

Together for Health

Cancer Delivery Plan
Annual Report 2014



1. Introduction

The publication of the third all Wales annual report for cancer demonstrates the commitment of the Welsh Government to deliver a more accountable and transparent NHS for the people of Wales. This annual report highlights the progress we have made in our cancer services and identifies areas for future improvement.

Reports have already been produced by Health Boards, setting out local progress against "Together for Health – Cancer Delivery Plan". This report provides a national overview. Taken together, the reports demonstrate our commitment in Wales to the improvement of cancer services.

Good progress is being made in implementing the actions set out in our Cancer Delivery Plan:

- There has been a 17.5% improvement since 1995 in the one year survival rate and a 20.1% improvement in the five year survival rate in Wales.
- There has been a steady increase in the uptake of the Human Papilloma Virus (HPV) vaccine across Wales with levels in 2012-13 School year 8 at 86%.
- In the cancer patient experience survey (CPES) 2013, 89% of patients said that their care was excellent or very good and 88% of respondents were given the names of their clinical nurse specialist.
- Analysis of the free text comments from the CPES revealed positive experiences in terms of professional, caring and supporting attitudes of specialist and general nursing staff and of the treatment delivered, be it surgery, radiotherapy or chemotherapy.
- Over the past 12 months tissue donations to the Wales Cancer Bank increased by 3.3% to 14%.
- At the all Wales level performance against the 31 day target; for those patients referred to hospital for reasons other than suspected cancer, but are subsequently diagnosed with cancer has mostly been achieved since July 2013.
- The Cancer Networks have led important initiatives to review and improve the performance of cancer services across Wales, namely:
 - peer review of upper and lower gastrointestinal and urological cancer services which have broadly found services to be committed and aware of further service improvements required; and
 - cancer pathway working: establishing clinical leads for upper and lower gastrointestinal, head and neck, urology, gynaecological and lung cancer and undertaking a pilot of a single suspected cancer pathway.
- The uptake for the bowel screening programme has increased by over 4% since last year and is now at over 52%.
- A policy has been published clarifying the role of the key workers in NHS Wales.
- Primary care clinical teams have undertaken significant event analyses on all patients diagnosed with gastrointestinal and lung cancers.

- Some health boards have made significant strides in establishing acute oncology teams ensuring patients with previously undiagnosed cancers and those experiencing complications of cancer or treatment of cancer have timely access to excellent care.

There are however a number of areas where further progress is required or where new issues need to be addressed:

- In Wales the survival rates from smoking-related cancers (stomach, lung and kidney) are lower than the European average.
- There is a considerable difference between cancer incidence, mortality and survival between the most deprived areas of Wales and the least deprived areas. Cancer incidence is 21% higher in the most deprived areas in Wales compared to the least deprived and cancer mortality in Wales is 46% higher. The one year survival rate in the most deprived areas is 17% lower than the least deprived areas. For five year survival the difference is even greater with survival 28% less in the most deprived areas compared to the least deprived.
- Recruitment into clinical trials has reduced by 4.4% to 14.4%, just below the 15% target.
- The free text comments from the CPES highlight areas where further support for patient is required. Whilst the majority of comments were positive, areas for improvement highlighted include delays in primary care prior to the diagnosis of cancer, poor communication between levels of care and greater availability of specialist nurse support, especially at the time of diagnosis and after completing treatment.
- Our performance against the 62 day waiting time target for those newly diagnosed with cancer remains an area of concern as this target has not been met consistently across Wales for some considerable time. Health boards must develop clinically led initiatives between cancer service departments and service improvement teams to undertake pathway improvement work using established quality improvement methodologies.
- Not all health boards have yet to develop robust acute oncology care services. They must put developments in place as soon as possible in the coming year.
- Primary care will review lessons learned from the significant event analyses and share these between themselves and secondary care colleagues.
- The establishment of a new single disease summary dataset and multi-disciplinary team module in CANISC¹.

This remains a key priority for Boards and clinical teams and we expect to see progress in these areas in 2015.



Andrew Goodall
Chief Executive, NHS Wales



Paul Roberts
Chair, Cancer Implementation Group

¹ CaNISC is an online computer system that provides information for health professionals on cancer patients across Wales. This allows health professionals to access important clinical information wherever the patient receives specialist care and helps to provide the best possible care to patients.

2. How many new cases of cancer occur in Wales, each year, the number of deaths and how long people live after a diagnosis of cancer²?

2.1 Overview

Analysis of incidence, mortality and survival rates provides an important insight into the effectiveness of our work to prevent and treat cancer. They are showing that despite increasing incidence rates, death rates are falling and survival rates are improving.

More than 18,000 people were diagnosed with cancer in Wales in 2012. This equates to around 610 cases³ for every 100,000 people. In 2010, across the United Kingdom, the highest incidence rates for all cancer combined are seen in Wales for males and in Scotland for females.

The number of people being diagnosed with cancer is increasing. Between 1995 and 2011 there were on average around 16,400 new cases of cancer per year. The most commonly diagnosed cancers are breast, bowel, prostate and lung cancer. For men the most common cancer is of the prostate and women of the breast. Cancer can develop at any age, but is most common in older people. The increase in incidence rates is due, in part, to the rise in the elderly population.

Despite this increase in incidence rates, deaths from cancer have decreased. An average of around 8,400 people died from cancer each year in Wales between 1995 and 2011. There has been a falling trend over the past fifteen years, with rates falling on average by around 0.3% each year⁴.

New and more effective treatments mean that many more people can now expect to live longer after their cancer treatment. Although survival rates are improving, the rates are still quite variable amongst commonly occurring cancers. The 5 year relative survival rate (for patients diagnosed between 2003 and 2007) varied from 3% for pancreatic cancer; 7% for lung cancer to 86% for prostate cancer and 85% for female breast cancer³. Much more needs to be done to improve survival where it is currently poor.

2.2 Cancer incidence rates

This measures how many new cases of cancer are found each year and tells us how well we are doing at preventing cancer in Wales. If we are achieving our objectives, we would expect to see over time:

- A slower rise in the rate of increase compared with historic trends.
- A reduced gap between the most and least deprived areas of Wales.
- Incidence rates comparable with the best in Europe⁵.

This is a long term indicator and it will be a number of years before we will see any changes.

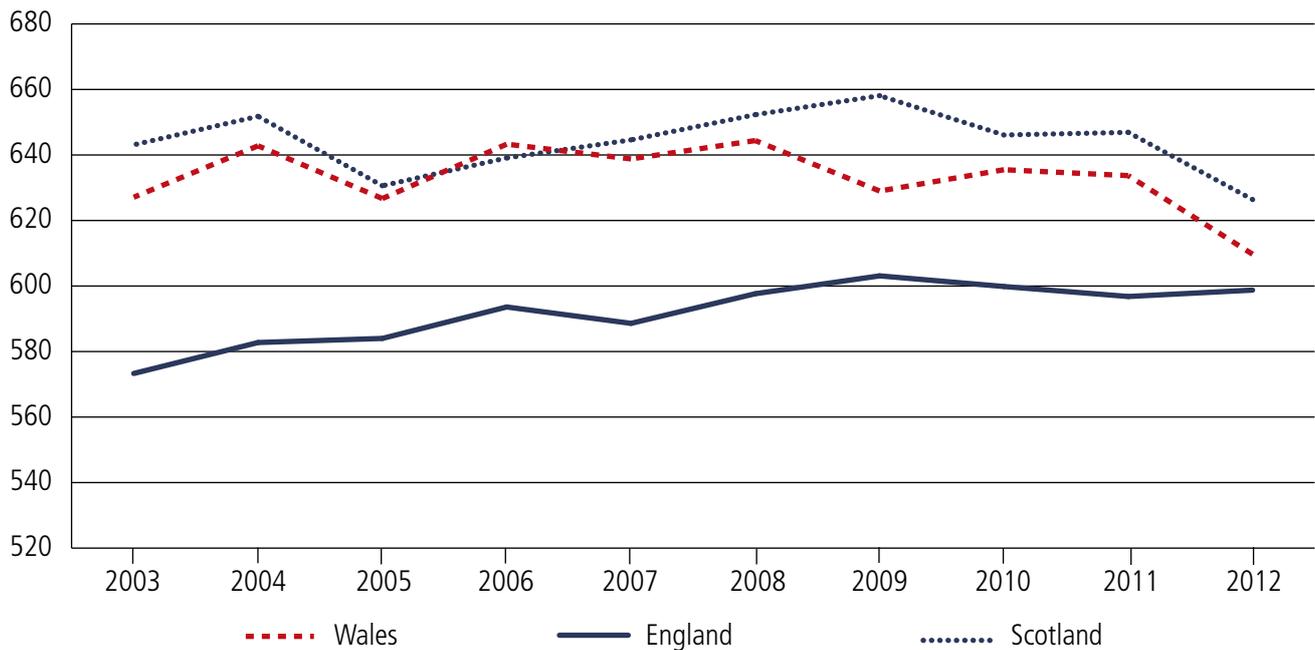
² More detailed information on incidence, mortality and survival can be accessed at www.howis.wales.nhs.uk/sites3/Documents/322/2013%20Provisional%20Technical%20Document%20-%20Section%202%20Profiles%20by%20Cancer%20Site.pdf.

³ European Age Standardised Rate per 100,000 population (2013 EASR).

⁴ Welsh Cancer Intelligence and Surveillance, Health Intelligence Division, Public Health Wales, 2014.

⁵ Those countries with cancer registration and mortality covering the whole population.

**Figure 1: Cancer Incidence Rate (all malignancies excluding non melanoma skin cancer).
European age standardised rate per 100,000 population**



Source: Welsh Cancer Intelligence and Surveillance Unit 2014 for Welsh statistics, ONS for English statistics and ISD for Scottish statistics.

Note: Figure 1 chart axis does not start at zero to illustrate differences more clearly.

Figure 1 shows that Scotland tends to have the highest incidence rates in the UK over time, followed by Wales. The general trend for Wales and Scotland is decreasing with slight increases in incidence noted in England.

In 2012 two thirds of all cancer cases in Wales were diagnosed in people aged 65 and over⁶. During the period 2003-2012 there was little change in most age-specific cancer rates per 100,000. This suggests that the increase in numbers of cancer cases can be partly explained by people living longer and the ageing population.

Bowel cancer is the most common cancer⁷. This is due to an increasingly aging population, increased awareness and the impact of the bowel screening programme.

It has been predicted that referrals for common cancers will continue to rise over the forthcoming years, because:

- Common cancers such as prostate, large bowel and breast are being diagnosed in early, curable stages due to improved screening and education.
- The population in Wales is rising year on year.
- There are an increased number of elderly cancer patients surviving longer following diagnosis.

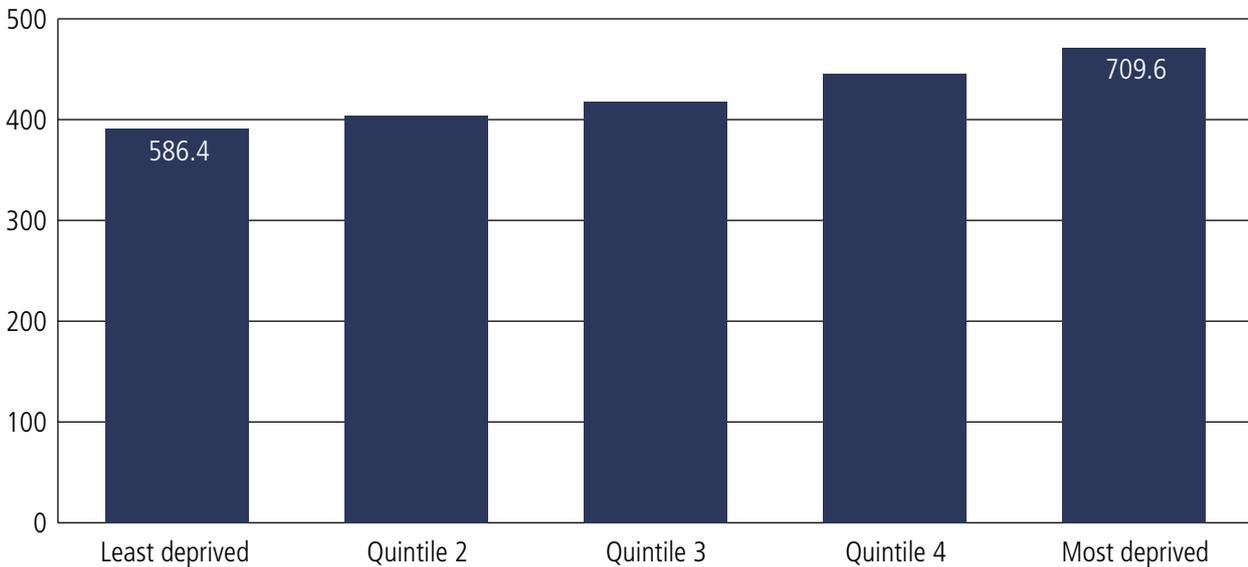
The Welsh Cancer Intelligence and Surveillance Unit (WCISU) predict that cancer incidence of the prostate, large bowel and breast in Wales will rise by 49%, 34% and 32% respectively by 2015 compared to the reported levels in 2003.

