Together for Health

Cancer Annual Report 2016

Mae’r ddogfen yma hefyd ar gael yn Gymraeg. This document is also available in Welsh.
1.0 Introduction

Wales has a population of around 3.1 million. The number of new cases of cancer diagnosed each year continues to rise at an average rate of almost 1.5% per year, leading to more than 19,000 new cases diagnosed in 2014, an increase of 14% between 2005 and 2014. The number of people surviving cancer is increasing. By 2020 there will be 150,000 people living after a prior diagnosis of cancer; this is around 5% of the population. For many people cancer is now a chronic condition which requires a new approach to longer term care, focusing on maintaining a high quality of life through and beyond treatment. Although the mortality rates for cancer fell between 2005 and 2014, there was still a 7% increase in the number of cancer related deaths because of changes in the size of the population, especially in older age groups, and due to changes in cancer incidence.

Inequalities in the incidence, survival and mortality remain major issues for some common cancers, such as lung cancer. This reflects past trends in smoking in men and women, and smoking gradients across areas of different deprivation. Other factors such as past asbestos exposure, radon gas and air pollution also play a part. Other conditions in society that lead to preventable inequalities in lifestyle in addition to smoking, such as obesity, alcohol and physical activity, may account for up to 4 in 10 cases of cancer in Wales.

Our annual report illustrates our commitment to improve cancer services for the people of Wales and the progress being made. We are doing this by focusing upon a number of areas - through prevention, early diagnosis, effective and timely treatment, the provision of high quality information, research and supporting those living and dying with cancer.

There are numerous excellent examples of cancer services improving throughout Wales, dealing with the unprecedented demand for care whilst facing ongoing financial challenges. It is clear that services need to undergo transformational change if they are to cope with the increased cancer incidence, the increasingly complex needs of patients and the introduction of exciting new treatments and technologies. The majority of patients do have a good experience of cancer services in Wales but our priority now must be to improve the outcomes and experience for all cancer patients.

1.1 Our achievements

Cancer survival rate is increasing
Cancer survival is improving overall in Wales. For the first time over 71% of people diagnosed with cancer in 2009-2013 survived for at least one year, and over 54% diagnosed in 2005-2009 survived for at least 5 years.

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1 Welsh Cancer Intelligence and Surveillance Unit (2015) Cancer in Wales
2 Adjusted for changes in the age structure of the Welsh population
The NHS in Wales is treating more people for cancer

During the financial year 2015-16 a total of 16,313 people started treatment for cancer. This is 1,219 people (8%) more than five years earlier (2010-11). Of these (15,033 (92%) were treated within either the 62 or 31 day targets. This is 455 more people (3%) more than in 2010-11.

Age adjusted cancer death rates are falling

The mortality rate for those aged under 75 has reduced by 10% over the last 10 years. The lung cancer mortality rate has fallen by 17% to 76.5 per 100,000 in men.

Preventing cancer

We are starting to make progress in combatting many of the risk factors for cancer. Smoking rates continue to fall – they were 21% in 2013 and 19% in 2015, as does the rate of adults reporting binge drinking, from 26% in 2013 to 24% in 2015. Also in 2015; 58% of adults report being physically active for at least 150 minutes in the previous week. This demonstrates that as a nation we are addressing the key actions to prevent cancer.

Saving lives through cancer screening and immunisation

The successful roll out of the HPV vaccination programme will protect many young women from cervical cancer. In 2015-16, 90% of girls resident in Wales who turned 14 received one dose of the HPV vaccine in school year 9. This is also helping to reduce the rate of cervical abnormalities detected through cervical screening and is expected to ultimately lead to a reduction in cervical cancer. More than 700,000 invitations were issued to participate in breast, bowel or cervical cancer screening, the uptake of which was 72.5% (102,815) for breast, 54.4% (152,794) for bowel, and 77.8% (190,614) for cervical.

Diagnosing cancer as early as possible and supporting people living with and beyond their diagnosis

Working with Macmillan Cancer Support, the NHS in Wales has invested time and resources to support GPs with earlier diagnosis. In 2015-16 there were over 8,000 suspected cancer referrals, an increase of 12% compared to the previous year. The Macmillan framework for cancer in primary care programme has created an exciting and innovative programme for earlier diagnosis and is supporting patients living with the impact of cancer in the community. In response to the changing face of cancer, now presenting as a chronic disease for many people, the framework for change programme provides clinical leadership to bring about a change in how primary and secondary care work together and to implement wide spread and sustainable improvements for cancer services in Wales.

Improvements in cancer staging

Staging gives us an indication as to how well our services are performing with regard to earlier diagnosis. Cancer stage at diagnosis is an indication of how extensive a cancer is after presentation to health services. It is important that clinical and all diagnostic information is used to enter this stage accurately in
the electronic cancer patient record, CANISC. In 2011 less than 42% of all cancers had their stage recorded. In 2015 over 76% of all cancers are now having their stage recorded on CANISC.

Developments in acute oncology
The investment in acute oncology service is supporting early identification of cancer by an acute oncology team and assessment by a specialist oncologist to ensure that the patient is placed on the appropriate care pathway. It is thought that this will improve their experience of care and reduce their length of stay as a medical emergency.

Too many patients are diagnosed through an emergency route. The investment in an Acute Oncology Service (AOS) at Abertawe Bro Morgannwg University Health Board will support early assessment by a specialist oncologist to ensure that the patient is started promptly on the appropriate cancer pathway. The AOS is in the process of being rolled out at Singleton and Morriston hospitals and in Hywel Dda University Health Board, following a successful six-month trial in 2015. Its aim is to streamline the care of cancer patients when they come to hospital. Patients will not all be admitted to an oncology ward, so this service sets out to support them no matter where they are being cared for, to make sure they receive the relevant specialist input and treatment. For some, the AOS may help fast track a return home. For others it may mean that hospital admission can be avoided.

The AOS now comprises a doctor and two clinical nurse specialists looking after patients at the Swansea hospitals, as well as four clinical nurse specialists working in Hywel Dda. They will be supported by radiology, pathology and palliative care services.

A focus upon clinical research
£4.5 million will be invested in the Wales Cancer Research Centre over the next three years (2015-18). The centre undertakes and supports cancer research of the highest quality, building on Wales’ international research reputation, with a clear focus on collaboration, innovation and improved patient outcomes. Over the past five years, there has been an increase of over 50% in the numbers of patients participating in clinical trials. Over 18% (3421) of cancer patients participated in a clinical trial in 2015-16.

Investments in cancer services
Spending on cancer services has risen from £347 million in 2011-12 to £409 million in 2014-15. The Welsh Government has provided nearly £10 million for replacement linear accelerators and is supporting the £200 million new Velindre Cancer Centre. £15 million has been allocated in the budget for better diagnostics.
1.2 Areas to focus on

There is much more to do to improve cancer care in Wales, including improving patient outcomes for rarer cancers, preventing cancers developing in the first place, early diagnosis of symptomatic cancers, improved access to treatment and better care for cancer patients and survivors.

Tackling lifestyle risks and variation in outcomes

There is still a lot to be done to ensure we address the wider lifestyle risks for cancer and there is a need to tackle inequalities in access to cancer services and outcomes for patients. Incidence of cancer varies by 22% between the most and least deprived areas in Wales. Many of the lifestyle risks applicable to cancer are common to many other major health conditions. Factors such as smoking, excessive drinking, obesity, physical inactivity are being addressed across a number of public bodies. As a small country with a small number of providers we need to do substantially better to tackle differences in services and reduce inequalities. Targeted prevention including diet, smoking cessation services, lifestyle advice and equitable access to care will help to drive down socio-economic and geographical variation in outcomes.

Late diagnosis

Despite the improvements noted above, we will continue to tackle late diagnoses. Too many people are diagnosed through emergency routes. This will require us to focus upon a range of activities to support patient awareness, access to GP services, GPs’ response to detection and referral of cancer, in particular lung cancer, where survival rates remain lower than other parts of Europe.

Improve access to diagnostic tests

Through the cancer innovation fund we will work with both primary and secondary care to ensure there is access to diagnostics facilitating the earlier diagnosis of cancers. This will involve utilising the experiences from countries such as Denmark who have implemented new and innovative approaches to support early diagnosis of cancer.

Improving treatment times

Performance against waiting times has been challenging. We have seen a huge increase in referrals, including 56% more urgent GP referrals for suspected cancer than five years ago. However, although the targets have not been consistently achieved this year, significantly more patients are being treated within the target times; an 11% increase in those treated within target times from 5 years ago. It is important to ensure that patients are treated in clinical priority in line with our standards, health boards have developed recovery plans to ensure that this happens.

