

In October 2013, the minister for health and social services commissioned a review of the IPFR process, looking in particular at inter-panel consistency and communication with patients. The review group made recommendations to improve the IPFR process by strengthening clinical input and improving inter-panel consistency and communication with patients. The review did not recommend a national panel on the grounds that *'it was deemed impractical and imprudent to frequently bring together key staff and clinicians across Wales to make decisions about IPFR'*.¹²⁹ The Health and Social Care Committee of the Welsh Assembly, in their report into the CDP which was published shortly after the IPFR review, disagreed and recommended the creation of a national panel.¹³⁰

Interviewees raised several concerns in relation to access to drugs. The main issues were variation in the availability of drugs between LHBs; the perception that Wales was worse off than other parts of the UK in terms of funding for new cancer drugs; delays in boards' decisions about NICE approved drugs; and the lengthy process for IPFRs.

"The health authorities have direct control on decisions about which drugs they're going to use, and fund...so there's a big issue in Wales at the moment. There are lots of

cries...for a national panel to agree drugs and also the individual patient requests. But the government is refusing to do that". (Third sector interviewee)

"We're not terribly good in Wales at having access to things...straightaway. ...If things are NICE approved there's often a delay in being able to access [them]". (Clinical Nurse Specialist)

It was also noted that the IPFR process, which is administered by the LHBs, is not straightforward and can lead to delays in patient access.

"Yes, [IPFR applications] can be very lengthy and I think from experience, your first application almost universally gets rejected, and then you have to appeal and so that becomes a very protracted arrangement; and you have to be very persistent...in order to get any...additional therapy or treatment funded. So, yes, that is a problem". (Senior clinician)

Other interviewees also supported the call for a national panel for agreeing access to drugs, but felt there was a risk that, with media interest and possible pharmaceutical industry pressure, patients would come to regard new drugs as disproportionately important and lose sight of the importance of surgery and radiotherapy in cancer treatment.

Interviewees expressed concern that the public perceive that, because Wales does not have a Cancer Drugs Fund, patients have poorer access to medicines than in England. Others did not necessarily share this view but felt the difference in arrangements was unhelpful. In the view of some clinicians, Wales does better than England in terms of referring patients for new drug treatments:

"...The direction of travel is accelerating access to those drugs where an appraisal hasn't yet happened [i.e. NICE or AWMMSG has not reviewed]. So ultimately we can expect if there's a negative appraisal, unless there's exceptions, patients shouldn't have that treatment. But it's not fair on patients if they see a big new development that the appraisal process [takes such a long time]". (Senior clinician)

Some respondents felt that the health service should be more prudent with spending on drugs and be prepared to tell patients that further drugs will not help them. Most respondents did not appear to feel that patients were being deprived of effective treatments.

Recent changes to the way cancer drugs will be appraised by NICE, including the incorporation of the Cancer Drugs Fund into its process as a 'managed access' fund, are a positive step in the right direction. As such, from July 2016 NICE will be able to make a decision to conditionally approve access to drugs. Wales, which follows NICE guidance, does not currently have a 'managed access' approach, and so it is unclear how the Welsh Government will deal with these conditional approvals. These changes therefore deserve consideration from the Welsh Government about how this will impact on drug access in Wales.

5.4 LOCATION OF SERVICES

Geography, and the part it plays in access to treatment, was a key theme in this research. The fact that the main population centres are in the South determines the location of specialist treatment.

5.4.1 TRAVEL TIMES

Many interviewees commented on the distance some patients need to travel and some suggested this can delay patients from remote areas commencing treatment.

“...Because we’re so rural and because the [service] is in another Health Board...our patients have got to travel sometimes an hour and a half, two hours or more to get to the radiotherapy department, so this can have an impact, although they’ve got facilities to stay there. But that, again, causes problems and they’ve got to wait for a bed to become available in the hospital or the ward, so this can have impact on them starting the treatment”. (Nurse)

Respondents highlighted that new ways of working can help to bring some elements of treatment closer to patients’ homes. Radiotherapy, however, as mentioned above, is administered in three locations in Wales and this entails travel for patients.

“...We try and make sure that they’ve got their consultant and dietetics and CNS support...in their nearest hospital, but with the radiotherapy department, because we haven’t got that in our health board, they’ve got to travel for that and the chemotherapy, although they can have chemotherapy nearer home as well”. (Nurse)

“We’ve only got two centres in South Wales that can deliver radiotherapy for a relatively large geographical area, and so there is some evidence that patients more removed from the radiotherapy centres, receive less radiotherapy. ...But we do have access to it and, in theory, if we want it [we’re] able to access it, but for some of the more borderline cases the patients, more elderly patients, they find that travel is a barrier.... So, I think there are problems...” (Senior clinician)

5.4.2 CONSOLIDATED SERVICES

While recognising that patients benefit from receiving treatment close to home, interviewees did not support dispersing specialist treatment facilities more widely. They supported maintaining fewer centres for specialist treatments to ensure high-quality services.