⁶ Welsh Cancer Intelligence and Surveillance, Health Intelligence Division, Public Health Wales, 2014.

⁷ Welsh Cancer Intelligence and Surveillance, Health Intelligence Division, Public Health Wales, 2014.

Many diseases or health conditions show a correlation to areas of deprivation. This is also true of cancer where the incidence rate is 21% higher in the most deprived areas of Wales, compared to the least deprived (figure 2). That means that there are around 123.2 extra cancer cases per 100,000 people living in the most deprived areas.

Figure 2: Cancer incidence by deprivation in Wales, all ages, all persons 2008-2012 (all malignancies excluding non melanoma skin cancer)



Source: Welsh Cancer Intelligence and Surveillance Unit 2014 (using EASR 2013 and Welsh Index of Multiple Deprivation (WMID 2014))

2.3 Cancer mortality rate

This tells us how many people die from cancer each year⁸. If our strategy is successful, over time we would expect to see:

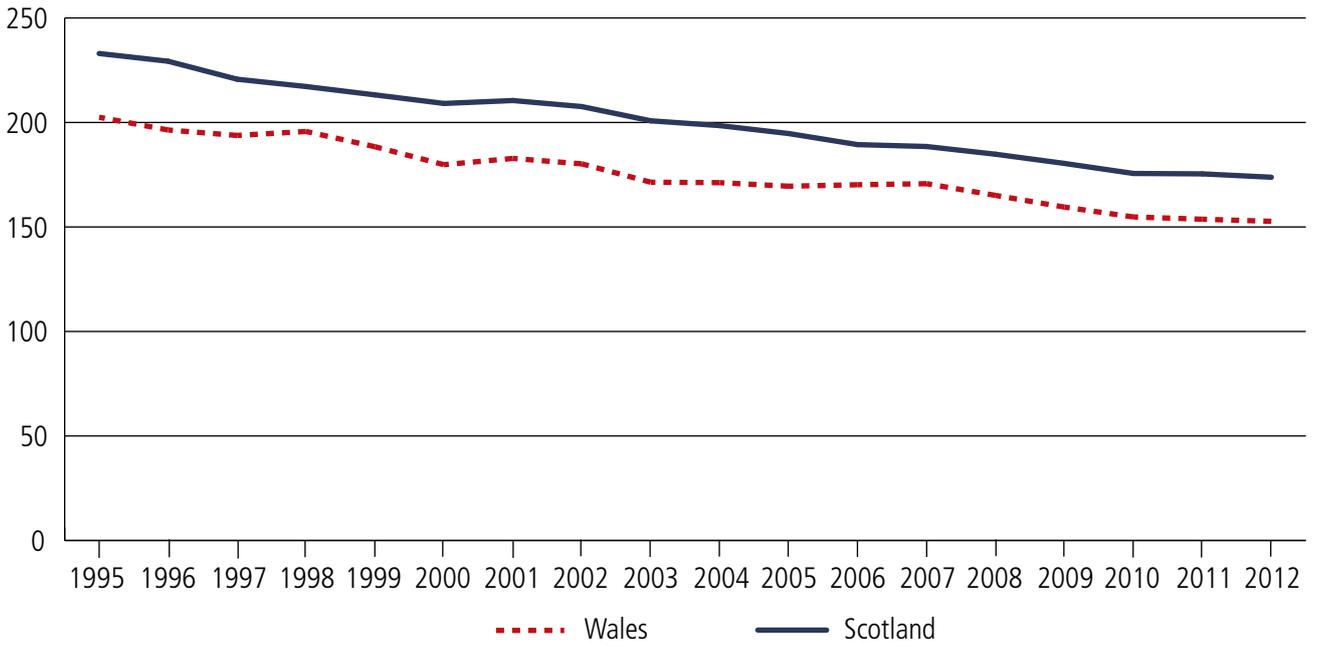
- A continued fall in the rate of deaths from cancer.
- A reduced gap between the most and least deprived areas of Wales.
- Mortality rates comparable with the best in Europe⁴.

Figure 3 shows that there has been a steady decline in the overall rate⁹ of people dying from cancer over the last sixteen years. Scotland has a higher mortality rate than Wales and was around 13% higher than Wales in 2012. There has been a 25% reduction in mortality from 1995 to 2012 in Wales for those aged under 75 years.

⁸ Expressed as an age standardised rate to allow comparisons between years and countries.

⁹ Based on the EASR (2013) per 100,000 population for persons under 75.

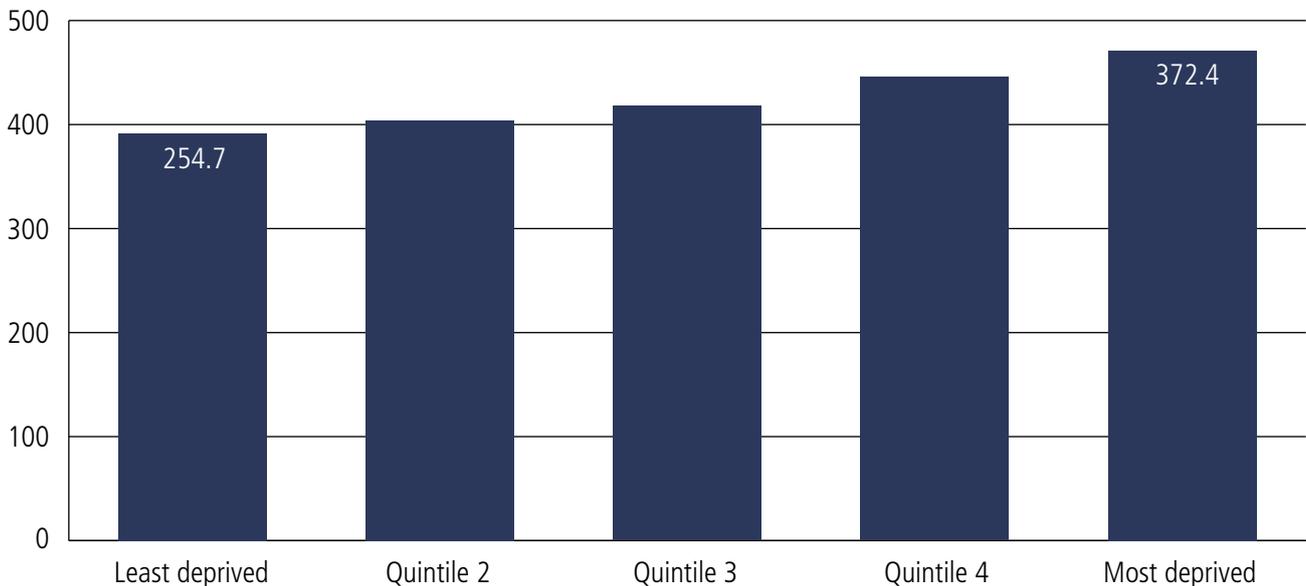
Figure 3: Cancer mortality under 75, European Age Standardised Rate per 100,000 (all malignancies excluding non melanoma skin cancer)



Source: Welsh Cancer Intelligence and Surveillance Unit 2014 for Welsh statistics and ISD for Scottish statistics

While cancer incidence is 21% (figure 2) higher in the most deprived areas in Wales compared to the least deprived, cancer mortality in Wales is 46% higher as highlighted in figure 4.

Figure 4: Cancer mortality rate (EASR) by deprivation in Wales 2008-2012 (all malignancies excluding non melanoma skin cancer)



Source: Welsh Cancer Intelligence and Surveillance Unit 2014

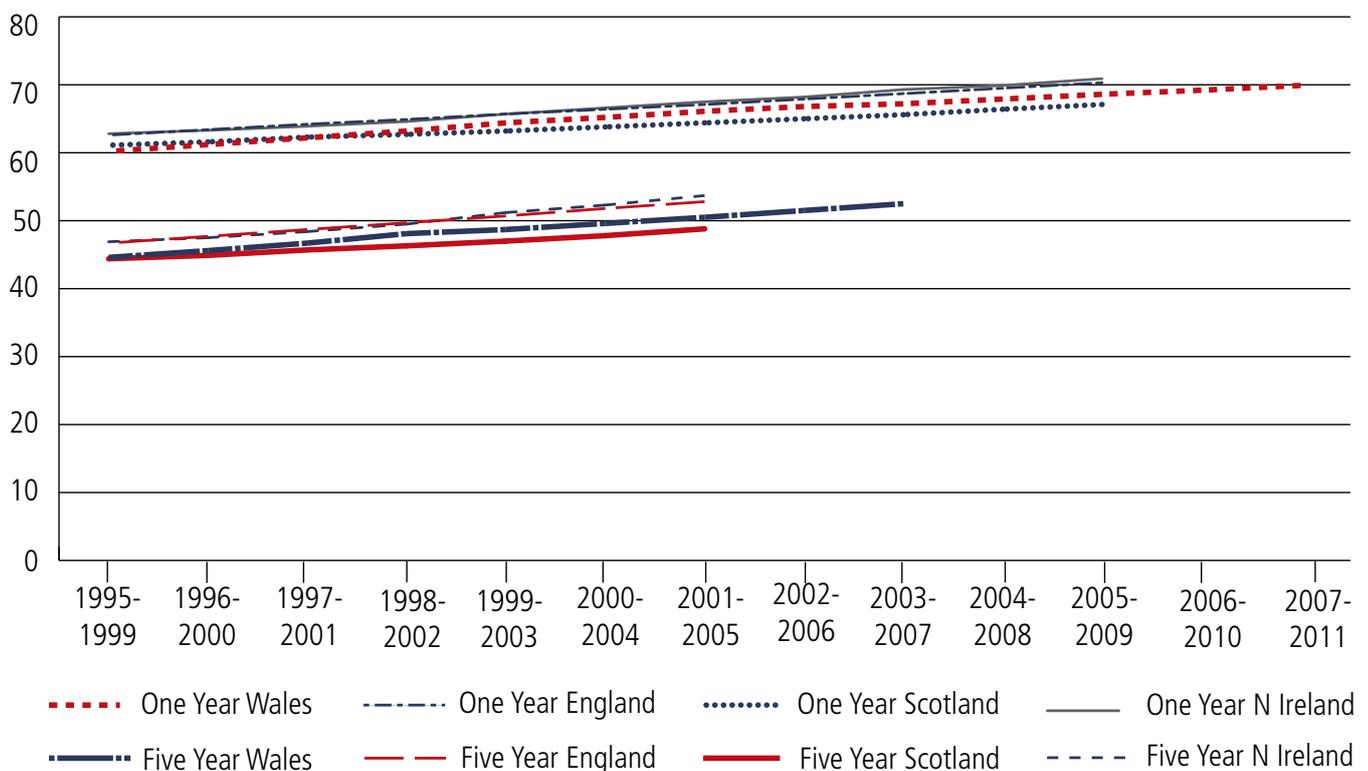
2.4 One and five year survival rate

This measure shows us how many people are alive one and five years after they have been diagnosed with cancer. Survival is likely to be longer if the disease is detected early, the person is in relatively good health and the treatment is effective. If our strategy is successful, over time, we would expect to see:

- An increase in 1 and 5 year survival rates.
- A reduced gap between the most and least deprived areas of Wales.
- 1 and 5 year survival rates comparable with the best in Europe⁴.

Figure 5 shows that Northern Ireland tends to have the highest relative survival of all the UK countries for one year and five year survival. England tends to have the second highest followed by Wales and Scotland. There has been a 17.5% improvement since 1995 in the one year survival rate and a 20.1% improvement in the five year survival rate in Wales.