Advice from expert clinicians, patients and the third sector is that no patient should wait more than 62 days from the point of when cancer is first suspected to the start of treatment, and so we must do better. We can do this by reforming clinical pathways, rather than just pushing stretched services
even harder. This will include learning from international practice and improving the way we manage patients through complex diagnostic and treatment pathways.

Focus on lung cancer
There has been a special focus on improving the outcomes of patients with lung cancer, given their poor survival and experience of cancer service throughout Wales. Lung cancer incidence also has wide inequalities. The recently reported National Lung Cancer Audit has shown that Wales has significantly improved the proportion of cases undergoing curative surgery. This is a huge credit to the response of lung cancer services in Wales. However more remains to be done to improve outcomes for lung cancer patients.

Patient experience
It is important to ensure everyone has the best possible experience whilst undergoing cancer treatment and key workers are an essential element of the patient experience. We will make sure that all patients have a key worker and that this is recorded. The outcome of a second patient experience survey will be published in 2017 and we will ensure that we can track our progress in this area and highlight areas where further improvements can be made.

We know that navigating through the healthcare system is a complex issue for patients and we know from the preliminary feedback from the survey above that more patients describe having a key worker to help guide them through the system. The same results also suggest a low provision of care plans and holistic needs assessment and there is work to do to improve this position.

The progress we have made in delivering the “Together for Health – Cancer Delivery Plan” would not have been possible without the expertise and commitment of the teams we have in our GP surgeries, screening services, NHS hospitals, hospices and the charities that support cancer patients across Wales. It is important to recognise the valuable work undertaken by the third sector in supporting and caring for people with cancer and their families, and also the support provided by carers and families. This support is an essential element of the delivery plan, without which the NHS would struggle to deliver such excellent service.
Andrew Goodall
Chief Executive, NHS Wales

Tracey Cooper
Chair, Cancer Implementation Group
2.0 Impact of the Together for Health – Cancer Delivery Plan

The last five years have seen significant progress in improving care for patients with cancer in Wales.

Focus on lung cancer
Reflecting poor survival rates in lung cancer a programme of targeted work on lung cancer was established by the cancer implementation group across a range of healthcare aspects. Public awareness campaigns commenced in 2016, commissioning in thoracic surgery has seen investment building on the improvement in surgical rates seen in peer review this year. Pathway improvement work is underway to improve access to treatment and work within primary care is providing a focus on patients in the community pre and post treatment.

Development of acute oncology services
Acute oncology services (AOS) are evolving across Wales to support people with cancer, either known, or yet to be diagnosed, who present acutely to the NHS. AOS brings together multi-disciplinary clinical expertise to facilitate the rapid identification and appropriate prompt management of patients that present acutely with complications following their cancer treatment, complications as a consequence of their cancer, or who present acutely with previously undiagnosed cancer. Models of care and early funding have helped the development of services within health boards with a view to their further maturity. National AOS standards which define the core aspects of the service that must be provided for cancer patients across Wales have been endorsed by the cancer implementation group.

In September 2014 Cwm Taf University Health Board submitted a successful bid to Macmillan to establish a three year pilot project for an Acute Oncology Service. The Cwm Taf acute oncology service began formally in June 2015. During the first 10 months of the service:

- 569 patients have been seen by the team.
- the median reduction in length of hospital stay (LOS) was from 11 to 5 days for patients with carcinoma of unknown primary (CUP).
- the median LOS since the introduction of service has been 5 days for all cancer diagnoses. This equates to a 1 day reduction in LOS. Median LOS in the preceding years 2011-2015 was 6 days.
- the national Macmillan pathway launch for metastatic spinal cord compression (MSCC) took place in Cwm Taf and the MSCC local pathway has been implemented in the health board.

Macmillan framework for cancer
In response to the changing nature of cancer and the increase in the number of people surviving cancer treatment, who need ongoing care, Macmillan has
funded an innovative five year initiative called the Macmillan framework for cancer in primary and community care programme.

The Macmillan framework for cancer programme clinical team works as a community of practice across Wales to share good practise and innovation. A series of web based resources and guidance on ‘what good cancer care looks like’, is being developed.

**Peer review**

The peer review programme, developed and implemented over the past five years has proved highly valued and the programme is now re-visiting the first cancer teams seen three years ago as part of a cyclical approach. This reassessment after three years has seen improvement across all teams within all health boards. The first teams revisited were those involved in Lung Cancer and the indications are that the next group being assessed are also showing similar signs of improvement over the same time period.

The last year has also seen the peer review of rarer cancers with the review of neurological cancers nearing completion. This approach has demonstrated the versatility of peer review in Wales through involvement of expertise from large specialist centres in England.

In the coming years the cycle of review will continue alongside further reviews of other rare cancers and specialties such as oncology.

Led by the cancer network, in conjunction with Health Inspectorate Wales, the cancer peer review programme has led the way in Wales with other major health conditions now adopting this model.

The Macmillan framework for cancer programme is looking at how peer review can be expanded to become a ‘whole system’ review, including input from primary care to the peer review process in selected health boards, with a view to developing a model for successful primary care engagement.

**Organisational redesign**

A new single cancer structure for Wales has been developed by bringing together the north and south Wales cancer networks and the National Specialist Advisory Group into the Wales Cancer Network, hosted by the Wales Collaborative. Key clinical leadership and support mechanisms in one body will underpin cancer service improvement and place the patient at the heart of everything cancer services do. The Wales Cancer Network is providing leadership and resources on an all Wales basis.

**Established key worker policy and implementation**

Key worker guidance has been developed, agreed and distributed by the cancer implementation group. Work has been undertaken by the cancer networks to make sure that health boards are following the guidelines and that measures are in place to monitor compliance.
Wales patient experience survey
The first national cancer experience survey was undertaken in 2013 and the second survey is being carried out during 2016 and will report in Spring of 2017.

National cancer conference
In 2015, the first Welsh National Cancer Conference was held. A key theme of this conference was early diagnosis of cancer. A second conference was held in October 2016.
3.0 Cancer in Wales

3.1 Cancer incidence

More than 19,000 people were diagnosed with cancer\(^3\) in Wales in 2014. This equates to around 629 cases\(^4\) for every 100,000 people. The number of people being diagnosed with cancer is increasing and continues to rise at an average rate of around 1.5% per year. There has been a rise in the number of new cases of cancer of 14% (2375 cases) over the last 10 years. In 2014, there were 19,118 new cases of cancer diagnosed amongst people living in Wales compared with 16,743 in 2005. Of these, 9,849 were diagnosed in men and 9,269 were diagnosed in women. Figure one shows that Scotland tends to have the highest incidence rates, followed by Wales.

![Figure 1: Cancer incidence European age standardised rate per 100,000 population](image)


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\(^3\) Throughout this report the term cancer refers to all cancers apart from non-melanoma skin cancer

\(^4\) European Age Standardised Rate per 100,000 population (using the 2013 European standard population)
3.2 Cancer and older people

Cancer can develop at any age, but in general is more common in older people.

The number of people registered with a new diagnosis of cancer in Wales in 2013 remains low up to age 40 years in women and 45 years in men. After that the annual number of cases starts increasing steeply with age for both men and women (figure 2). At younger ages the numbers are similar for each gender.

More women than men are diagnosed with cancers between the ages of 30 to 54, and at 90 years and over. The increase starts earlier in women due to women specific cancers such as breast and cervical cancer. For older age groups there are increasingly more women than men alive. More men than women were diagnosed with cancer between age bands 60-64 years and 80-84 years.

The largest increase in numbers has occurred in 65-69 age groups in both men and women, as well as the 70-74 groups. These shifts have resulted in the most common age at diagnosis for both men and women in 2013 occurring between 65 and 69 years (1,688 men, 1,362 women). This is about 10 years younger than it was a decade previously. Demographics explain most of these changes in the number of people diagnosed with cancer in specific age groups in men and women.

![Figure 2: Age at diagnosis with cancer - 2014](image)

*Source: Welsh Cancer Intelligence and Surveillance Unit’s Cancer Registry 2016.*

Age-standardisation adjusts rates to take into account how many old or young people are in the population being looked at. When rates are age-standardised, it means that differences in the rates over time or between geographical areas do not simply reflect variations or changes in the age structure of the populations. The age-adjusted cancer incidence rate
decreased in men by just over three per cent in the 10 years up to and including 2014. However at the same time, the rate for women increased by over five per cent. The age-specific cancer rate rose more steeply in men than women. By 2014, rates in men were over 50% higher than in women for ages 70 years and over.