“As long as you explain to patients that we believe that this is best, you can have a better outcome because we’re going to bring services together onto one area rather than spread it out, on the whole patients are very accepting of that. I think the danger is that we try and do everything absolutely everywhere”. (Senior clinician)

“I think that the politicians and the public equate access to treatment as being a local hospital having all the services necessary to provide that. ...For very specialist treatment, you can’t have all of those services in very local areas, and we’re grappling with that”. (Senior clinician)

5.4.3 ADAPTING TO GEOGRAPHY

Some interviewees offered thoughts on how working in new ways could help minimise the extent to which geography shapes patients’ experience of care. For example, it was suggested that rural areas in Wales could learn from other countries which face comparable challenges e.g. Canada and Australia:

“[For clinical follow-up appointments] do we really need to be bringing people a two hour drive to a waiting room where they sit there for hours...and then they have a half hour discussion with the oncologist and they drive back? ...When we could be doing

that by Skype...” (Third sector interviewee)

Others argued that clinicians have adapted to pressure from patients and it is now more widely accepted that chemotherapy can be provided locally.

“...Whereas ten years ago you’d get an oncologist in this cancer centre saying, ‘no, no this has to be given in my unit where I can keep an eye on my patient’. I think you now get much more understanding that chemotherapy might be much better given away from the consultant...in the patient’s local unit and that the protocols are written properly and if the monitoring is organised in a way that it’s sensible then there’s no reason [not to].... I think it is a good thing and actually...the default position now is that the patient will have their chemotherapy at least in their District Hospital”. (GP)

5.4.4 VARIATION IN PRACTICE

Interviewees highlighted that the decision to treat, and what treatment programme patients follow, depends on LHB policy. As such, provision may not be consistent for patients.

“...No doubt there is significant variation between services right across Wales, and that, I believe, inevitably means that there are differences in quality between those services”. (Senior clinician)

“...We had an example this week: if you have a certain blood condition in one health board you will have the treatment that is matched with NICE guidelines, of surgery and radiotherapy, and if you’re in another health board, you’ll just have radiotherapy”. (Third sector interviewee)

As mentioned above, there is a lack of data to understand variation in access to treatment centres, in particular access to specialised services like radiotherapy. Data is clearly needed to understand performance and where improvements are needed.

Comments about transport provision also suggested a lack of consistency. One GP in an outlying area said that hospital transport into Cardiff was not available; while a respondent in a remote area said that hospital transport was always available.

“...I don’t see offers of the cancer centres having to have volunteer drivers who can go collect the people and bring them back. ...I know that they try and give beds to people who have to travel a long way...but I think that that bed access is limited”. (GP)

5.4.5 CROSS-BORDER ISSUES

Interviewees highlighted that patients in North Wales are routinely referred to centres in England which are closer and easier to travel to.

“If you live in North Wales, a lot of the cancer treatments are available to you from Liverpool and Manchester, so you’re able to access a more consistent, higher quality, more progressive kind of service than they have access to in South Wales”. (Clinical Nurse Specialist)

“Our population is under 1 million, there’s quite a lot of treatment that we actually don’t provide locally. ...We look at NICE guidance [and] we can’t and shouldn’t sustain [those] services, so an example would be we don’t do any thoracic surgery in north Wales. We send patients to Liverpool or Manchester so you’ve got a network as well. ...Patients don’t mind travelling but it’s...added complexity that can be a challenge”. (Senior clinician)

5.5 WORKFORCE ISSUES

Nurse and oncologist shortages were mentioned specifically and the problems were seen to be particularly acute away from the major population centres. Similar messages have been received via the peer review process.

Respondents felt that overcoming the geographic inequality, which many of them highlighted, was made more difficult by an insufficient number of trained staff to support 'satellite clinics'. One respondent was concerned that mobile and outreach services represented inefficient use of skilled staff because of the low numbers of patients using the services. Nurses trained in chemotherapy were seen by one clinician as a scarce resource and subject to a high turnover.

5.6 CLINICAL TRIALS

The CDP originally set 10% as the target for new cancer patients each year participating in clinical trials with at least 7.5% of those participants taking part in more complex studies.¹³¹ This was subsequently increased to 15% overall in the 2013 Cancer Annual Report.¹³²

Recruitment to clinical trials was consistently below 15% prior to 2012. In 2012-13 it rose to slightly over 18%; in 2013-14 this fell back below the 15% target in part due to the closure of the Cancer Research UK Stratified Medicine Pilot.¹³³ In the latest published figures, for 2014-15, recruitment into clinical trials was 18.2%, above the 15% target.¹³⁴

Several respondents said access to clinical trials was very variable across Wales. Explanations given for this included travel issues for patients in remote areas and staffing limitations in some centres. Access is easier in the major centres.