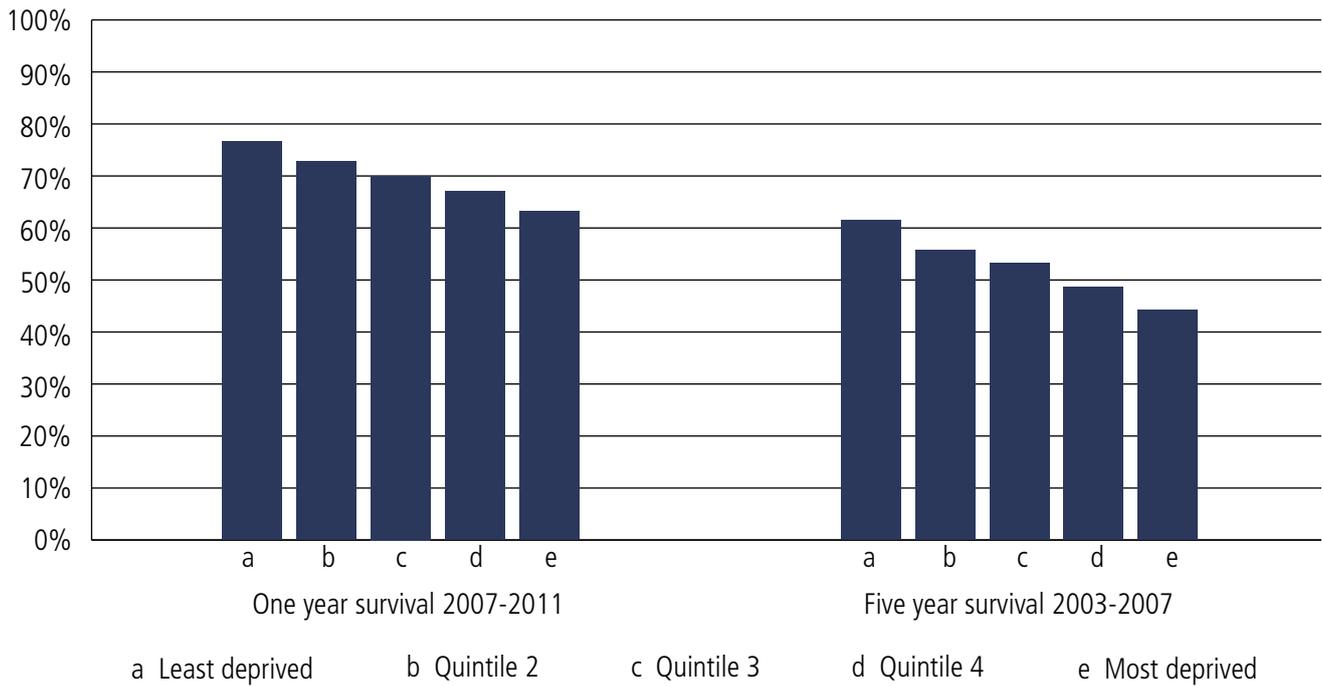
Figure 5: Percentage of patients surviving all cancers (excluding non melanoma skin cancer), all ages



Source: UKCIS 4.5b – April 2012 and Welsh Cancer Intelligence and Surveillance Unit 2014 for Welsh statistics. Updated survival figures are not available for England, Scotland and Northern Ireland

There is a considerable difference between survival in the most deprived areas of Wales and the least deprived areas. The one year survival rate in the most deprived areas is 17% lower than the least deprived areas. For five year survival the difference is even greater with survival 28% less in the most deprived areas compared to the least deprived (figure 6).

Figure 6: One and five year relative survival rates by deprivation in Wales. All people, all ages, all malignancies excluding non melanoma skin cancer



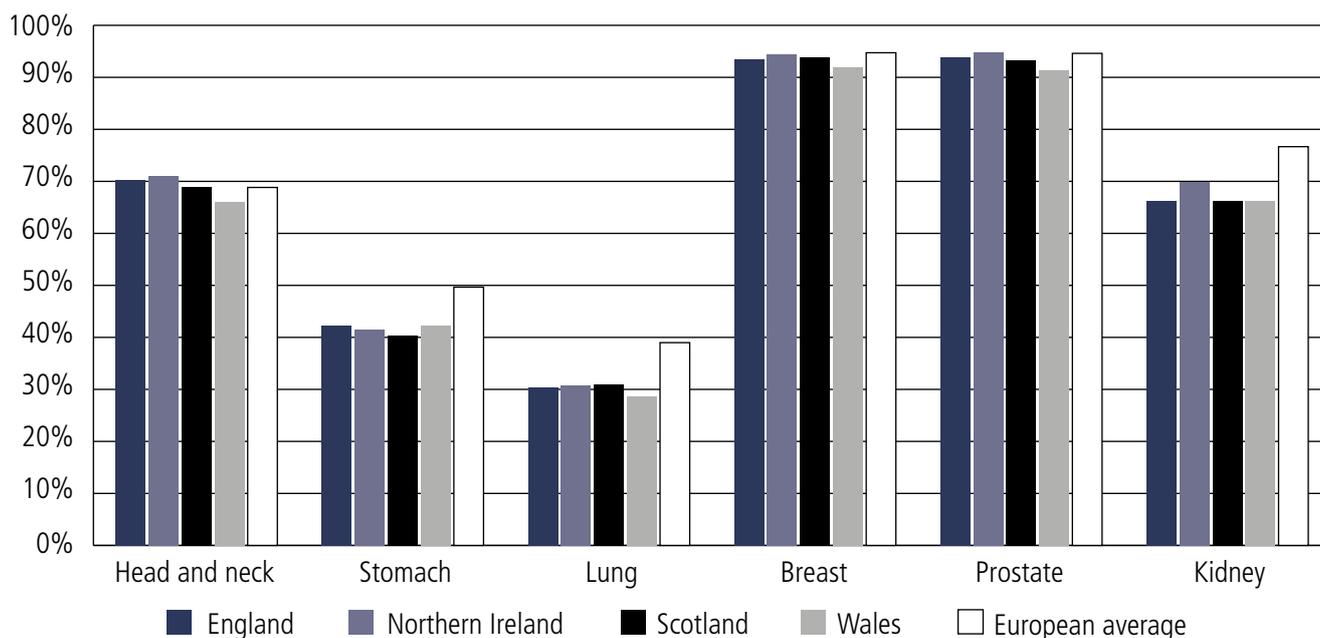
Source: Welsh Cancer Intelligence and Surveillance Unit 2014

2.5 How does Wales compare with the rest of Europe?

Despite improvements in Wales, we are still lagging behind a number of other European countries. Comparison is possible through EUROCORE 5¹⁰, a consortium of 29 countries from all parts of Europe which compare their data as a means of exploring opportunities to improve practice. According to EUROCORE 5; cancer survival from adult cancers across Europe has improved considerably.

¹⁰ www.eurocare.it/Eurocare5/tabid/64/Default.aspx – EUROCORE 5 produces population based survival estimates for 29 European countries. In December 2013 data was issued looking at five year relative survival figures for adult patients aged 15 and over diagnosed between 2000 and 2007 for 10 cancer sites. This was issued along with survival from childhood cancers in children aged 0-14 years.

Figure 7: Percentage of patients surviving 1 year (International Cancer Survival Standards) 2000-2007



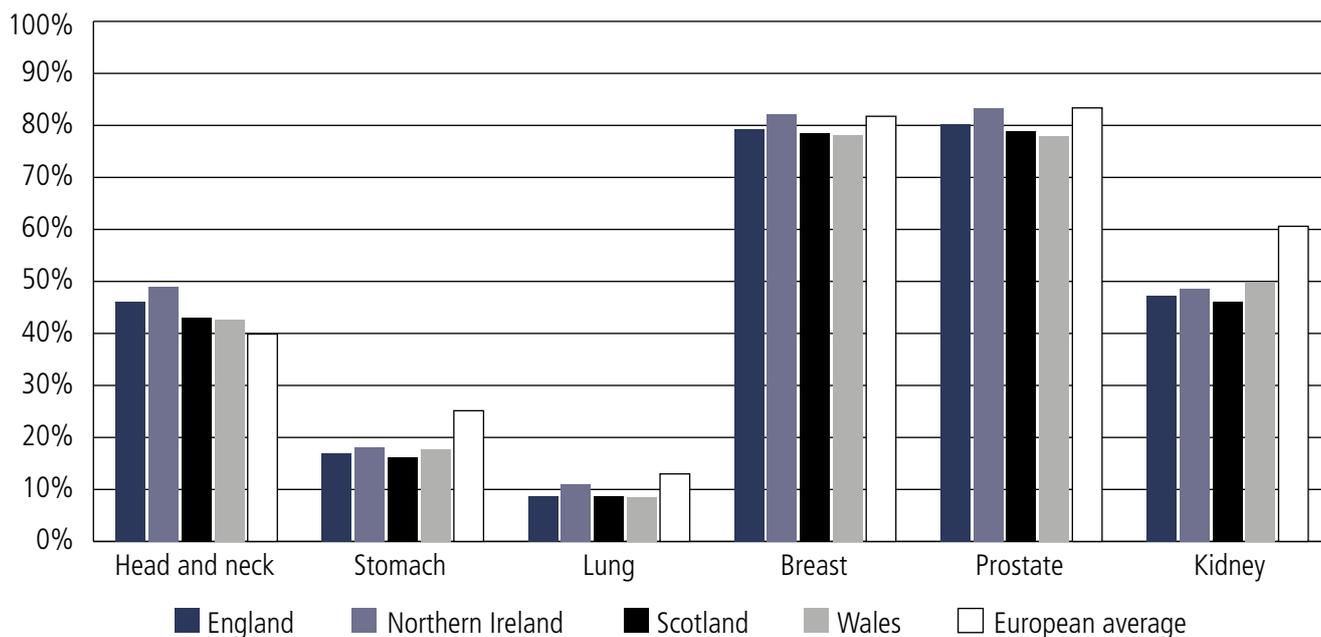
Source: EUROCARE 5

Figure 7 shows the percentage of patients surviving up to one year for some common cancer sites. For stomach, kidney and lung, which are associated with smoking, survival rates in Wales lag behind the European average.

For breast, prostate and head and neck cancers the percentage of patients surviving up to one year in Wales is lower than the European average and that of the other UK nations.

Longer term (5 years) survival rates are shown in figure 8. This shows that for head and neck cancers long term survival rates in Wales are much higher than the European average. However performance against the other cancer sites is less favourable. Long term survival for breast and prostate cancers is lower in Wales than the European average.

Figure 8: Percentage of patients surviving 4 < 5 years (International Cancer Survival Standards) 2000-2007



Source: EUROCORE 5

Despite the continued apparent relatively low survival from many cancers in Wales, we know from previous and other studies that over time it is improving at a greater rate than many other countries. We also know that there have been many improvements in cancer health services in Wales over the last few years. It may be some time before these improvements have an impact on long term survival.

3. Cancer services in Wales

A number of NHS performance measures have been developed to help us understand how well we are detecting and treating cancer in Wales. The baseline for each measure was published in the cancer annual report, published in 2012. In this report we will look at the progress that has been made against the performance measures. We also review service improvements across health boards that will drive up the quality of cancer services in Wales.

4. Preventing cancer

Our population is getting older and overall health is improving. But wide inequalities in health between socioeconomic groups and geographic areas persist, and overall population health status in Wales is far from the best in Europe.

Cancer is caused by damage to a person's DNA. An individual's lifestyle and exposure to things in the environment such as UV rays, and the cancer causing chemicals in tobacco, can damage DNA. This damage builds up over time.

Cancer Research UK¹¹ suggests that in the UK, more than one in three people will develop cancer at some point in their lives. Every year, in Wales more than 18,000 people are diagnosed with the disease. It is estimated that more than 4 in 10 cancer cases could be prevented by lifestyle changes, such as:

- not smoking;
- keeping a healthy body weight;
- cutting back on alcohol;
- eating a healthy, balanced diet;
- keeping active;
- avoiding certain infections (like HPV);
- staying safe in the sun;
- avoiding certain chemicals in the workplace.

Many of these lifestyle changes are difficult to tackle and are related to the wider social determinants of health and social inequalities.

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. A study in 2011 estimated that smoking causes nearly a fifth of all cancer cases in the UK¹². Excess alcohol consumption causes 4 in 10 cancer cases and unhealthy diets cause nearly 1 in 10 cancer cases in the UK¹³.