3.3 Common cancers

In 2014 the most common cancers in Wales numerically were female breast cancer, prostate, lung and bowel (colorectal) cancer. Prostate, then bowel, followed by breast, melanoma and lung cancers had the largest average annual increases in numbers between 2002-2004 and 2012-2014. Liver cancer rates increased by 65% in men and 42% in women. Almost all the increase in lung cancer numbers occurred in women – over eight times more than in men. Women in Wales have a high lung cancer incidence compared to many other European countries.

Figure 3: Average change in the number of new cancer cases by cancer type in Wales 2002-04 and 2012-14

Some cancers decreased in numbers. Stomach cancer was down by 12% (122 cases) in men and 30% (191 cases) in women. Oesophageal cancer in women was down 14% (72 cases), and chronic myeloid leukaemia in women was down 28% (17 cases).

Referrals for some types of cancers are likely to continue to rise over the forthcoming years. This is due to a number of factors: the population is increasing and ageing and there is the continued influence of some risk factors.

Source: Welsh Cancer Intelligence and Surveillance Unit’s Cancer Registry 2016.
3.4 Deaths from cancer

In 2014, 8,933 people died of cancer in Wales: 4,740 men and 4,193 women. This is an increase of 7% since 2005. There has been a 10% increase in the number of deaths in men compared with a much smaller increase of 4% in women.

The largest number of deaths occurred in age bands 75-79 years (1,432 deaths) and 80-84 years (1,419 deaths). The largest increases from 2005 to 2014 were of 44 per cent for men and 24 per cent for women in those aged 85 years and over.

Figure four shows that there has been a steady decline in the overall age-adjusted rate\(^5\) of people dying from cancer over the last 20 years, despite the increase in the actual number of cancer deaths. In Wales mortality rates from cancer have fallen by 26% over this time frame. Although age-adjusted cancer mortality for people under 75 in UK countries is highest in Scotland, it is similar in Wales, England and Northern Ireland (figure 4), with a 2% reduction from 2010 to 2014 in Wales.

![Figure 4: Cancer mortality under 75, European age standardised rate per 100,000](image)


The most common cancer related death in Wales was lung cancer, with 1,968 deaths registered in 2014. Bowel cancer was the second most common cancer death, with 927 deaths, and prostate cancer was the third most common, with 613 deaths.

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\(^5\) Based on the European Age Standardised Rate per 100,000 population (using the 2013 European standard population) for persons under 75.
Cancer survival is steadily improving in Wales. One year survival from all cancers combined is continuing to increase, although the rate of increase in more recent years is slower than earlier years. Over 71% of people diagnosed with cancer between 2009 and 2013 survived at least one year.

Five year survival (for patients diagnosed 2005-2009\(^6\)) is also increasing, but more slowly than in previous years. This increase is still encouraging, over 54% of people diagnosed with cancer can expect to survive for at least five years, (52% men and almost 57% of women).

However, there are wide variations between different types of cancer and inequalities in survival across population groups and geographies in Wales.

The gap in survival between men and women continues to decrease. Although survival remains better in women, the gap has closed by a half over ten years for both one-year and five-year survival.

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\(^6\) To allow for all patients to be followed up for five years, survival calculations are only available for diagnoses made up to 2009 at present.
The cancers with the lowest one year survival are lung cancer, acute myeloid leukaemia, liver and pancreas and liver. Despite this, these cancers have shown improvements in one year survival.

IN 2009-2013, testicular cancer has the highest one year survival rate of 98.1%, followed closely by melanoma, prostate cancer and female breast cancer (all over 96%)\(^7\). Almost 76% of people diagnosed with bowel cancer now survive for at least one year.

Similar to one year survival, the lowest five year survival rates are for cancers of the pancreas, liver and lung at or below 5%. For lung cancer the five year survival rate is 6.5%. Five year survival for testicular cancer is again high at 96.7% for the latest period of 2005-2009. Five year survival for prostate cancer and female breast cancer is over 85% for 2005-2009.

### 3.6 Cancer and deprivation

The incidence of many diseases or health conditions tend to be linked to area deprivation and individual socioeconomic status. This is also true of many types of common cancer. Overall cancer incidence rate is 22% higher in the most deprived areas of Wales, compared to the least deprived (figure seven). That means that there are around 128 extra cancer cases per 100,000 people living in the most deprived areas.

\(^7\) Welsh Cancer Intelligence and Surveillance Unit’s Cancer Registry 2015
Lung cancer has a wide gap in incidence between the most deprived fifth in Wales compared to the least deprived – with the highest incidence in the most deprived areas. This gap has widened by 6% over the last eight years. Bowel cancer incidence also increases with area deprivation, but inequalities are much less, with little change over time. Like lung cancer, female breast cancer and prostate cancer incidence has a deprivation gap, but unlike lung cancer, the higher incidence is in the least deprived areas.

The gap in one-year survival between the least and most deprived areas of Wales has decreased over the last 9 years (2000-2004 to 2009-2013), whereas the gap in five-year survival has increased slightly (2000-2004 to 2005-2009). The deprivation gap for overall one-year survival for bowel cancer has widened by 15% over the last 9 years (2000-2004 to 2009-2013), whereas the deprivation gap for breast, prostate and lung cancers have narrowed considerably.

There are marked deprivation inequalities in overall five-year survival for bowel, breast and prostate cancers, but not for lung cancer. These survival gaps are wider than for one-year survival. The gap is widest for bowel cancer, which increased by 21% over 6 years.

The gap in mortality rate between the least and most deprived areas of Wales is wide for lung cancer compared to other common cancers. This gap has widened by 11% over the last eight years.

Source: Welsh Cancer Intelligence and Surveillance Unit’s Cancer Registry 2016
4.0 Improvements to the cancer pathway

Cancer services in Wales are overseen by a NHS Wales-led Cancer Implementation Group (CIG) which includes representation from the Cancer Network, third sector, primary care, Public Health Wales, health boards, NHS Wales Informatics Service and the Welsh Government.

The national CIG is accountable to the Chief Executive of NHS Wales for the overall coordination of the delivery plan implementation and acts as a forum for the development of national solutions to common delivery problems. The Chair of the Group also acts as a key link to the all-Wales chief executives group and the NHS Collaborative. Increasingly the CIG is steering improvement activity rather than delivering projects as its delivery mechanisms mature.

Over the past 12 months, CIG has focused on ensuring that sustainable changes are made to the way services are delivered across Wales for patients who have cancer. An important development has been the merger of the north and south Wales Cancer Networks and the National Specialist Advisory Group into the Wales Cancer Network. This brings together key clinical leadership and support mechanisms into one body to better support the wider service and provide an all-Wales resource to support cancer service improvement and place the patient at the heart of everything we do. Increasingly the Network is providing or supporting the regular clinical leadership needed to draw people together and create synergies among different services, policies and projects.

Since 2015-16, Welsh Government allocated £1 million annually for the delivery of the priorities identified by the CIG.

A poor interface between primary and secondary care is recognised as a major cause of delays for cancer patients. Following a visit to Denmark to review their model of care for suspected cancers at the GP and hospital interface, planning is underway to pilot a Danish-style GP access diagnostic model at Neath Port Talbot Hospital (NPTH). The rapid diagnosis clinic will provide a comprehensive assessment by radiology and general medical specialists within a few days of GP referral for those patients with serious but vague, non-specific symptoms. The pilot will initially take referrals from NPTH GP clusters. If it is successful, a wider implementation at Abertawe Bro Morgannwg University (ABMU) Health Board will follow. This work will build on the primary/secondary care engagement fostered in the development of the ABMU lung cancer diagnostic pathway, where patients with a suspicious CXR are now routinely booked for a CT scan, removing the delay involved in the GP having to request further investigations.
Peer review has continued into its fourth year with services for head and neck, breast and skin cancer being subject to this process for the first time in 2015. 2016 has seen the first review of haematology and neurological cancer services alongside the reassessment of lung and upper gastrointestinal cancer services as part of the three year review cycle.

Peer review involves health board cancer teams being visited and scrutinised by similar teams from other health boards, with the outcome being a report highlighting good practice and areas of practice recognised as in need of further development. Health boards are required to prepare a plan in response and consider their achievements against this plan annually.

Primary care representation and participation at peer review was provided for the first time in 2016, at the lung peer review in Abertawe Bro Morgannwg University Health Board and Aneurin Bevan University Health Board.

The peer review process is informed by evidence of the cancer team's performance, either through local, national or international audit or measurement against the Welsh National Cancer Standards 2005. Other measures are also considered, such as any relevant guidance from the National Institute of Clinical Excellence.

The second cycle of lung cancer peer review in Wales undertaken in 2016 had excellent engagement in the process of peer review, both in terms of those being reviewed and those undertaking the reviews.