5.7 SUMMARY

Treatments for cancer fall into three categories: surgery, radiotherapy and systemic anti-cancer therapy. In general, interviewees gave a positive assessment of access to cancer treatments in Wales. A recurring theme, however, was variation in access across Wales.

Concerns were raised about surgery capacity, particularly the number of surgeons and specifically related to lung cancer surgery. In radiotherapy, our research identified variation in access to cutting-edge equipment and in the time patients wait before undertaking treatment.

Long travel times and variable support to help patients' access treatment centres were thought to delay some patients from starting treatment. In addition, patients in North Wales are routinely referred to cancer services in England, which produces unique geographic differences in access to care.

Concentration of some services was recognised to support high-quality treatment. But better strategic planning and coordination to provide more equitable access is needed. A national body to oversee and set standards for specialist cancer services would support this.

Concerns were raised that LHBs discretion over funding approved cancer drugs has led to variation in access for patients. In addition, the Individual Patient Funding Request process, which provides access to unapproved drugs for some patients, is slow; and decisions, which are made by LHBs, are not consistent across Wales.

Developments in drug policy in England demand consideration. The Cancer Drugs Fund, which provided access to non-NICE approved drugs and which Wales did not emulate, is being incorporated into NICE's appraisal process. Given Wales generally follows NICE decisions, it is

important to consider how these reforms will impact on budgets and patient access in Wales.

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

RECOMMENDATIONS

- 8. The Welsh Government should reconsider its 2014 decision and introduce a national decision-making panel for Individual Patient Funding Requests to improve consistency. The new strategy should also outline how Wales will ensure access to cutting-edge treatments is maintained as NICE processes are amended following reform of the Cancer Drugs Fund in England.**
- 9. The Welsh Government should review the existing approach to commissioning specialist treatments, such as radiotherapy, chemotherapy and low-volume surgery. The new strategy should establish a national commissioning body to better plan and coordinate these services across Wales. The new strategy should also set a clear ambition to improve access to clinical trials across Wales, and detail of how this will be supported.**
- 10. The new strategy should develop a national dataset for chemotherapy and radiotherapy activity. LHBs will need to supply the information and data completeness should be reported via the annual national cancer report.**

6: CONCLUSIONS AND RECOMMENDATIONS

In 2014 more than 19,100 people were diagnosed with cancer in Wales. That number is likely to rise in the coming years. The outcomes achieved for these people have been improving over time. The CDP, which ran from 2012 until this year, has supported that improvement. Today 70% of people diagnosed with cancer will live for at least one year; more than half will live 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. The development of a new cancer strategy for Wales is an opportunity to accelerate progress towards this goal. It is vital that it defines an approach that allows the NHS in Wales to meet rising demand while continuing to improve outcomes. It should set ambitious, measurable targets and commit resource to support delivery.

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

More empowered national leadership, supporting greater collaboration, would be beneficial. In performance management, stronger accountability and a more comprehensive collection of performance indicators would support improvement.

To support early diagnosis action is required to raise public awareness, improve access to primary care and increase diagnostic capacity. Access to specialist cancer treatments and drugs requires reform to achieve greater consistency.

The new strategy should consider each of these areas and bring forward proposals for change.

We make recommendations, below, outlining the changes we believe would be beneficial. The new leadership structure for cancer services in Wales lays a foundation for improvement in the coming years. It is vital that the Welsh Government capitalises on this opportunity by bringing forward an ambitious strategy.

6.1 RECOMMENDATIONS

- 1. The Welsh Government should develop a comprehensive strategy for cancer which sets ambitious goals and allocates sufficient resource to ensure cancer services can improve outcomes while meeting rising demand and reducing variation in care. Measurable targets should be set 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. We suggest the following targets:**
 - **One-year survival should reach 75% by 2020.**
 - **Five-year survival should reach 58% by 2020.**
- 2. The new cancer strategy must ensure that the new organisational structure for cancer services provides clear leadership and accountability mechanisms. The creation of the Wales Cancer Network is an opportunity; it should have responsibility for implementing the cancer strategy, tackling variations in care, and**

have authority to shape behaviour at LHB and Trust level through performance management levers.