¹¹ www.cancerresearchuk.org/cancer-info/cancerstats/causes/comparing-causes-of-cancer/results/.

¹² Cancer Research UK.

¹³ Cancer Research UK.

Prohibiting smoking in private vehicles carrying children under 18 has the potential to protect children from the harms associated with passive smoking. Passive smoking can lead to a host of chronic diseases, which are very largely avoidable. Legislation would seem to be the most appropriate way forward to eliminate this harm and exposure to second-hand smoke. The First Minister and the Minister for Health and Social Services issued a written statement on 15 July 2014 announcing that a consultation on proposals to prohibit smoking in private vehicles when children under the age of 18 are present will be launched shortly, in line with established procedures.

The Welsh Government is supporting the 'Five Ways to Wellbeing' approach and has recently launched the 'Add to Your Life' initiative. The 'Five Ways to Wellbeing' are a set of evidence-based actions developed by the New Economics Forum (NEF) which promote people's wellbeing. They are: Connect, Be Active, Take Notice, Keep Learning and Give. These activities are simple things individuals can do in their everyday lives.

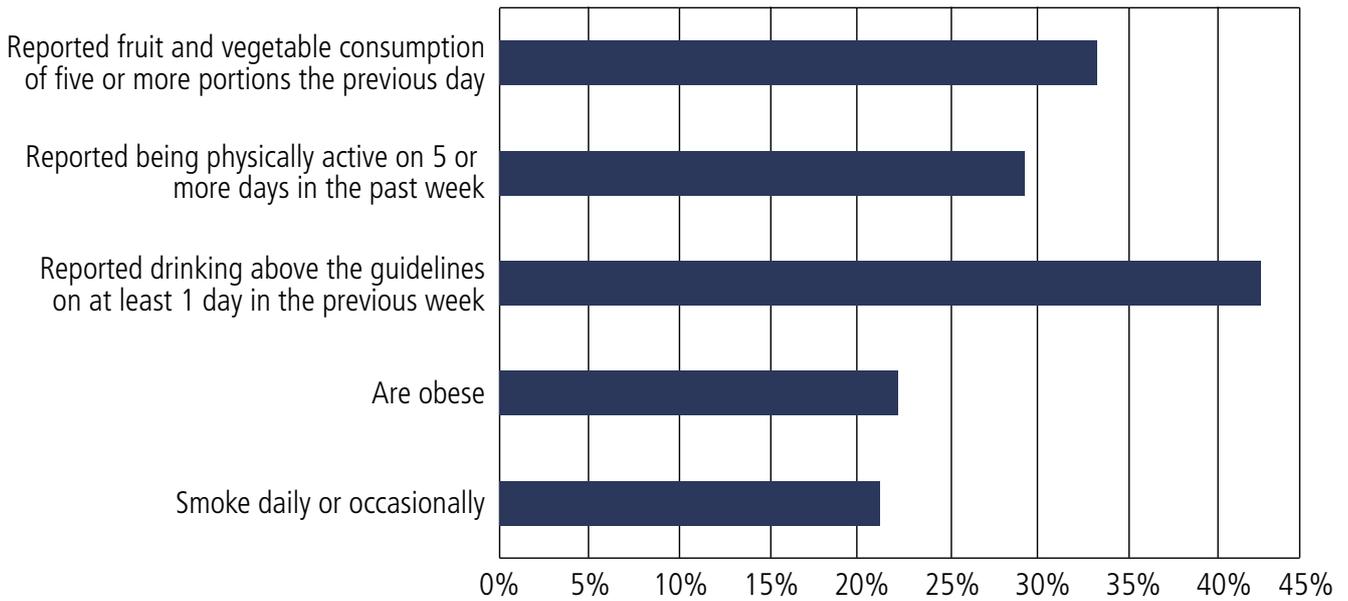


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Add to Your Life is an online health assessment for people aged 50 and over, and is a new initiative to support individuals to better understand their own health and the actions they can take to improve their health and wellbeing, providing access to high quality information and advice via a single website. There is still a great deal to be done as highlighted in figure 9.

¹⁴ Logo originally developed by Aneurin Bevan Gwent Public Health Team. Adapted by Cwm Taf Public Health Team.

Figure 9: Percentage of adults in 2013 who...



Source: Welsh Health Survey, 2013

The Public Health Wales Observatory has published a new web-based resource on obesity in adults, using data from the Welsh Health Survey.

The resource, available on the Public Health Wales Observatory website, presents information on the prevalence of overweight and obesity by age and sex, and at a range of geographical levels. An animated map also shows the change in levels of obesity across Wales over recent years.

Human Papilloma Virus Vaccine (HPV)

Since its introduction in 2008, girls in year eight have been offered the vaccine, which protects against two strains of the HPV virus which cause the majority of cervical cancers. The programme is expected to reduce the incidence of the disease by a further 60% over the next 20 years.

The latest figures for Wales for the 2012-13 academic year found 86% of 12-13 year-old females completed the three-dose course of the vaccine – a small increase from last year.

5. Detecting cancer quickly

Early diagnosis and treatment increases a person's chance of survival and reduces likely harm to that person's health and their family's quality of life.

Early detection of cancer greatly increases the chances for successful treatment. There are two major components of early detection of cancer: screening and education to promote early diagnosis.

5.1 Screening services

The national, population based cancer screening programmes are evidence based interventions that aim to detect cancer early, when chances of treatment and survival are highest. There are three national cancer screening programmes in Wales: Breast Test Wales, Cervical Screening Wales and Bowel Screening Wales.

- *Thank goodness for mammograms, I was diagnosed very early.*
- *I did not know that I was ill, until I went for bowel screening, I had no symptoms at all, I would advise anyone to do the test if it was available to them.*
- *I cannot praise the NHS treatment I received highly enough. Following a bowel screening, I had an emergency op (I did not have any symptoms).*

Wales Cancer Patient Experience Survey 2013

The current uptake for each of the cancer screening programmes for 2013-14 is presented in table 2.

Table 2: Uptake/coverage: cancer screening programmes 2013-14

	Number eligible/ invited	Number tested	Uptake/Coverage
Bowel Screening Uptake (aged 60-74, tested within 2 years) Target: 60%	277,493	145,906	52.6%
Breast Screening Uptake (aged 50-70, tested within 3 years) Standard 70% Target 80%	144,411	104,104	72.1%
Cervical Screening coverage (aged 25-64, tested within 5 years) Target 80%	730,885	573,313	78.4%

Source: Public Health Wales Screening – October 2014

The aim of the breast screening programme is to reduce morbidity and mortality from breast cancer. Breast Test Wales invites eligible women aged 50-70 for breast screening every three years. Women aged over 70 can self refer. The uptake for breast screening in Wales is similar to previous years and meets the standard.

The aim of the cervical screening programme is to reduce the incidence of and mortality from cervical cancer. Cervical Screening Wales invites women aged 25-50 every three years and those aged 50-64 every five years. The coverage of cervical screening is very close to the standard of 80%, meaning that nearly eight out of ten women in Wales attend for their smear test. Uptake is slightly higher than that seen in previous years, however this year the figures only include women aged 25-64 due to the change in age range of women invited, so we cannot make a direct comparison.

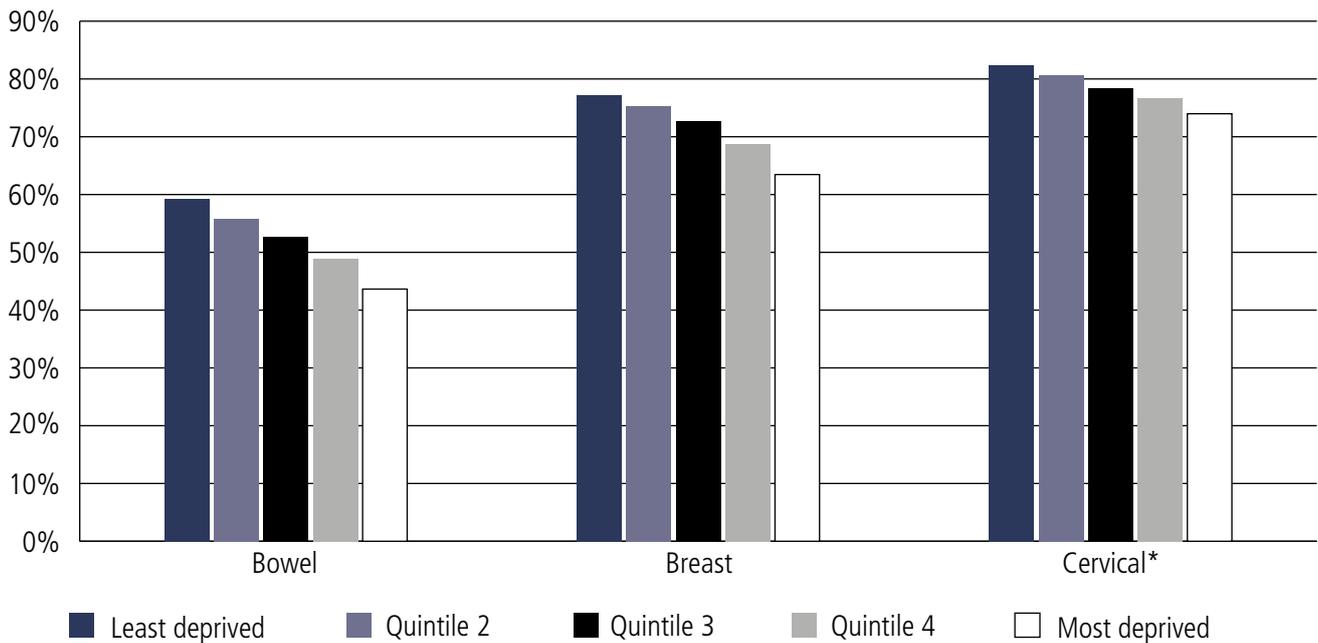
The aim of the bowel screening programme is to reduce morbidity and mortality from bowel cancer. Bowel Screening Wales invites eligible men and women aged between 60 and 74 to take part in bowel screening every two years. Although it does not meet the 60% target, uptake of bowel screening in Wales has increased by over 4% since last year (The 2012-13 uptake was 48.2%) which is positive news.

Work is taking place to develop, implement and evaluate strategies to improve uptake of bowel screening. This includes:

- the development of a framework to address inequity;
- the development of key messages and an introductory letter. Both of these are being piloted and evaluated; and
- the development of the participant champion role and collaboration between specialist screening practitioners and the screening engagement team.

Uptake for all the cancer screening programmes has shown a close relationship with deprivation. This means that those in the most deprived groups are least likely to go for screening. This relationship is most pronounced in bowel screening but as can be seen from figure 10 is present for all three cancer screening programmes. Figure 10 shows the uptake/coverage by quintile of deprivation for each programme, with groups becoming more deprived moving left to right.

Figure 10: Uptake/coverage by deprivation quintile. Wales, 2013-14



Source: Public Health Wales Screening – October 2014

* Cervical screening coverage (age 25-64, screened within 5 years)

Attempts are in place to address these inequities in screening across Wales. Public information plays an important role, having clear consistent messages that are delivered in the way that is most appropriate to the audience. Key messages have been developed for each of the programmes and are available on the websites¹⁵. A partnership approach is central to ensuring that the public participate in screening programmes. The screening division within Public Health Wales is working with partners including local public health teams, Communities First, other community groups and the Third Sector.

¹⁵ Cervical Screening Wales:
www.screeningforlife.wales.nhs.uk/sitesplus/documents/1129/CSW_A4infosheet.pdf.
 Breast Test Wales
www.screeningforlife.wales.nhs.uk/sitesplus/documents/1129/BTW_A4infosheet.pdf.
 Bowel Screening Wales
www.screeningforlife.wales.nhs.uk/sitesplus/documents/1129/BSW_A4infosheet.pdf.