The peer review indicated that areas of consistent good practice were highlighted as:

- the resection rate (where resection main curative intervention) had nearly doubled in recent years from being well below the National Audit (England and Wales) average to being above
- there was more comprehensive support for patients by specialist nurses and greater clarity these were the patient’s key worker
- acute oncology services are now evident at various levels of progress across all health boards in Wales
- improved access to specialist diagnostic services
- improved use of patient surveys to reflect on service quality being delivered
- continued high compliance with national audit data completion
- development and access to advanced radiotherapy techniques such as stereotactic ablative radiotherapy.

It also highlighted the following areas where the practice was mixed or inconsistent:
• access to oncologists within multi-disciplinary teams, particularly with respect to cover, was variable
• pathway working, with some excellent examples of developing onward referral from abnormal radiological findings to some areas of unacceptably long reporting times
• variable awareness of variation in practice for example in awareness of population survival rates, or cancer conversion rates, and the reasons for this variation
• variable engagement with primary care, some examples where this has certainly increased but inconsistent discussion of reflective findings of significant event initiative undertaken in primary care for all diagnoses of lung cancer
• inconsistent use of lung cancer teams in smoking cessation programmes

The following areas are where concerns were raised in all or most services:
• the waiting times for surgery remain a major concern (despite the increase in the lung cancer resection rate) with evidence of adverse outcomes as well as major cause of cancer waiting time breaches
• access to an informatics platform that can share information across services and develop in line with national audit requirements and allow services to benchmark performance across and outside of Wales
• respiratory physicians have a major remit regarding providing acute care in secondary care services and maintaining a focus on cancer services and improvement initiatives is becoming increasingly difficult.

Through a collaborative clinically led process, Cwm Taf University Health Board has developed a new pathway for patients who present to primary care with non-specific symptoms who do not fit an existing urgent suspected cancer pathway. In such cases GPs often try and navigate their way through the system requesting a multitude of diagnostic investigations to determine the cause of the symptoms and resulting in numerous appointments for patients. The new pathway that has been clinically developed brings primary and secondary care clinicians to deliver a more integrated service which strengthens the role of radiologists to fully utilise their skills and expertise.
4.1 A refreshed cancer delivery plan

A refreshed delivery plan was published in November 2016. This refreshed plan builds on the progress and successes to date and provides continuity for the service up to 2020. Where necessary legacy actions will be taken forward but the new plan reflects the lessons learnt over the past few years and provides a greater focus on key areas where the delivery plan can make a difference.

The development of the plan has been led by the Wales Cancer Network, reporting to the CIG and has involved extensive stakeholder input from across the health service and third sector. It reflects new emphases which have emerged, such as prudent healthcare and the Wellbeing of Future Generations Act.

Key areas of focus in the refreshed plan include integrating the primary and specialist parts of the cancer pathway, supporting improved access and timeliness to diagnostics, improving productivity and capacity, as well as improving standards and supporting patients through and beyond active treatment. Continued close working between the Welsh Government, Cancer Implementation Group, Wales Cancer Network, Wales Cancer Alliance and care providers are key to delivering the next phase of the cancer plan at pace and with impact.

The refreshed cancer delivery plan aim is to close the gap with the best performing European countries by giving everyone with cancer the highest standard of care. This will be demonstrated through improving survival, reducing premature mortality and maintaining high levels of positive patient experience.
5.0 Preventing cancer

A person’s risk of getting cancer depends on a combination of things, including genes, environment and aspects of their lives, some of which can be controlled. Some people do inherit damaged DNA from their parents, which can give them a higher risk of certain cancers. However, the proportion of cancers caused by inherited faulty genes is small.

Cancer Research UK suggests that in the UK, more than one in two people will develop cancer at some point in their lives, mainly in older age. More than 19,000 people are diagnosed with cancer each year in Wales. It is estimated that around 40% of cancers are contributed to by factors such as tobacco, obesity, alcohol and physical activity, for example, and that much of this population burden is potentially preventable.

**Figure 8 - Percentage of adults who - 2015**

- Reported fruit and vegetable consumption of five or more portions the previous day
- Reported being physically active for 150 minutes or more a week
- Reported drinking above the guidelines in the past week
- Are obese; BMI (kg/m2) 30 and over
- Smoke daily or occasionally


Figure eight clearly shows a large proportion of people in Wales could do more to reduce their risks of cancer.

According to Cancer Research UK, smoking accounts for more than one in four UK cancer deaths, and nearly a fifth of all cancer cases. It also increases the risk of many other types of cancer. Lung cancer is responsible for almost 22% of cancer deaths in Wales (1,968 deaths) and a number of lung cancer cases are related to smoking. Yet 19% of adults in Wales report that they smoke daily or occasionally.

Drinking alcohol is known to increase your risk of some cancers, including cancers of the breast, liver, mouth, pharynx, larynx cancer and oesophagus.

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9 Cancer Research UK
In Wales, in 2015, 59% of adults were overweight or obese, of these 24% are obese. Being overweight or obese can increase your risk of some cancers, such as cancers of the breast and bowel cancer.

5.1 Human papilloma virus vaccine

All girls aged 12 to 13 are offered HPV (human papilloma virus) vaccination as part of the NHS childhood vaccination programme. The vaccine protects against cervical cancer. It is delivered largely through secondary schools, and consists of two injections into the upper arm, spaced at least six, and not more than 24 months apart. Research has indicated that the HPV vaccine protects against cervical cancer for at least 20 years. The programme is expected to reduce the incidence of the disease by a further 60% over the next 20 years.

Uptake of one dose of the HPV vaccine in girls turning 14 years of age during the 2015-16 school year 9 was 90%. Uptake of two doses is currently 67% (as at the end of March 2016). This represents the first school year group to be offered the two dose schedule. Vaccination sessions for the second dose of HPV vaccine in this group may not have been completed across all areas and will have continue to increase until the end of the 2015-16 school year.

Public Health Wales and health boards are waiting to hear the recommendations from the Joint Committee on Vaccination and Immunisation and Wales Immunisation Group on the HPV vaccination for adolescent boys.

5.2 Cancer prevention awareness

Public Health Wales has produced frameworks for action on physical activity, nutrition and tobacco control. These make recommendations for activity to be delivered by local partners and for investment in physical activity.

Through its health improvement programmes, Public Health Wales aims to use evidence based interventions to reduce tobacco smoking and alcohol intake, improve diet and increase physical activity levels for the population of Wales. To this aim, it has produced a series of evidence briefings, which specify what interventions work for healthy eating, obesity and overweight, physical activity, tobacco and alcohol.

As noted earlier in this report, a small range of lifestyle factors are responsible for 40% of cancers—these are not new, and these risks have been understood for some time. It is changing however. Whereas smoking was the leading cause of avoidable ill health it is now obesity, which along with other dietary factors account for five of the top 10 leading causes of early death and disability. Public Health Wales is focusing its prevention campaigns upon key risk behaviours.
The Welsh Government’s physical activity plan, 'Creating an Active Wales', aims to make physical activity a natural part of people's lives. This means creating an environment that:

- makes it easier for people to be more physically active
- supports children and young people to lead active lives
- encourages more adults to be more active, more often
- increases people's participation in sport.

There is good scientific evidence that being physically active can help people lead healthier and even happier lives. Regular physical activity can reduce the risk of many chronic conditions not only cancer, including type 2 diabetes, heart disease, stroke, obesity, mental health problems and musculoskeletal conditions. Even relatively small increases in physical activity are associated with some protection against chronic diseases and an improved quality of life.

The Welsh Government launched Change4Life Wales in 2010 as part of a broader response to help people to achieve and maintain a healthy body weight, to eat well and be physically active. Change4Life Wales runs annual health campaigns focussing on and aiming to address smoking, obesity, healthy eating, physical activity and alcohol. Along with annual campaigns the Change4Life Wales website provides information on how to achieve a healthy lifestyle encouraging people to take small steps to improve their health. By March 2016 over 77,546 individual sign ups have been made to the programme and many more have accessed advice from the website, Facebook and Twitter.

Actions to increase physical activity are embedded in the Cymru Active Travel Challenge. Over three challenges the challenge aims to motivate over 4,500 employees across Wales to increase the frequency of active travel and use of public transport for everyday journeys; and to replace single occupancy car journeys.

The Welsh Network of Healthy School Schemes was established in 1999. Schools can apply to be independently assessed for the WNHSS National Quality Award (NQA) after nine years involvement. They need to demonstrate an excellent whole-school approach to a range of health topics, including food and fitness. 99% of maintained schools in Wales are actively involved in the scheme, with 122 having achieved the NQA.