3. The Welsh Government should review the metrics it uses to evaluate the performance of cancer services. The new strategy should develop metrics, which provide insight into performance throughout the cancer pathway. The following measures of performance should be considered:
 - The proportion of patients seen by a consultant within 14 days of referral from general practice.
 - The proportion of patients receiving a definitive diagnosis within 28 days of suspicion of cancer.
 - The proportion of patients commencing treatment within 14 days of a decision to treat.
4. The new strategy should move to consistently reporting waiting times from the point at which cancer is suspected; this would more accurately reflect patients' experience. The national roll out of the single pathway should be a priority for the new strategy.
5. The strategy should introduce a target to reduce the number of cancers diagnosed late, at stages three and four, and increase the proportion diagnosed at stages one and two. Since 2012, data completeness of stage at diagnosis has improved; the new strategy should set targets to continue this improvement.
6. Public Health Wales should consider further public cancer awareness campaigns following an evaluation of the 2016 lung cancer campaign.
7. The Welsh Government should conduct an urgent review of the state of direct access to diagnostic tests for GPs. It is vital that the next strategy should ensure there is sufficient resource committed to diagnostic services – both equipment and workforce – to meet rising demand and to support GPs consistently implementing NICE referral guidelines.
8. The Welsh Government should reconsider its 2014 decision and introduce a national decision-making panel for Individual Patient Funding Requests to improve consistency. The new strategy should also outline how Wales will ensure access to cutting-edge treatments is maintained as NICE processes are amended following reform of the Cancer Drugs Fund in England.
9. The Welsh Government should review the existing approach to commissioning specialist treatments, such as radiotherapy, chemotherapy and low-volume surgery. The new strategy should establish a national commissioning body to better plan and coordinate these services across Wales. The new strategy should also set a clear ambition to improve access to clinical trials across Wales, and detail of how this will be supported.
10. The new strategy should develop a national dataset for chemotherapy and radiotherapy activity. LHBs will need to supply the information and data completeness should be reported via the annual national cancer report.

APPENDIX ONE: METHODS

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

1. Interpretation of routinely available quantitative datasets.
2. Cancer policy review. The period 1999-2014 was chosen because it encompasses the effects of major policies such as the Calman-Hine report, 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 incidence, survival, mortality and prevalence of cancer, including analyses of any temporal and socio-economic patterns, and any that reflected the impact of the diverse geography of the devolved nations. We considered projections made to estimate future cancer burden. We identified routinely available data and publications on routes to diagnosis and early diagnosis.

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

CANCER POLICY REVIEW

We identified and described the major cancer policy themes in this section. (Our stakeholder interviews present qualitative information on the perceived effectiveness of these policies). We considered policies in a hierarchical way starting from high-level, national policies and national clinical and management leads. This follows through to regional or Health Board level policy and its governance in tertiary, secondary and primary care.

We recognised that policies do not flow in simple, linear ways and that national clinical guidelines, prescribing guidance and formularies, and other health policies (such as waiting times targets) have important roles that need to be described.

DESCRIPTION OF STRUCTURES AND LEADERSHIP

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

STAKEHOLDER INTERVIEWS

Our stakeholder interviews were the main source of reflections on how – and how well –

policies to achieve early diagnosis and access to treatment were perceived to work. Telephone interviews are relatively inexpensive and facilitate access to geographically disparate participants.

An interview schedule was used (Appendix two). For the sample, we identified a wide range of individuals, some via third parties and websites, and sent email invitations with information about the study. In order to maximise diversity in the sample we employed the principle of maximum variation sampling, a purposive approach that seeks to select participants to include the widest possible range of characteristics.

To encourage freedom of expression anonymity was guaranteed. Of the 30 people contacted we were able to interview 15. This sample gave us access to experiences and perspectives from a range of clinical, socio-demographic and professional contexts. The following breakdown indicates the range.

- Civil servants/administrators (2)
- Clinicians including some with national and regional role (5)
- Nurses (3)
- GPs including some with regional and national roles (3)
- Other including representatives of third sector and patient organisations (2)

Clinicians, nurses and GPs were based geographically as follows:

- South Wales 8
- West Wales 2
- North Wales 1

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

We identified key themes about early diagnosis, treatment and cancer policy and leadership and highlighted common themes for these three key areas.

ETHICAL CONSIDERATIONS

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

APPENDIX 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 check list 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?
<i>Areas of interest:</i> <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 national, regional and local

	policies, targets, guidelines and standards
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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:	other improvements that could be made (in this area of practice)
<i>Standard vs advanced radiotherapy</i>	
<i>Funding</i>	barriers to improvements being made (individual or structural)
<i>Formulary</i>	changes such as reorganisation or introduction of a new system that have had an impact on this problem (positive or negative)
<i>Location of services</i>	
<i>Staffing and skills</i>	part played by national, regional and local policies, targets, guidelines and standards
<i>Access (having to apply to Trust for approval/requiring an IPFR application etc.)</i>	
<i>Capacity (e.g. in RT services, surgery etc.)</i>	

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:
<i>Remote and rural areas – transport issues</i>
<i>Access to clinical trials – policy and practice</i>

Policy and Leadership

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

7. What or who has the greatest influence on cancer services in your view and why?	Effectiveness of national coordination
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 regional coordination
	Effectiveness of local coordination
8. What do you see as the main issues and challenges facing cancer services in Wales at present?	

END

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

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