6 Diagnosing cancer early

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- *There was a long delay between GP's first referral [date removed] endoscopy/scan appointments and eventual appointment with consultant to start treatment [dates removed].*
- *Once I was diagnosed with cervical cancer my care was excellent. But before that I had abnormal smears and several colonoscopies. It took nearly a year before I was diagnosed, which I feel was too long.*
- *It is thanks to the radiographer in [hospital removed] that my cancer was found after having pneumonia, I had no other symptoms so would never have known it was there.*
- *I was very lucky to have been seen and diagnosed so quickly following my GP appointment when I told him I had found a lump.*
- *I had early diagnosis which meant my treatment helped having had an early start.*
- *All tests and treatments carried out promptly and staff on the whole were very good.*
- *The speed with which my diagnostic test, scans and surgery were organised. All the doctors exuded a sense of urgency which I found reassuring.*

Wales Cancer Patient Experience Survey 2013

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Recognising possible warning signs of cancer and taking prompt action leads to early diagnosis. Increased awareness of possible warning signs of cancer, among physicians, nurses and other health care providers as well as among the general public, can have a great impact on the disease. Some early signs of cancer include lumps, sores that fail to heal, abnormal bleeding, persistent indigestion, and chronic hoarseness. Early diagnosis is particularly relevant for cancers of the breast, cervix, larynx, colon and rectum, skin and mouth. It is often stated that late presentation is a key factor in what are considered to be poor cancer survival rates in the United Kingdom. As such early referral from primary care is important. However all referrals whether cancer or not need to be diagnosed even if to eliminate cancer and as a result rapid access to diagnostics and turnaround of result is also key to early treatment.

Aneurin Bevan University Health Board has worked with Macmillan to pilot GP facilitator posts. The aim of the pilot was to increase the development of GP awareness programmes for cancer symptoms. It was so successful that Macmillan is now planning to roll this out across Wales.

The Macmillan GP facilitators have been seen as “change agents” and have pushed forward in primary care with leadership, communication, education, service redesign and strategy. The pilot has also demonstrated the importance and potential for greater integration across secondary and primary care. This is fundamental for this group of patients as they need to have a patient pathway that is as seamless as possible through healthcare services.

6.1 Primary care oncology

The changing nature of cancer and the increase in the number of people surviving cancer treatment, who will need ongoing care, highlights the need to better integrate cancer care across primary and community care to enable patients to receive continuous, co-ordinated care in the community.

Primary care oncology covers opportunities for cancer prevention and education to first point of contact with symptoms and the opportunity for earlier diagnosis. It also involves “background” co-ordinating, and supportive care during active treatment, and a strong and protracted role in recovery from treatment and “survivorship” care.

Primary care oncology has been identified as priority for 2015 by the Cancer Implementation Group, Macmillan Cancer Support working in partnership with the Cancer Networks in Wales has secured investment to develop an overarching framework for oncology in primary and community care for Wales.

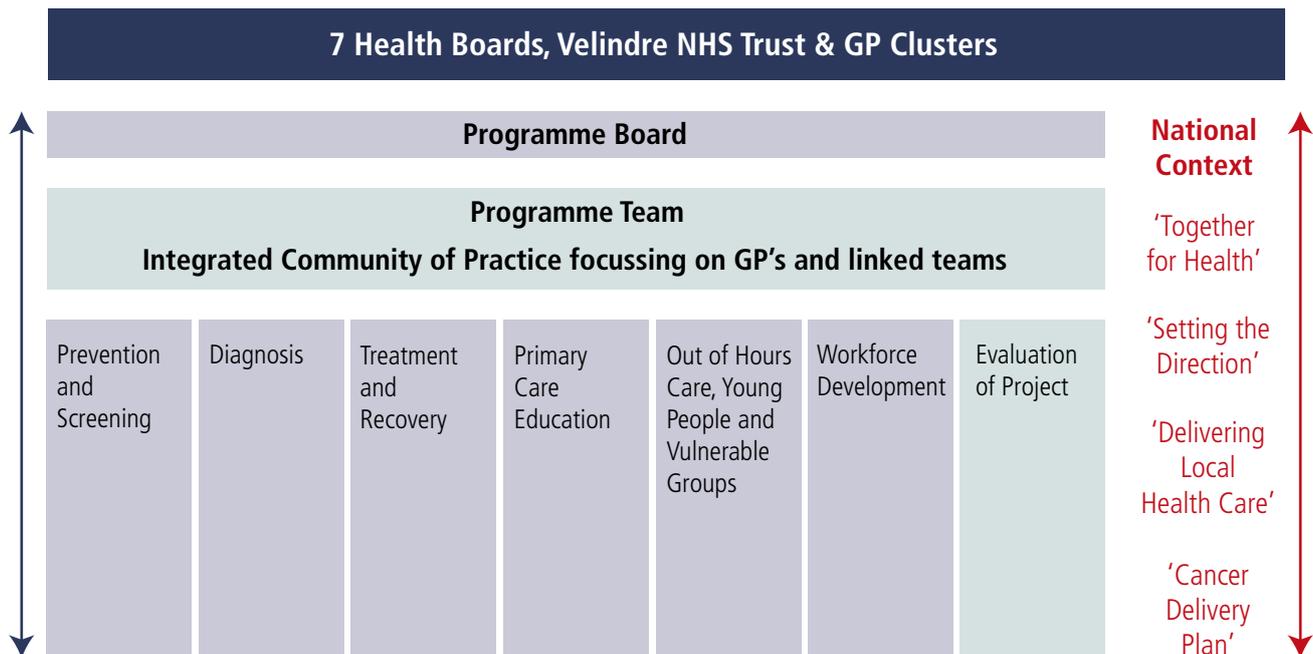
The Framework will act as a guide for GPs, health boards and Welsh Government by setting out tools, processes and information on how primary care can manage and support people affected by cancer in their practice population who have or may have had a cancer diagnosis.

It aims to develop clinical leadership in primary care by developing a community of practice principally through GPs, nurses and the wider community, who will work with GP clusters, health boards and Velindre NHS Trust, cancer networks, Welsh Government and Macmillan Cancer Support, crucially identifying local needs for cancer patients and supporting cancer service improvements.

This five year primary care oncology programme will support better integrated cancer care across primary, community and secondary care settings and develop clinical leadership. It will facilitate opportunities to support GP education, develop work streams to enhance the first point of contact with symptoms and earlier diagnosis, strengthen co-ordination of care during post treatment and support survivorship phase.

This development offers Wales an exciting opportunity to lead on an innovative and integrative approach to cancer in primary and community care. It recognises the need to enhance care closer to the patient’s home, including care after treatment. It would also enable patients to have the support they need to better care for themselves.

6.2 Outline programme of work



6.3 Performance measure 1 – The percentage of people whose cancer is diagnosed at each stage

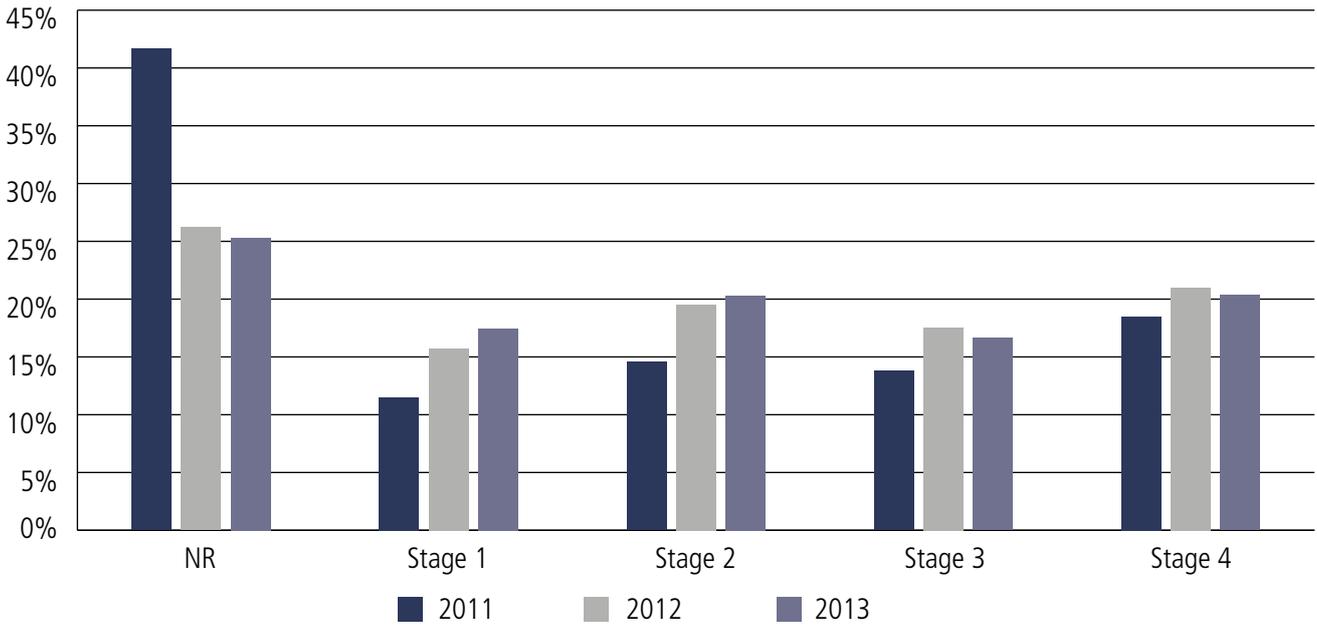
Evidence suggests that delayed help-seeking and poorer cancer survival may be linked to low cancer awareness and attitudes reflecting fear, denial and fatalism in deprived populations. To date, interventions designed to increase cancer awareness and encourage help-seeking have not been targeted at communities with high levels of social deprivation.

The Tenovus Health Check is a touch screen questionnaire delivered by a trained lay advisor. The aim is to raise awareness of cancer risk factors and symptoms by answering 30 questions in three domains: your history, your lifestyle and your health. Individualised risk is determined and signposting is then undertaken.

The aim of this project is to develop the health check as a way of engaging people in deprived areas of Wales to become more aware of cancer and visit the GP early. The pilot project is being run across Cwm Taf and Aneurin Bevan University Health Boards.

Recording the stage at which cancer is diagnosed is important as it gives us an indication as to how well our services are performing with regard to early diagnosis. In our first annual report, we were concerned about the high number of cancers where stage was not being recorded on CANISC (almost 42%) and a target was set that 70% of all cancers should have stage recorded within 12 months. Health boards have worked hard to implement effective procedures to ensure that this target was achieved and last year over 73% of all cancers had stage recorded. Performance against this measure has continued to improve with almost 75% of cancers having their stage now being recorded on CANISC. By March 2016, 90% of all cancers need to have their stage recorded on CANISC.

Figure 11: Percentage of people whose cancer is diagnosed at each stage



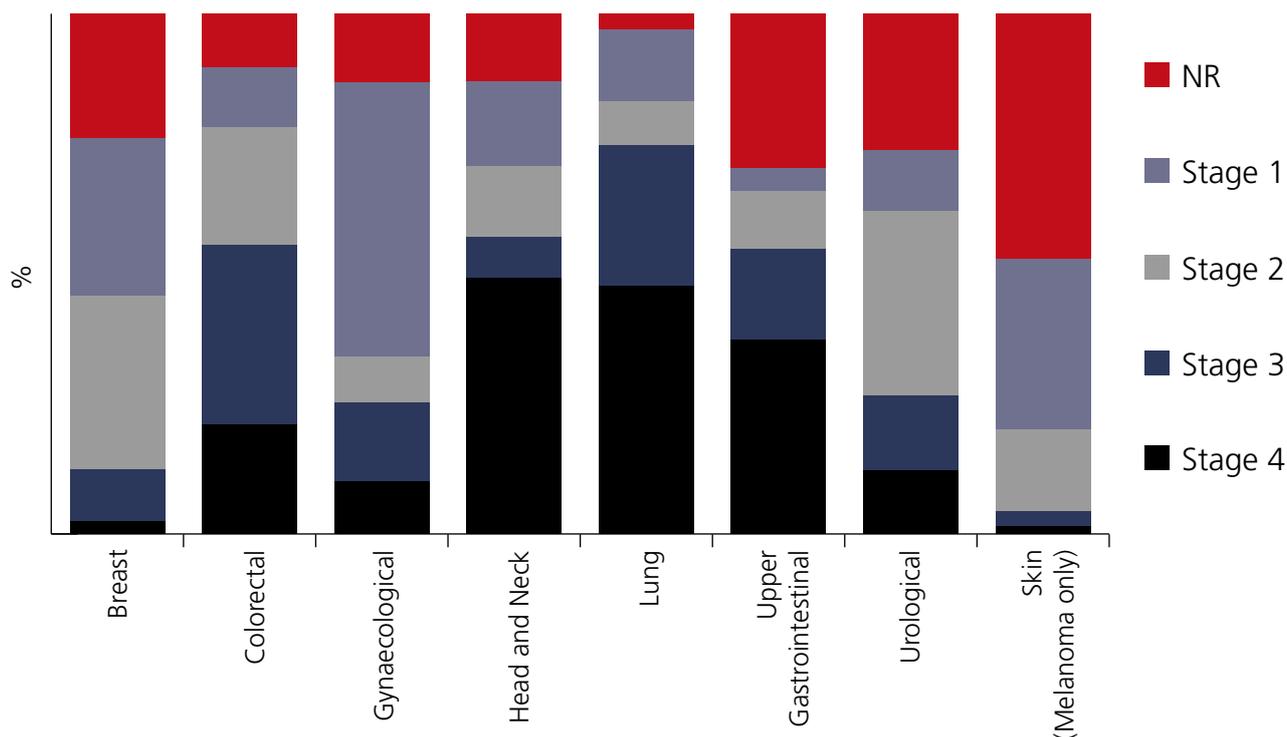
Source: CANISC ¹⁶

We want to see more cancers being diagnosed at an early stage. Figure 11 highlights that slow and steady progress has been 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; and
- fast diagnosis and staging when referred to hospital.