Public Health Wales is working closely with Welsh Government and health boards to develop effective early years interventions utilising concepts from the 10 Steps to a Healthy Weight programme such as eating fresh fruit and vegetables on a daily basis.

Lets Walk Cymru provides local communities with a walking resource that is free, easily accessible and suitable for a wide range of abilities. Approximately 130 walking groups have been established across Wales; over 14,000 walkers registered; 4,114 new walkers since April 2014; 13, 789 walks since April 2014 and 886 new walk leaders trained since April 2014.
The Healthy Working Wales programme aims to improve health and wellbeing to help people stay in work or return to work. The programme supports employers, to help employees to establish healthy lifestyles habits, including alcohol, tobacco, physical activity and healthy eating to reduce the risk of preventable diseases. At the end of March 2016, 3,181 organisations in Wales, employing 459,202 people, have engaged in the Healthy Working Wales range of programmes since July 2011, representing 33% of the working population of Wales.

In North Wales cancer prevention talks from NHS cancer staff have continued to be made available free to schools on demand and demand has increased with some schools now receiving talks for the second year running.

### 5.3 Cancer screening

Cancer screening involves testing apparently healthy people for signs of the disease. It can detect cancers at an early stage and in some cases, even prevent cancers from developing in the first place. There are three population based national cancer screening programmes in Wales; these are managed by Public Health Wales.

The breast screening programme aims to reduce morbidity and mortality from breast cancer. Breast Test Wales invites eligible women aged between 50 and 70 for breast screening every three years. Women aged over 70 can self refer. The uptake for breast screening in 2015-16 in Wales is similar to previous years and meets the minimum standard. A total of 1,207 cancers were detected in women screened aged 49 and over in 2014-15. This represents 10.6 cases per 1,000 women screened. Of the 1,207 cancers detected this year, 79% (954) were invasive lesions. In 2013-14 78.3% (967) were invasive and in 2012 79% (755) were invasive.

The aim of the cervical screening programme is to reduce the incidence of, and morbidity and mortality from, invasive cervical cancer. Cervical Screening Wales invites women aged 25-50 years every three years and those aged 50-64 every five years. The coverage of cervical screening in 2015-16 at 77.8% is close to the standard of 80%. 7,700 new patients were seen at colposcopy clinics in Wales in 2015-16, 71.5% having been directly referred by Cervical Screening Wales and 28.5% for clinical reasons.

Bowel Screening Wales (BSW) invites eligible men and women aged between 60 and 74 to take part in bowel screening every two years. BSW was launched in October 2008 and aims to reduce the number of people dying from bowel cancer in Wales by 15% by 2020 in the group of people invited for screening. To achieve this aim the bowel screening programme must identify cancer early when treatment is more successful and also identify and remove polyps that may otherwise go on to become malignant. In the year 2015-16 BSW diagnosed 205 people with cancers and detected and removed polyps in 1,149 participants. The proportion of colorectal cancers diagnosed by
screening is greater in Wales than in England at 12% compared to an overall average for England and Wales of 10%\textsuperscript{10}. There are indications that the rate of emergency admissions for colorectal cancer has reduced in Wales since the bowel screening programme was implemented and this is currently being evaluated further.

Table 1: Uptake in cancer screening programmes

<table>
<thead>
<tr>
<th></th>
<th>Number eligible/ invited</th>
<th>Number tested</th>
<th>Uptake/ coverage</th>
<th>Minimum standard / target</th>
<th>Change from 2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Screening Uptake 2015-16</td>
<td>144,529</td>
<td>102,815</td>
<td>72.5%</td>
<td>70</td>
<td>+0.1%</td>
</tr>
<tr>
<td>Bowel Screening Uptake 2015-16</td>
<td>281,082</td>
<td>152,794</td>
<td>54.4%</td>
<td>60</td>
<td>+3.6%</td>
</tr>
<tr>
<td>Cervical Screening Coverage 2015-16</td>
<td>264,705</td>
<td>190,614</td>
<td>77.8%</td>
<td>80</td>
<td>-0.2%</td>
</tr>
</tbody>
</table>

Source: Public Health Wales - December 2016

Table one demonstrates that the bowel screening programme is below the target of 60% and much work is being undertaken to evaluate interventions to improve participation levels, which is reflected in the 3.6% increase in participation this year.

The uptake of bowel screening is low in Abertawe Bro Morgannwg University Health Board, particularly in men from more deprived areas. A pilot has taken place to improve bowel screening coverage. There was engagement and participation from all 32 GP practices in four clusters in the health board with low bowel screening take up. This and other pilot projects have provided valuable information which will inform future development of interventions.

The introduction of screening programmes in Wales is based on the expert advice of the UK National Screening Committee and Wales Screening Committee to ensure programmes do more good than harm and are cost-effective. However, for programmes to reach their potential the uptake of screening services by the public needs to improve and a combination of awareness raising and more acceptable testing will help to achieve this. Targeted action in areas of high deprivation, where it is known uptake of

\textsuperscript{10} NBOCAP 2015
screening programmes is lowest, will also support a reduction in inequalities of health outcome. This must increasingly involve a range of local community services to improve awareness and public engagement with the national screening programmes.

68 practices across Gwent participated in a project to try to increase uptake in bowel screening by raising awareness in patients who had not responded to their invitation to take part. Practices undertook opportunistic brief advice, sent encouragement letters and telephoned patients. Initial data shows that nearly a fifth of patients who had previously not responded, had since participated. Feedback from practices on the process has been generally positive.

5.4 Early detection of cancer

Betsi Cadwaladr University Health Board has made significant improvements in its diagnostic services. Pathology services have been centralised and the health board is one of the first two health organisations in the U.K. to introduce a digital pathology system. All three acute hospitals now have two CT scanners and PET-CT is provided via a mobile service in Wrexham; these developments have significantly reduced waiting times and travel times for patients in 2015-16.

It is important to make sure the public, GPs and others in the healthcare system are able to recognise the possible warning signs of cancer and are able to take prompt action. Some early signs of cancer include a persistent cough, lumps, sores that fail to heal, abnormal bleeding, persistent indigestion, and chronic hoarseness. Early diagnosis is particularly relevant for cancers of the lung, breast, cervix, larynx, colon and rectum, skin and mouth. Early referral from primary care is important. However all referrals whether cancer or not, need a prompt diagnosis even if to eliminate the possibility of cancer. Rapid access to diagnostics and turnaround of result is key to early treatment.

During 2016 the NHS in Wales, with Macmillan Cancer Support, has invested time and resources in exploring a number of initiatives around early diagnosis. These include:

- working with Aneurin Bevan University Health Board to allow patients to access a CT scan
- developing vague symptom pathways and diagnostic centre approaches in Cwm Taf and Abertawe Bro Morgannwg University Health Boards
- collating themes from primary care national clinical priority for earlier diagnosis for GI, lung and ovarian cancers
• community pharmacy access to chest x-rays in Hywel Dda University Health Board
• developing primary care computer based tools to aid assessment of symptomatic patients, assessing risk and linking to local referral pathways in Cardiff and Vale University Health Board.

As part of the early cancer diagnosis programme, clinicians within Cwm Taf University Health Board identified two urgent suspected cancer pathways for redesign to improve time to diagnosis. As a result two new pathways have been approved which incorporate a one-stop investigation model at the front end of the pathway which significantly reduces the time between investigation and diagnosis. The prostate pathway commenced in November and the haematuria pathway is due to commence in January 2017.

5.4.1 Research into Action
Wales has continued as an active partner in the International Cancer Benchmarking Partnership (ICBP) this year. The ICBP findings on earlier diagnosis of cancer, have informed two of the Cancer Implementation Group’s national work streams.

Firstly, as part of the lung cancer initiative, a greater understanding of public awareness and the barriers that delay people going to their GP has been developed. This shaped the first Welsh lung cancer awareness campaign that was launched in July 2016. The launch included advertising on ITV Wales, S4C and radio with additional Wales online media interviews involving lung cancer survivors, GPs and radiologists. The campaign reached localities with a higher incidence of lung cancer by using bus adverts on selected routes. Briefings, posters, leaflets and symptom cards were prepared to inform involvement of GPs, pharmacists, local communities and cancer charities. The short and longer term impact of the campaign will be evaluated and reported on in due course by the Wales Cancer Intelligence and Surveillance Unit.

The ICBP has recently commissioned a contemporary international cancer survival benchmark for eight cancers, across at least six countries and 20 jurisdictions. The Wales Cancer Intelligence and Surveillance Unit will be leading on this project for Wales. This updated cancer survival benchmark will underpin in-depth analyses, to provide further insights into the factors that contribute to international variations in survival’.