¹⁶ TNM stages are grouped according to UICC defined groups.

Figure 12: Percentage of people whose cancer is diagnosed at each stage by tumour site 2013



Source: CANISC¹⁷

Figure 12 highlights the variations across the different tumour sites. Almost 50% of head and neck and lung patients are diagnosed at stage 4. The majority of breast cancers are diagnosed at stages 1 and 2 and there are a high percentage of skin cancers (melanoma) which are not recorded.

The 2014-15 quality outcomes framework contains a cancer specific indicator: “Understanding cancer care pathways and identifying opportunities for service improvement”. This involves GPs reviewing the care of all patients newly diagnosed with lung and digestive cancer, summarising learning actions to be shared, identifying and including any relevant actions in their practice development plan and summarising themes and actions for review.

¹⁷ TNM stages are grouped according to UICC defined groups.

7. Fast, effective care

Stereotactic Body Radiation Therapy (SBRT) is a special class of high precision radiotherapy that has historically been applied to treatment of intra-cranial tumours. SBRT is typically used for small lung cancers in patients who are unable to have surgery, either due to the location of the tumour or other health conditions that could make surgery risky. In 2013, the Welsh Government awarded Velindre Cancer Care £4.6 million to replace a current linear accelerator (linac) with a machine capable of delivering a specialised stereotactic RT service for South Wales.

This specialist equipment will deliver stereotactic radiotherapy and radiosurgery. It will also allow patients currently being treated at the Gamma Knife Centre in Sheffield for benign conditions such as acoustic neuroma to be repatriated over the next few years.

7.1 Access and cancer waiting times

Our aim is to assess and treat patients as promptly as possible. Health boards have worked hard to achieve waiting time targets. It is important that these improvements are sustainable and lead to system changes. Improving patient pathways using appropriate service improvement methodologies will improve patient experience for a wider proportion than those just for their first definitive treatment. The Welsh Government is committed to listening to patients and clinical experts to ensure future targets reflect best practice.

- I went to my GP on the Thursday and I was seen by the following week. The consultant in the hospital which I had biopsies taken and told that same day I had cancer, and it was dealt with very quickly and I was very happy with the care I was given and how quickly it was treated.*
- The wait to start treatment is too long. I was initially told I should start treatment by August. I have an appointment for [date removed]. The long delay is disappointing. I was diagnosed in February.*

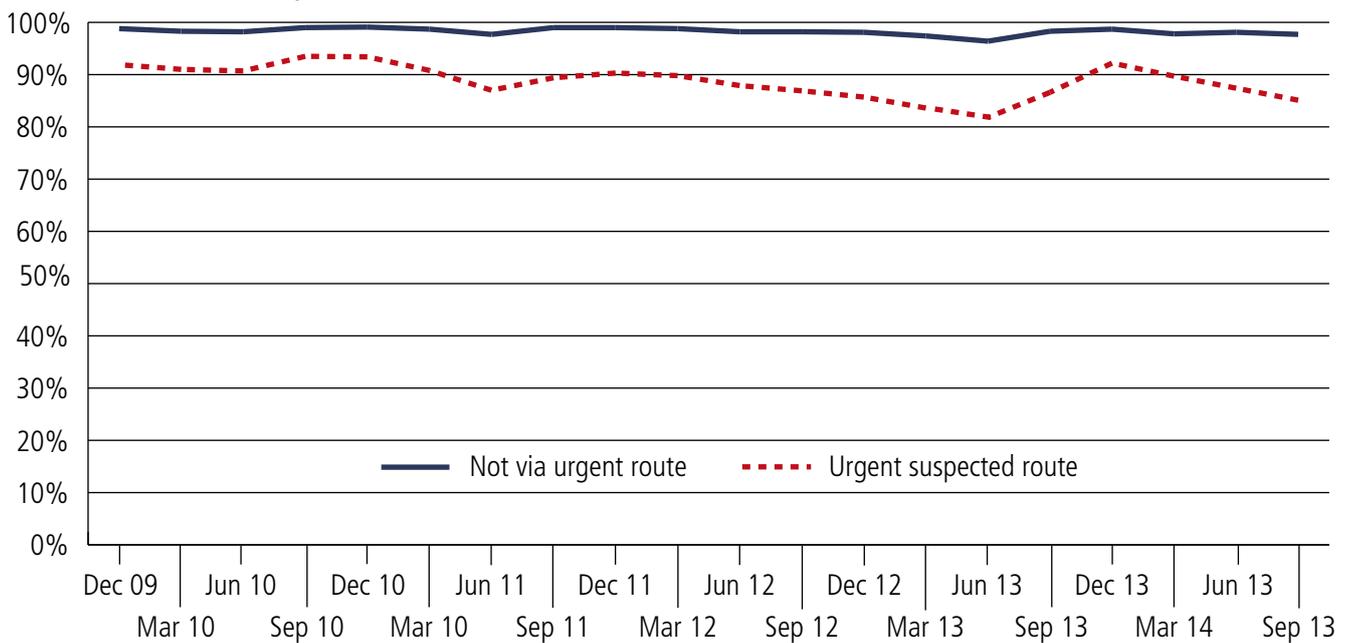
Wales Cancer Patient Experience Survey

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

7.2 Performance measure 2 – The percentage of people starting their cancer treatment in line with the cancer waiting times target

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 September 2014, 97.8% of patients who reach their diagnosis in this way started treatment within 31 days of the decision to treat.

Figure 13: Percentage of patients newly diagnosed with cancer starting definitive treatment within 62 days (via the urgent suspected cancer route) and 31 days (not via the urgent suspected cancer route)



Source: Welsh Government Statistics

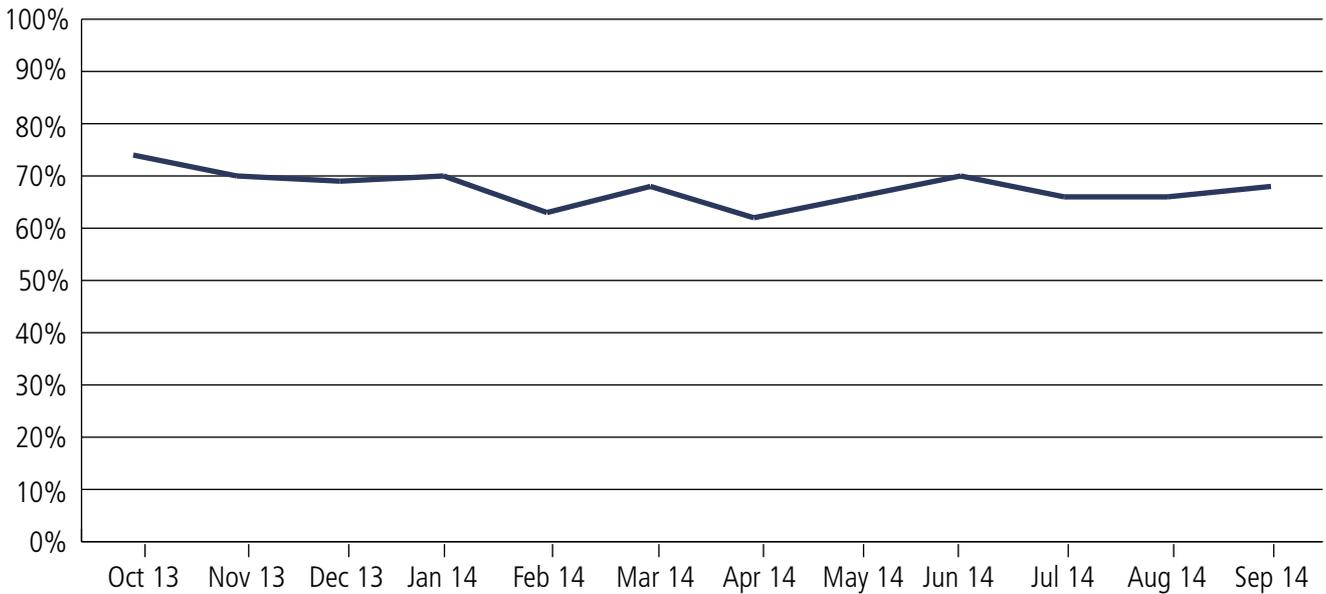
The second target is that at least 95% of patients newly diagnosed with cancer should start cancer treatment within 62 days of being referred by their GP. On a quarterly basis, this target has not been met at the all Wales level since the quarter ending June 2008. For the quarter ending September 2014, 85.1% of patients started cancer treatment within 62 days.

The 62 day target covers all milestones of the patient journey to 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, analysis of waiting time performance shows that if the first outpatient appointment takes place after 10 working days, then the NHS has had difficulty in terms of meeting the overall target.

The Welsh Government and its Delivery Unit is working closely with all the health boards to make sure that any patients not treated within 62 days, get treated as soon as possible. We are also working to make sure that we meet this standard in the future.

Figure 14 highlights that performance against the 10 working day milestone for patients subsequently diagnosed with cancer has been between 62% and 74%. This is not good enough and health boards will need to focus their performance against this guideline over the next year.

Figure 14: Percentage of patients having first appointment within 10 working days in Wales



Source: Cancer network, calculated on patients diagnosed and treated between 1/10/2013 and 30/09/2014 with a date first seen recorded.

A new robotic surgery suite for prostate cancer patients has opened at a Cardiff hospital. Prostate cancer is the most common form of the disease in men in Wales, with one in eight affected. More than 2,500 men are diagnosed with prostate cancer in Wales every year and 550 die.

The robotic surgery suite which can remove a cancerous prostate through small incisions, is the first in Wales. The technology exists in some hospitals in England, but the University Hospital of Wales' robot is the latest model – one of only six in the world.

This will allow surgery to be performed through small "keyholes" rather than large incisions and will result in shorter recovery times, fewer complications and a shorter hospital stay for patients.

The hospital's robot was funded by the Welsh Government and surgeons from Swansea and Newport will also be able to use it.

For cancer patients their pathway is often complex. Cardiff and Vale University Health Board have developed and introduced a new tracking system (Tentacle) to provide an effective administrative overview. This will identify where patients are on the pathway and enable the health board to optimise their appointments for imaging and definitive care.

Tentacle is currently being used within the following tumour sites – gynaecology, head and neck, dental, ophthalmology, dermatology and urology. The remaining sites will be added to the system over the next few months.

7.3 Acute oncology services

- *One experience of having to be admitted through A & E via triage on [name removed] ward. A & E staff had very little knowledge of the specialist treatment required and how to manage it.*
- *The staff in A&E were very good and very kind, and jolly on the two occasions I had to be admitted during chemo. So busy in A&E but excellent staff, very patient and caring.*

Wales Cancer Patient Experience Survey 2013

A significant proportion of cancer patients are admitted as emergency cases either with a previously undiagnosed cancer or as a result of unexpected development associated with cancer treatment. These patients will typically be admitted via emergency departments under the care of acute medical specialities. Cancer patients take up, on average, 12% of acute medical beds¹⁸.

An acute oncology service is a service which ensures that all patients with a known diagnosis of cancer are rapidly recognised when they present as an emergency. It also develops pathways to ensure early oncological involvement in patients who present unwell in emergency departments and are found to have a new diagnosis of cancer. The early assessment by a specialist oncologist should reduce extensive and often unhelpful investigations and ensure that the patient is placed on the appropriate pathway thus reducing the length of stay as a medical emergency. The cancer delivery plan has an expectation that all the main hospitals within Wales will have an acute oncology service by 2016 to better support this group of patients.

The development of the first oncology service in a south Wales hospital has significantly improved the care of cancer patients.

The service was set up by Aneurin Bevan University Health Board and Velindre Cancer Centre following a request from the Welsh Cancer Network to ensure more specialist care was available for inpatients.

Many patients were being admitted to hospital due to cancer related issues yet as there was no resident cancer specialist, they often had prolonged stays without specialist assessment or treatment.

The new service improved care in three areas; patients being admitted with acute new cancers, patients with acute cancer related complications and patients with problems due to treatment such as pain, bleeding or sepsis.

The service was launched in August last year and in its first five months demonstrated a significant improvement in care. It was involved in 1,271 cancer related patient admissions and 980 patients were identified by the new alert system. It reviewed 47 patients with new acutely presenting cancers and most of these saw a specialist within 24 hours, compared with an average previously of a delay of around six days. There was more rapid diagnosis, less unnecessary investigations and palliative care was involved at a much earlier stage. There was also an improvement in care for complications as a result of treatment such as chemotherapy or radiotherapy and a reduction in the length of hospital stay for many patients.

¹⁸ National Cancer Intelligence Network – 2012.

7.4 National cancer standards

Health boards self assess the quality of cancer services they provide each year against the national cancer standards; these cover a range of clinical process measures including communication with primary care, patients and carers, clinical service configuration, multi disciplinary team working and adherence to and audit of clinical guidelines. The majority of cancer standards are “generic” and are applicable to all cancer sites. The remainder are “site specific” and applicable to particular cancer types.

Table 3: Health board’s performance against the generic and site specific national cancer standards – April 2014

Health Board	Generic	Overall Site Specific
Abertawe Bro Morgannwg University Health Board	97%	98%
Aneurin Bevan University Health Board	100%	98%
Betsi Cadwaladr University Health Board	97%	94%
Cardiff and Vale University Health Board	81.82%	95.8%
Cwm Taf University Health Board	96%	88% – 100%
Hywel Dda University Health Board	100%	86%
Velindre Cancer Centre	100%	97%

Source: Health board annual reports

Each health board has implemented procedures to monitor and report against their compliance with the cancer standards, which will be verified by the peer review process. Table 3 highlights that there is some room for improvement in all health boards and health boards will be expected to demonstrate improvements next year.

7.5 Peer Review

The peer review process for cancer services in Wales, led by the Health Inspectorate Wales working in partnership with the cancer networks in north and south Wales was launched in 2012.

Peer review of cancer services in Wales is a quality assurance programme that assesses the quality of the service being delivered by multi-disciplinary teams and health boards in Wales. This assessment is set against a framework of specific healthcare standards and national guidelines.

The broad aims of peer review are to reassure health boards on the quality of cancer services in Wales. The process has now been undertaken by the lung, upper GI, urology, lower GI, and head and neck services. Peer review of gynaecology services is on-going and will be followed by reviews of breast, skin, pancreatic and haematology services during 2015.

There have been a number of challenges in relation to the peer review process with regards to availability of data for completion of the self assessment documentation, especially for those cancer sites that do not have a national audit, and the level of engagement by some health board teams in the overall process. A small number of immediate risks were identified as a result of the peer review visits and these were reported immediately to Health Inspectorate Wales,

who then brought these to the attention of the health board in line with their procedures for managing such findings. Issues were raised during the upper GI and urology peer review visits which have resulted in revisits of those services taking place for certain Health Boards.

Overall, the level of clinical engagement in the process has been excellent, and clinicians who have participated as either reviewers or as members of the teams being reviewed have reported that they have found the process to be an extremely useful development for cancer services in Wales.

Although health boards are still addressing their action plans, the findings of the peer review process have already led to a number of changes in cancer services including the reconfiguration of cancer teams to provide more robust and better resourced teams, the funding of new posts including clinical nurse specialists and other clinical staff, and the development of clinical policies and protocols to minimise unnecessary variation in standards of care across health boards.

The impact of the peer review process is immediate and teams have responded to the peer review process with improved processes and practices in responding to patient needs and embracing service improvement initiatives. There is improved documentation around operational policies and the participation in business meetings to address issues such as undertaking and responding to patient experience surveys and patient pathway improvement work. Further work is required to ensure even greater engagement between cancer teams and health board management teams and clinical ownership of health board local cancer plans.

7.6 Participation in national clinical audit

Health boards have participated in a number of HQIP national clinical audits in 2013-14. The key findings were:

National Prostate Cancer

- 100% of Welsh hospitals have isotope bone scanning facilities on site (92% of English Trusts) and all specialist multi disciplinary teams (MDTs) have access to this staging modality in keeping with recommendations (NICE, 2014).
- All centres in Wales can offer Intensity modulated radiotherapy (IMRT) which is increasingly considered to be the new standard (91% centres in England).
- 60% of hospitals in Wales can provide the full array of personal support services including cancer advisory centres, sexual function and continence services, and psychological/ counselling services (50% of Trusts in England).
- 83% of local MDTs in Wales are attended by a member of the palliative care team. (16% in England). However, lack of attendance at meetings of the MDT does not reflect the potential involvement in the extended multidisciplinary team.
- 24-hour access to specialist advice on palliative care is available 80% of Welsh Hospitals providing prostate cancer care (77% in England). One centre in Wales (20%) can provide radial treatment and robot-assisted laparoscopic prostatectomy (England 43%).

Oesophago Gastric Cancer

- There has been an increased use of definitive chemo radiotherapy and EMR in treating these cancers.
- Postoperative complications remain frequent, occurring after a third of oesophagectomies and a fifth of gastrectomies.
- The percentage of patients with positive longitudinal resection margins after oesophagectomy has improved since the 2010 Annual Report, from 6.4% to 3.7%.

National Lung Cancer Audit

Overall measures of the standards of care have been sustained and in some areas have marginally improved compared to previous years with small rises in:

- The proportion of patients having their cancer subtyped.
- The proportion of patients with small cell lung cancer receiving chemotherapy.
- The proportion having access to a lung cancer nurse specialist (LCNS).

National Bowel Cancer Audit

- Death after surgical resection is falling.
- Two year patient survival is 80% if the cancer is resected.
- 86% of rectal cancer cases had evidence of MRI staging and 93% of those undergoing resection were circumferential resection margin (CRM) negative.

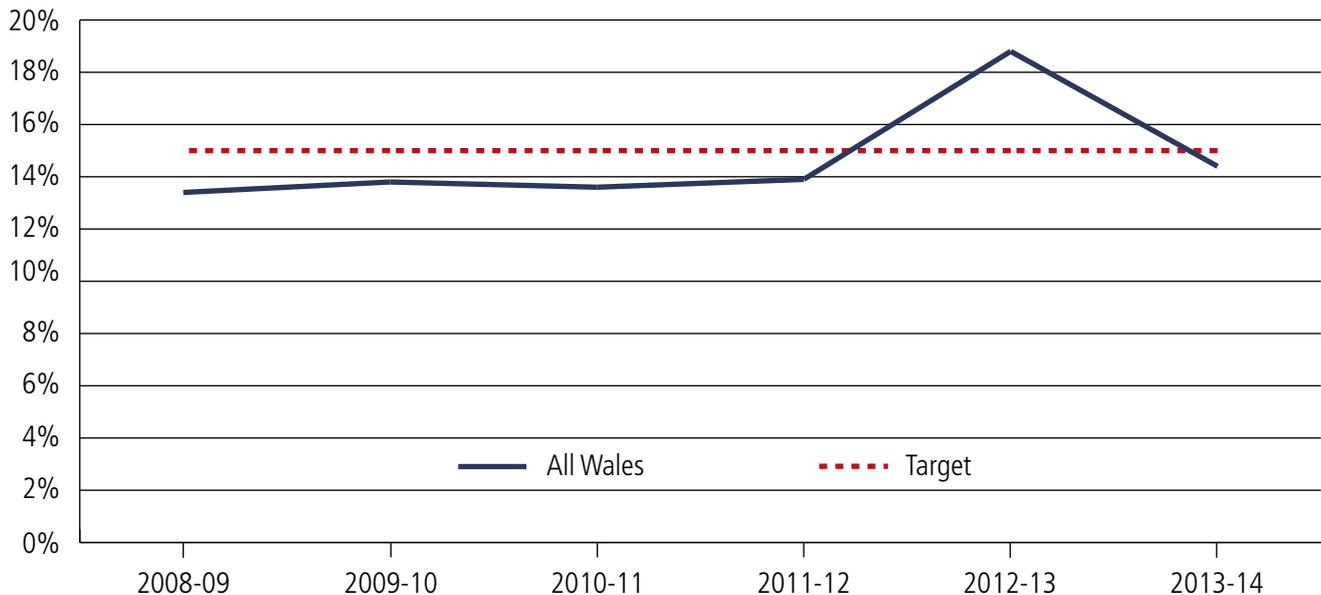
Health boards are expected to participate fully in all cancer audits and make sure that they have in place robust action plans to respond to the recommendations within the audit.

8. Research

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

8.1 Performance measure 3 – The percentage of patients recruited into high quality clinical research

Figure 15: Percentage of patients recruited into high quality clinical research



Source: NISCHR Clinical Research Centre¹⁹

Overall recruitment into clinical trials has reduced by 4.4% this year. Both interventional and non interventional studies have decreased in their recruitment. The total percentage of patients recruited into high quality trials is 14.4%. This is just below the target of 15% of new cancer patients to participate in high quality studies on the National Institute for Social Care and Health Research (NISCHR) portfolio or commercial research register. This reduction in recruitment can be partly accounted for by the closure of the CRUK Stratified Medicine Pilot study which contributed significantly towards the overall recruitment in 2013/14 and also the lack of large recruiting trials open to recruitment. It is disappointing to note that this target has been missed; health boards now need to improve and then maintain this level of recruitment.

¹⁹ Using the 2011/12 UKCRN recruitment data provided by the National Institute for Healthcare Clinical Research Network – June 2012.

The Clinical Research Facility (CRF) sited in Cardiff and Vale University Health Board continues to support trials in haematological cancers and has expanded its portfolio to include early phase work. This service development has enabled patients from throughout Wales who are referred to this tertiary centre for treatment of their haematological malignancy to be offered early phase therapy in clinical trials that would previously only have been available in centres in England such as the Royal Marsden. The CRF is part of the national treatment accelerated programme funded by Lymphoma and Leukaemia Research. This funding provides nursing support for haematological trials and to date (August 2014) more than 50 patients have been enrolled in early phase clinical trials. Currently there are 12 clinical trials in haematological cancer open to patient recruitment in the CRF with 6 of those being early phase trials. In addition there are 2 additional phase 1 studies in the set-up phase which will be open to recruitment later this year.

Table 5: The percentage of patients recruited into high quality clinical research by tumour site 2012-13

	Total recruitment to research trials	Total recruitment to interventional trials
Lung	18%	3%
Breast	29%	16%
Colorectal	10%	3%
Head and Neck	25%	4%
Urology	23%	5%
Gynaecological	9%	3%
Skin	6%	1%
Haematological and Lymphoma	26%	19%
Upper GI	3%	1%

Source: NISCHR Clinical Research Centre²⁰

Table 5 highlights how successful recruitment has been into a number of research trials. Participation in lung, breast, head and neck, urology and haematological and lymphoma trials is well above the 15% target. For interventional studies participation in breast and haematological and lymphoma trials are above the 7.5% target.