5.4.2 Improving rates of cancer detection
International studies consistently show Wales toward the bottom of international comparators for cancer survival and highlight stage at diagnosis as a possible causative factor. The significantly higher number of patients
diagnosed through the secondary care cancer pathway and the proportion of cancers diagnosed at stages three and four suggests Wales needs to better identify cancers at earlier stages. Detecting cancer early is vital as it makes it more likely treatment can be less intensive, less expensive and more likely to achieve improved outcomes.

The issues behind the lower than desired detection rates are complex. Informed by international studies, possible reasons include a lack of public awareness of ‘alarm’ symptoms and lack of willingness to bother GPs; the challenge for GPs to identify cancers with ‘vague’ symptoms and a greater reluctance to refer onwards partly due to concerns about accessibility of testing; there are also unnecessary delays in the structure of the diagnostic pathway and additional delay due to secondary care gatekeeping and down-grading of referrals. This can contribute to unacceptable delays and a poorer prognosis.

Having delivered a lung cancer awareness campaign the Cancer Delivery Plan 2016-2020 identifies the need for delivery of further campaigns that will have a part to play in helping raise awareness of ‘alarm’ symptoms in cancers with poor outcomes – the Wales Cancer Network will lead on the response to the Cancer Delivery Plan and consider what actions are needed to deliver ongoing awareness campaigns.

Members of the lung cancer multidisciplinary team and others in relevant departments at Cardiff and Vale University Health Board have been working as part of an outcomes focused joint working project with Novartis. The aim of the project has been to improve outcomes for patients diagnosed with lung cancer by making the diagnostic pathway more efficient and effective. Much has already been achieved, including improving the efficiency of sample processing in histopathology, earlier CT scans and CT guided biopsies and making better use of existing IT. Early indications are that the diagnostic process has been speeded up and that treatment decisions can be made earlier. Additional Welsh Government funding for the introduction of routine genetic testing, using next generation sequencing, as part of the lung cancer diagnostic process will help to ensure that more patients can get the most appropriate treatment and be potentially identified for participation in clinical trials.

The National Institute for Health and Care Excellence has recently introduced guidelines which encourage referral at a low threshold of suspicion. It is expected that this change to the guidance will result in an increase in referrals and a fall in the conversion rate in order to detect more cancer at an earlier stage. This will require high quality information for patients and increased capacity in diagnostics and expert advice from specialist cancer teams. In Wales the National Clinical Priority for prevention and early diagnosis of cancer has engaged GPs in exploring local patient experience and identifying service improvement actions.
The CIG has championed this reflective approach and facilitated a visit to learn from a high performing health care system. Diagnostic pathways are being rethought in light of learning from the NHS Wales delegation to Denmark and an early pilot of a diagnostic centre in Cwm Taff University Health Board. This approach which is based on referral and direct access to certain tests are key areas for development in Wales. The improvement to diagnostic access and capacity more generally are challenges in Wales. This is related to under provision of imaging equipment and acute workforce shortage in pathology and radiology. The national imaging and pathology programme boards, the development of a radiology academy and the wider NHS workforce strategy will be key levers for addressing the workforce shortages limiting access to diagnostic testing.

5.4.3 Macmillan framework for cancer
The Macmillan framework for cancer in primary and community care programme which aims to

- develop clinical leadership in primary care, through GPs, nurses and other health care professionals, for cancer service improvement
- develop a framework of tools and resources for health professionals in primary and community care to enhance early diagnosis so that people seeking help for signs and symptoms of cancer have an improved experience and are well-supported during pre diagnosis, and early interventions are made to support health and wellbeing to maximise the effectiveness of proposed treatments and care, wherever possible
- support the delivery of person-centred care from diagnosis to when cancer treatment ends so that people live well with and beyond cancer
- improve communication between primary and secondary care and enhance integrated care at key transition points.

During 2016, there has been a successful campaign to recruit GPs, nurses and programme support across Wales. The clinical team are now leading and supporting local work streams to develop the Macmillan framework for cancer programme across Wales. Further recruitment of GP facilitators to implement the programme is planned for 2017.

The framework for cancer programme priorities incudes:

- lung cancer diagnosis, including direct access route to a CT scan in Aneurin Bevan University Heath Board
- Neath Port Talbot ‘Vague Symptom Diagnosis Service’ and Cwm Taf University Health Board Cancer Diagnostic Hub.
- lung cancer pilot linking community pharmacy direct to a chest X ray project in Hywel Dda University Health Board
- develop unified approach to NICE cancer referral guidelines across all health boards
- review of national clinical priority data across all health boards
- developing primary care input to peer review across all health boards
- cluster and pathway IT solutions, including the development and uptake of IT tools embedded in primary care clinical software in Cardiff and Vale University Health Board
- breast and prostate referrals and follow up pathways review and re-design work in Betsi Cadwaladr University Health Board
- the Macmillan recovery package involves nurses exploring the cancer review and holistic needs assessment in three health boards
- primary care support to Velindre transforming cancer services education programme.

5.5 Cancer staging

Staging is a way of describing the size of a cancer and how far it has grown. When doctors first diagnose a cancer, they carry out tests to check how big the cancer is and whether it has spread into surrounding tissues. They also check to see whether it has spread to another part of the body. Staging is important because it helps determine what treatments might be necessary.

A high proportion of patients in Wales are presenting with late stage cancer at the time of their diagnosis and the importance of late presentation cannot be overstated. Patients with advanced stage of disease have worse survival outcomes; have a greater treatment burden with a consequential effect on their quality of life thereafter. The treatment of advanced stages of cancer is resource intense, both during the initial treatment phase and ongoing. Moving cancer presentation towards earlier stage diagnosis will have a positive impact for the patient whilst also lessening the need for intensive support and the financial burden on Welsh NHS organisations of 'survivorship' care.

Staging gives an indication as to how well cancer services are performing with regard to early diagnosis. In the first cancer annual report, almost 42% of all cancers in 2011 were not being recorded on CANISC and a target was set that 70% of all cancers should have stage recorded by the end of 2012 and 90% by 2016. Health boards have worked hard to implement effective procedures to ensure that these targets were achieved and performance has continued to improve with over 76% of all cancers having their stage being recorded on CANISC by the end of 2015.
It is important that more cancers are diagnosed at an early stage. Figure 10 highlights the slow and steady progress being made in increasing the number of cancers diagnosed at stages 1 and 2. Advanced cancer (stages 3 and 4) have the worst outcomes for patients and it is important to make sure that we do all we can to increase diagnosis of cancer at the early stages when the best outcomes are possible. This needs to include promoting:

- active engagement of the public in recognising symptoms
- recognition of alarm symptoms and early self referral to the GP
- recognition of alarm symptoms and instigation of early investigations by GPs
- fast diagnosis and staging when referred to hospital.

TNM stages are grouped according to UICC defined groups.
Figure 10 highlights the variations across the different tumour sites. Almost 50% of head and neck and lung patients are diagnosed at stage 4. There are a high percentage of breast, skin, upper gastrointestinal and urological cancers where stages are not recorded. 

Source: CANISC\textsuperscript{12}.

\textsuperscript{12}TNM stages are grouped according to UICC defined groups.
6.0 Cancer treatment

Upon suspicion of cancer, a patient will be referred urgently to see a consultant. It is important that patients are seen and assessed as quickly as possible. Speedy diagnosis will result in a patient being treated quickly; and if they do not have cancer that they do not have to wait a long time for cancer to be ruled out.

Ideally the first meeting with the consultant should take place within 10 working days of a person being referred by their GP with urgent suspected cancer. Whilst this is not a formal target for health boards, evidence indicates that the quicker a patient has their first outpatient appointment, then the faster the appropriate treatment is arranged. However, health boards have introduced one stop diagnostic clinics and systems in many specialities, where GPs can refer patients prior to seeing a consultant. In these cases the first appointment may be after 10 working days.

Figure 11 highlights performance against the 10 working day milestone for patients subsequently diagnosed with cancer. This has improved over the past 12 months. In April 2015 less than 50% (255 patients out of 519 referrals) of patients were seen within 10 working days. By the end of March 2016 this had improved to 62% (129 patients out of 208 referrals) although performance had been at 67% (316 patients out of 472 referrals) in January 2016. This is not good enough and health boards will need to focus their performance against this guideline over the next year.

Improving cancer access times is a top priority for Cardiff and Vale University Health Board. A reduction of the backlog of patients waiting past their target times has been reported both externally and internally on a weekly basis this year. This has been a key area for success for the health board. However the health board has not met the 62 and 31 day targets for cancer treatment this year, although performance against these targets is improving month by month. There are challenges in access to and reporting of CT and MRI for patients with suspected cancer and a wide variability in turnaround time for pathology diagnostics.

The Cardiff and Vale University Health Board urology project, to decrease the waiting time from referral to treatment for patients with urgent suspected prostate cancer, won the Improving Patient Safety category in the NHS Wales Awards 2016. The resulting changes in the pathway have led to a decrease in waiting times, as well as avoiding unnecessary biopsies and scans.

The robotic assisted laparoscopic prostatectomy (RALP) service continues to strengthen. There is an in-reach programme whereby surgeons from Abertawe Bro Morgannwg and Aneurin Bevan University Health Boards undertake robotic procedures for their patients. This procedure provides significant benefits over traditional open procedures. Cardiff and Vale University Health Board is working with other health boards to determine more areas where robot assisted laparoscopic surgery may provide further benefit for patients with cancer.
6.1 Suspected cancer referrals

Source: Cancer network, calculated on patients referred with urgent suspected cancer and diagnosed with cancer in 2015-16.
During 2015-16, 81,282 people were referred by their GP with a suspicion of urgent suspected cancer. Of these less than 10% were actually diagnosed with cancer – 6,963 people. The conversion rate for suspected lung cancer is high at 22.6%, whilst the conversion rate for head and neck cancers was 3.7%. There has been an increase of 12% in the number of referrals for suspected cancer from GPs between 2014-15 and 2015-16.

6.2 Cancer treatment times

In Wales there are two targets for waiting times. We expect the waiting times targets to be met and sustained on a consistent basis.

At least 95% of patients newly diagnosed with cancer should start cancer treatment within 62 days of being referred by their GP. On a quarterly basis, this target has not been met at the all Wales level since the quarter ending June 2008. For the quarter ending March 2016, 86.3% of patients started cancer treatment within 62 days.

Despite performance being below the agreed standard, 28% 1,265 more patients were seen and treated within 62 days in 2015-16 than five years ago (2010-11).

<table>
<thead>
<tr>
<th></th>
<th>2010-11</th>
<th>2015-16</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>&lt;31</td>
<td>&lt;31</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&lt;62</td>
<td>&lt;62</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>14578</td>
<td>15033</td>
<td></td>
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<tr>
<td></td>
<td>10063</td>
<td>9253</td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td>4515</td>
<td>5780</td>
<td>-8%</td>
</tr>
</tbody>
</table>

The 62 day target covers all milestones of the patient journey to the start of definitive treatment, such as the first appointment with a consultant as an outpatient, diagnostic tests and treatment. While the vast majority of urgent referrals begin treatment within the 62 day target, there are unfortunately a small number that do not start treatment within the target time. In some cases this may be due to the difficulties in diagnosing the cancer, or that the treatment required is complex. However, this is not always the case and there is more which could be done by health boards to ensure patients are treated quicker.

The Welsh Government is working closely with all the health boards to make sure any patients not treated within 62 days get treated as soon as possible. We are also working to make sure this standard is met in the future.
Some patients are referred to hospital for reasons other than suspected cancer, but are subsequently diagnosed with cancer. The target for these patients is that at least 98% should start their treatment within 31 days of the decision to treat. In the quarter ending March 2016, 97.4% of patients who reach their diagnosis in this way started treatment within 31 days of the decision to treat.

Source: Welsh Government
# 7.0 Clinical research

Health boards and NHS Trusts in Wales need to embed research within the culture of their organisations in order to:

- improve research access/opportunities for patients
- address key cancer clinical priorities
- deliver evidence-based care for patients and improve future outcomes.
- better gear up NHS organizations in readiness for the delivery of innovative cancer treatment

There is good evidence that treatment centres involved in clinical research achieve better outcomes for their patients.

<table>
<thead>
<tr>
<th>Abertawe Bro Morgannwg University Health Board have successfully recruited patients into clinical trials and this has resulted in changes to practice and treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>kidney cancer research is a strength of the clinical trials unit at Abertawe Bro Morgannwg University Health Board and one of the trials has shown positive results in patients with advanced or metastatic renal cell cancer. The trial has demonstrated that the new immunotherapeutic agent, nivolumab, increased median survival of patients from 19.6 months for standard second line everolimus to 25.0 months. Nivolumab will become the standard second line treatment for renal cancer as result of this trial. The results of this trial have been accepted for publication in the New England Journal of Medicine.</td>
</tr>
<tr>
<td>the Stampede trial continues to recruit successfully and as of March 2016 Abertawe Bro Morgannwg University Health Board is the fifth highest recruiter in the UK recruiting 181 patients.</td>
</tr>
<tr>
<td>the RECCORD study looked at data of around 750 patients in the UK with metastatic renal cancer. The study emphasised that lack of access to second line treatment in Wales and Scotland meant patients’ survival was significantly less than that of patients in England</td>
</tr>
<tr>
<td>the oncology trials unit was the top recruiter in the UK for the Oscar 1 study.</td>
</tr>
</tbody>
</table>
Overall recruitment into clinical trials has increased by 0.2% this year. The total percentage of patients recruited into high quality trials is 18.4% (3241 patients). This is above the target of 15%. Health boards now need to maintain this level of recruitment.

Interventional studies have increased in their recruitment. With an all Wales recruitment of 9% into interventional studies, health board and trusts have reached the interventional target of 7.5%. Recruitment to observational studies however has fallen from 13.3% in 2014-15 to 9% in 2015-16, but remains above the 7.5% target.

Wales has poorer outcomes for cancer survival than other countries with similar healthcare systems, and late cancer diagnosis is thought to be a significant factor. Early cancer diagnosis is critical as it results in the detection of cancers at a stage when they easier to treat, manage, and potentially cure, all of which lead to better survival. Late cancer diagnosis is complex and can occur at all levels of the patient pathway. However, the length of the ‘primary care interval’ - the time taken between presentation, and the GP’s investigation and referral is thought to be a contributing factor.

Participation in the “Wales Interventions and Cancer Knowledge about Early Diagnosis” project will seek to understand GP’s cancer knowledge, referral attitudes, and needs. These findings will be used to develop interventional tools that GPs can use to identify suspected cases of cancer with greater precision, helping prompt and speedier referral.
7.1 The Wales Cancer Research Centre

The Wales Cancer Research Centre’s first year of operation has seen considerable progress in moving towards an all-Wales centre.

The investment by Health and Care Research Wales of £4.5 million over the next three years is a great stimulus to cancer research in Wales, across the translational spectrum. It will allow research to be conducted at every stage, from understanding the cellular and molecular basis of cancer through to new therapies and trials. This will result in improvements of the health and well-being of individual cancer patients, offering the prospect of benefits for the population and economy of Wales.

The grant income from Health and Care Research Wales has resulted in £5.4m additional research funding and 33 additional research posts last year. Just as importantly, the coming years will see impact from the research undertaken, through the publication of research findings, for the benefit of other researchers, and its translation into routine clinical practice, for the benefit of patients and the public. During the first year of operation the Wales cancer Research Centre published 74 papers, of these, 24% were included in high impact journals with an average impact factor 6.7.

An exciting new avenue for research is the use of data. South West Wales automatically collects comprehensive datasets on all radiotherapy (RTDS) and chemotherapy (SACT) activity for its catchment across South West Wales. This has tremendous potential for benchmarking services against others, informing service development, and for pure research. Collaboration with the Wales Cancer Intelligence Surveillance Unit (WCISU) which is part of Public Health Wales, together with the Farr Institute at Swansea University is taking place. The Farr Institute hosts the Secure Anonymised Information Linkage (SAIL) dataset, which contains patient data from a very wide range of sources, which can be linked with SACT and RTDS to provide practical new insights into how we serve our population. Hopefully this project can be expanded to include the whole of Wales in the long run.
8.0 Support for patients with cancer

Betsi Cadwaladr University Health Board works closely with the North Wales Cancer Patient Forum. This is a voluntary group of people who have been affected by cancer; their aim is to enable the views and experiences of cancer patients, family and friends to be heard and used to improve the quality of cancer care in North Wales. The Forum has its own dedicated website and has been involved in joint working with the health board on a number of service reviews and improvements. Key achievements include highlighting the need for better cancer information resources in North Wales which has led to the establishment of Macmillan Information Centres at the three main hospitals in North Wales, developing an information booklet for cancer carers and helping train health professionals but providing a patient perspective of cancer care.

Health care professionals will endeavour to prepare a person for the moment they hear the diagnosis, however, receiving a cancer diagnosis can be a shock. The impact of cancer and cancer treatments can be complex and varied. These consequences can be felt across eight domains of care, as highlighted below. A cancer diagnosis is likely to feel overwhelming, but both the NHS and the third sector are available to support patients and their families across the care pathway, from diagnosis, through treatment, and to support those living with the impact of cancer.

The Macmillan funded occupational therapy service within Aneurin Bevan University Health Board has developed, in partnership with clinical psychology and palliative care, a dedicated cancer fatigue management group. These groups are for a four week programme, each session lasts two hours and are run as closed groups, with the same patients every day. They include informed presentations by occupational therapy, psychology, complementary therapies and dietetics. Group participation is encouraged and it involves small take away tasks and goal setting.

Meeting the needs of people affected by cancer does not require a profession-specific service, but rather, the recognition that it is the responsibility of all health and social care professionals providing and delivering care. NHS Wales recognises that a flexible and sustainable workforce is fundamental to meet the changing service requirements and deliver person centred care.
It is really important that people with cancer have the best possible experience whilst they are being treated. Evidence tells us that:

- a good experience makes people with cancer feel supported and respected
- evidence has shown that patient experience is linked to other outcomes including a patient’s health, use of resources and patients following their treatment plans
- providing patient centred care can reduce the time a patient stays in hospital and staff turnover
- there is a close link between staff and patient experience. When staff feel valued and respected, they are more likely to treat patients in the same way and be happier in their role.
- poor patient experience can be a warning sign for more widespread failings.

We are committed to ensuring all patients are cared for with dignity and respect. We will ensure that services are planned and delivered around the patient and their individual needs. The national cancer patient experience funded jointly by Macmillan Cancer Support and the Welsh Government in 2013 show cancer services are well regarded by patients. Overall, the care

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received by cancer patients in Wales was either ‘excellent’ or ‘very good’ according to 89% of patients who responded. That figure rose to 97% of patients who thought their care was ‘good’. It is encouraging to see so many patients had a positive experience of their cancer care and the evidence of effective systems being in place alongside support to individuals is very clear.

Communication and information between people affected by cancer and service providers needs to be improved to empower an equal partnership in cancer care. There is a need to use more regular, localised patient reported experience measures (PREMs) to assess and understand patients’ experiences, considering a whole team approach using this to inform service developments.

The CIG, working with Macmillan Cancer Support, has commissioned a second national survey during 2016 (report due Spring 2017) to support health board quality improvement and is committed to continuing to learn from patient experience and outcomes by exploring the potential for more regular and embedded PREMs and patient reported outcome measures (PROMs). The Wales Cancer Alliance, which brings together the main national cancer charities, will continue to work with the Wales Cancer Network to consider how best to systematically use patient experience to shape and improve healthcare services for people affected by cancer.

In order to understand the needs of the local population, a study into the feasibility of establishing chemotherapy outreach services in Powys is underway. Key to understanding the potential for either mobile chemotherapy services or a centre for chemotherapy in Powys is establishing a clear and evidence based picture of the chemotherapy and haematology activity of Powys patients. This includes understanding how many patients are receiving treatments, where are they receiving these treatments, what are the travel times for patients and importantly how many of these treatments can be undertaken safely in a community setting.

8.1 Key workers

Every person diagnosed with cancer in Wales should be allocated a key worker. This is a person who acts as a coordinator and supports the patient to access information, care, liaison and support throughout their cancer journey, between health professionals and the patient, including the relevant primary care teams, to ensure continuity of care and a seamless service.

Each health board will establish and agree a process for key worker allocation and recording; including arrangements to ensure patient access to a key worker meets their needs. The cancer key worker is fundamental to the facilitation of seamless service delivery for the health and wellbeing of a patient. Irrespective of the stage of cancer pathway, the key worker is ideally placed to coordinate with other non-cancer services to reduce duplication, and ensure prudent healthcare.
The 2013 cancer patient experience survey demonstrated the important and significant difference key workers can make to a person’s experience of cancer services. The cancer pathway is complex and a named key worker is fundamental to help the patient navigate the pathway and ensure a smooth patient journey. The key worker through the acute phase of treatment is usually the clinical nurse specialist, who as part of a wider multi-disciplinary team coordinates treatment and care. The healthcare system, and patients, should also be clear who their responsible doctor is at all stages of the care pathway.

47.2% of patients had a key worker recorded on CANISC in 2015-16. This is an increase of 15.2% compared to the previous year. It is thought that the majority of patients do actually have a key worker; the challenge is having an electronic capture of this and understanding how the key worker role works transitions across the cancer pathway and across care sectors. Figure 15 shows that in 2015-16 that head and neck and lung are the tumour sites with the highest recording of key workers at over 75%.

Figure 15: Percentage of patients with a key worker recorded on CANISC 2015-16

Source: Cancer network

8.2 Palliative care

People with cancer approaching their end of life require access to care and support whenever it is needed. The access to health and social care, support and symptom control must be the same wherever they die - at home, in hospital, in a care home or a hospice. These services need to be well
coordinated across primary, community, social and hospital care and between statutory and third sector organisations. It is hard to identify those likely to die within 12 months and initiate the necessary conversations. It requires considerable skill and experience. However, the right support can transform the end of life experience for everyone – the patient, family, carers and friends.

Figure 16 indicates that a person is far more likely to receive specialist palliative care if they have a cancer diagnosis than if they are terminally ill with a non-cancer diagnosis. In 2015-16, 51.9% of people who died from cancer received specialist palliative care compared with 16.7% of those who died from another illness.

**Figure 16: Percentage of patients supported by a specialist palliative care team**

- New patients with a cancer diagnosis supported by a specialist palliative care team
- New patients with a non-cancer diagnosis supported by a specialist palliative care team
- Patient deaths supported by a specialist palliative care team

*Source: CANISC*
Considerable work has taken place in Powys teaching Health Board to support patients nearing the end of their lives including:

- in partnership with St David’s Foundation they have developed a hospice at home service for the population of Ystradgynlais. This commenced in April 2016
- there has been a roll out of the care decisions guidance to the whole health board from April 2016 with education and support from the specialist palliative care team
- Macmillan funding has allowed recruitment to a senior nurse for cancer and palliative care services, a person centred care manager and two GP end of life facilitator posts.
- continued development of the virtual ward model across the county which facilitates the proactive and timely management of people at end of life to support preferred place of care
- a training programme has been delivered on the fundamentals of palliative care in mid Powys for health care support workers and care staff.

Those people dying from cancer of the lymphoid are least likely to access palliative care (figure 17). Not all people towards the end of their lives will require specialist palliative care. Health boards are working hard to ensure that all those who require specialist palliative care can access it.

**Figure 17:** Percentage of patients receiving palliative care by cancer type

![Figure 17: Percentage of patients receiving palliative care by cancer type](image)

Source: CANISC
The end of life care annual report published on 16 December 2016 sets out the progress that has been made over the last 12 months to improve services for those people approaching the end of their lives in Wales. The report can be accessed at:

9.0 Conclusion

Cancer accounts for nearly 7% of all NHS expenditure in Wales in 2014-15. This amounted to £409 million - one of the largest spending areas for NHS Wales\(^\text{15}\). It is important to ensure that this is invested wisely through the use of evidence, guidelines and expert input. This must also include surgery, radiotherapy and chemotherapy. The focus needs to be upon the whole system: primary care, diagnostics, workforce and informatics, and harness the patient’s perspective and the role of the third sector.

The refreshed cancer delivery plan published in November 2016 builds upon the excellent work that has been undertaken in the last few years. The plans provides real focus for the work requires to further improve cancer care over the coming years and places real emphasis on prevention and early diagnosis giving the best chance to longer term survival. It also has a strong focus on improved patient support through and beyond cancer treatment and how we can use patient experience to redesign the way we deliver cancer services in Wales. Development of the plan has been through wide engagement and this approach also means that the plan can expect greater ownership across health sectors with improved commitment to delivery.

The revised plan which had been developed by the Cancer Implementation Group in conjunction with relevant stakeholders, including the third sector, makes commitments to continue to improve survival rates for cancer; reduce early death caused by the disease and to close the gap with the best providers of cancer care in Europe.

The plan focusses on delivering better results for those with cancer; improving early detection of cancer through better access to diagnostics and ensuring the levels of care that cancer patients in Wales receive from the NHS are of the highest standard.

Moving forward the new single, clinically led, cancer network in Wales reporting to the CIG will oversee the implementation of the cancer delivery plan and complementing the cancer innovation pathway programme. The latter will ensure that we learn from existing and new improvement projects to reduce the inequality of care and outcomes seen in Wales.

\(^{15}\) NHS Programme Expenditure, Financial Information Strategy Programme, Public Health Wales NHS Trust.