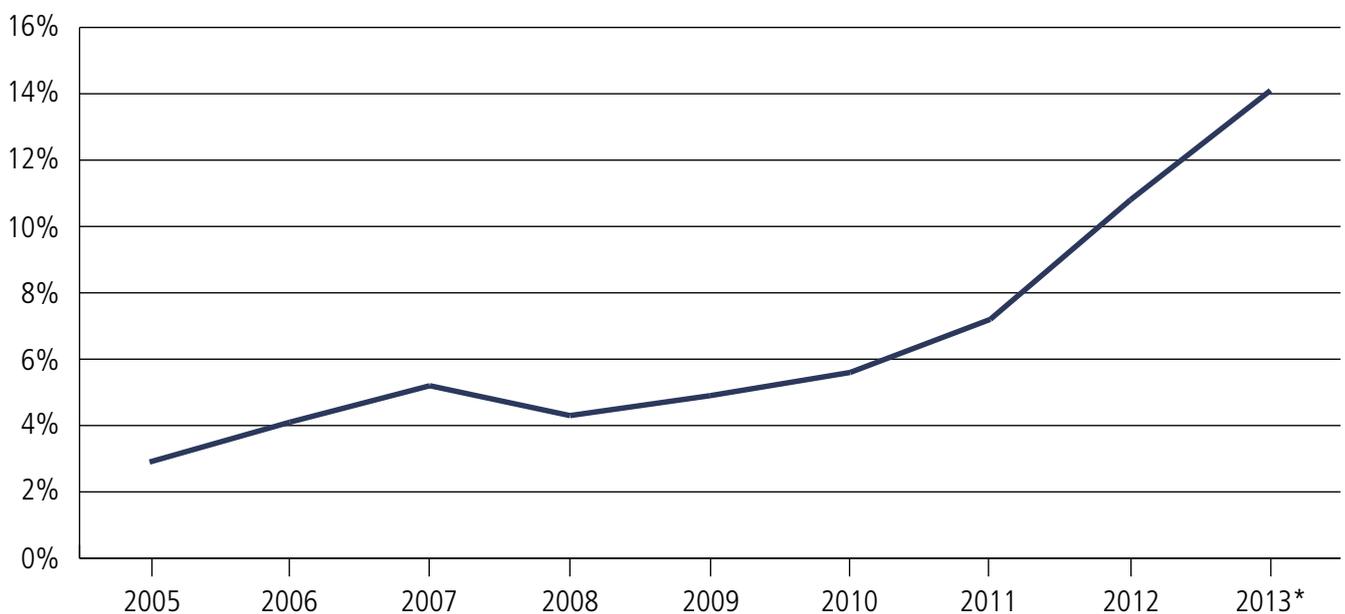
²⁰ Using the 2011/12 UKCRN recruitment data provided by the National Institute for Healthcare Clinical Research Network – June 2012.

9. Tissue donations to the Wales Cancer Bank

The Wales Cancer Bank collects samples of tumour, normal tissue and blood from all consenting patients in Wales who are undergoing an operation to remove tissue where cancer is a possible diagnosis. These samples will be banked to build up a research resource that will be used by research groups to help understand the molecular mechanisms involved in cancer and work towards the selection of the appropriate treatment for individuals. We would expect that by 2016, that 20% of people diagnosed with cancer will agree to donate samples.

9.1 Performance measure 4 – The percentage of people diagnosed with cancer who consent to donate samples to the Wales Cancer Bank

Figure 16: Percentage of patients diagnosed with cancer agreeing to donate to the Wales Cancer Bank



Source: Wales Cancer Bank May 2014

* Using 2013 WCB data against 2012 incidence data

By the end of 2013 just over 14% of patients with cancer agreed to donate samples to the Wales Cancer Bank. This is an increase in donations of 3.3% across Wales.

Between April 2006 and April 2014 over 10,000 people consented to donate samples to the Wales Cancer Bank.

In 2014, 1,836 patients consented, 399 of those were consented retrospectively in oncology clinics in Velindre. The gender and age profile of donors remains constant at 53% female donors and 76% of all donors are aged 61 or above. The percentage of patients consented post operatively has risen from 12% to 20% which reflects the continued consenting in Velindre.

The largest number of consents come from breast patients (23%), with colorectal (17%), prostate (14%), kidney (8%) and lung (7%) the next largest. The lung consents have increased over the last year with the emphasis on late stage lung patients for phase 2 of the stratified medicine project.

10. Meeting people's needs

Making sure people with cancer have a good experience of care is essential:

- 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.²¹
- Poor patient experience can be a warning sign for more widespread failings.
- 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.²²

- “
- *I was treated with respect, courteousness, understanding. From the receptionist receiving me at entry to the outpatient team as a whole was an excellent experience under a stressful time of treatment.*
 - *All of the staff that have treated me over the last two years have been outstanding. They have all showed such compassion and understanding. Nothing is too much trouble.*
 - *All the hospital staff were very kind and caring and helped me to be strong. I am very grateful to them.*
 - *Staff seemed to care and usually remember you on return and it makes you feel safe. Everybody treated me well and with respect and this was good for my well-being and morale.*

Wales Cancer Patient Experience Survey 2013 ”

The Welsh Government is committed to ensuring that 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. Welsh Government and MacMillan Cancer Support undertook a national cancer patient experience survey in 2013. The results show that cancer services are well regarded by patients. Health boards will be reviewing their survey results and taking action to ensure that improvements are made in this area.

The overall scores given by patients in Wales to the cancer patient experience survey were positive. 58% of patients said that their care was excellent, 31% said it was very good, 8% said it was good. Patients with breast cancer were the most likely to be positive on many questions; and the least likely groups of positive patients were in the urology, sarcoma, and lung tumour groups. 81% of patients said that they did not feel that they were treated as 'a set of symptoms' rather than a whole person over the last year.

²¹ Charmel P, Frampton S. Building the business case for patient-centered care. *Healthcare Financial Management*. 2008. 62(3): 80-5.

²² The King's Fund. Leadership and engagement for improvement in the NHS. www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/leadership-for-engagement-improvement-nhs-final-review2012.pdf.

10.1 Performance measure 5 – Percentage of people with a diagnosis of cancer who are assigned a key worker

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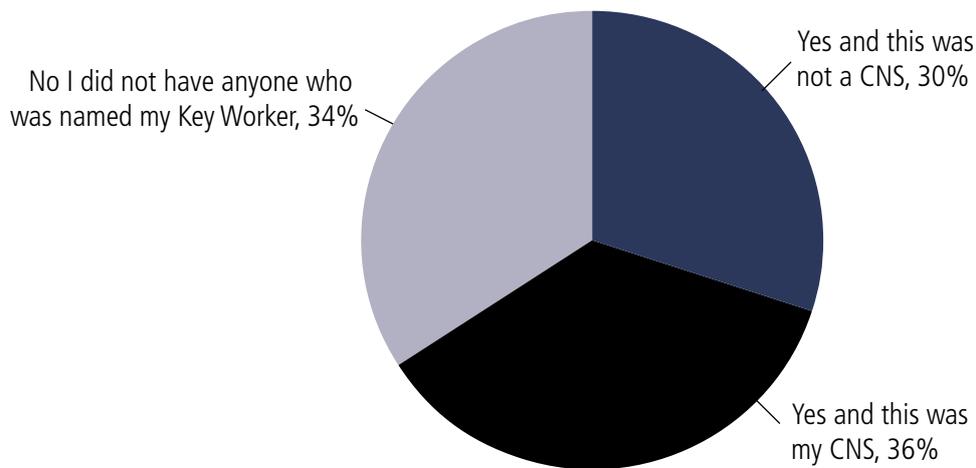
- *I was given contact details for specialist nurses but could never contact them.*
- *I felt I needed specialist nurse support (phone or personal contact) following my 3 operations, especially I experienced difficulty with chemotherapy. Needed emotional support, although I did not contact anyone.*
- *The CNS left after a very few weeks, approx. 3 1/2 years ago and there has not been one since.*
- *I did have a name of the key worker but they did never speak to me, when my family spoke to her they were told to speak to the hospital that is not acceptable. There were times I needed somebody to talk to.*
- *My key worker was the most important person on the planet during and after my treatment, she always clearly followed up what was said in clinic and still answers emails and chats on the phone even though I know she is so busy. Thank you.*
- *Specialist nurses were very efficient and helpful. Was nice to be treated by the same nurses every time.*
- *I was very impressed with my clinical nurse specialist, she was very caring. Gave me good advice and empathised with me and my family.*
- *The clinical nurse specialist coordinating all of the appointments including scan etc. and always being there if needed.*

Wales Cancer Patient Experience Survey 2013

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In the cancer patient experience survey 2013, 59% of patients confirmed that they were given the name and contact details of their key worker. For 32% of respondents the key worker was also their clinical nurse specialist (CNS), for 27% it was another person. 31% were not given details of a key worker.

Figure 17: Percentage of patients who were given the name and contact details of their key worker



Source: National Cancer Patient Experience Survey – 2013

Rather than just being assigned a key worker, it is important to make sure that the patient understands who this is and knows how to get in touch and able to develop a good relationship. The findings from the patient experience survey are encouraging:

- 82% of patients who had tried to contact their key worker said it was easy to contact him or her.
- 92% of patients said the key worker had definitely listened to them.
- 91% of patients of those who had asked questions of their key worker said they got answers they could understand all or most of the time. Similar questions were asked about a CNS.

Both CNS's and key workers have a substantial positive effect on patients views of their care; having either or both a CNS and a key worker is associated with higher scores from patients on almost all questions in the survey. Those patients who had a CNS who was also their key worker were more positive on a slightly larger number of questions than was the case for patients whose key worker was not their CNS. The coverage of key workers varies considerably between health boards but especially between hospitals.

Further work has been undertaken to clarify the exact definition and role of the key worker. National guidance has been sent to all health boards in 2014.

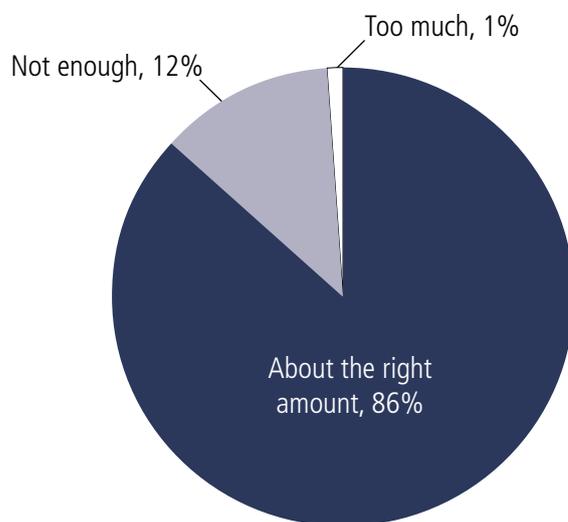
10.2 Performance measure 6: Percentage of people with a diagnosis of cancer who have a care plan

The cancer delivery plan has set a target that everyone with a diagnosis of cancer should have a care plan.

In the cancer patient experience survey 58% of patients said they had been offered the opportunity to discuss their needs and concerns in order to put together their care plan; 42% had not been offered this opportunity.

Patients were also asked whether they had been offered a written care plan. Only 22% of patients said that they had been offered a written assessment or care plan; 78% said they had not.

Figure 18: Percentage of respondents who were happy with the amount of information they received



Source: National Cancer Patient Experience Survey – 2013

As highlighted in figure 17, the majority of respondents feel comfortable with the amount of information they were given and 86% of patients overall said that they were given the right amount of information about their condition and treatment; 12% said they were not given enough and 1% said they were given too much.

There is a lot of work to be done across Wales to ensure that all cancer patients have a written care plan by 2016. Our priority is to increase the number of patients being offered the opportunity to discuss their needs and concerns in order to put together their care plan. It is acknowledged that greater clarity is required regarding what constitutes an effective care plan and this will be a major piece of work in the year for the Cancer Implementation Group's patient experience work stream. Following this clarification, health boards will be expected to ensure that all patients are then able to have a written care plan as a result of that discussion and that this care plan is available across all levels or primary, secondary and tertiary care.

Macmillan has continued funding the National Exercise Referral Scheme (NERS) project, which has allowed the continuing development of awareness of the benefits of physical activity for people affected by cancer. This funding has allowed the therapy team with Abertawe Bro Morgannwg University Health Board to extend the current cancer rehabilitation services. This year, the Macmillan NERS intervention has seen the amount of patients assessed for community cancer rehabilitation services almost double from last year to nearly 300 assessments for the scheme in 2014.

11. Caring at the end of life

People with cancer approaching the end of life need access to care and support whenever it is needed. Access to health, social care, support and symptom control must be consistent across Wales and these services need to be well coordinated.

Cwm Taf University Health Board has two Macmillan funded GP Facilitators who have been encouraging use of universal advance care planning tools, starting with a pilot of new admissions to nursing homes. This has now been extended to existing nursing home residents. The initial report of the pilot has shown that 9 advance care plans have been agreed, 7 of which helped to avoid a hospital admission, and 3 of which enabled the individuals to die in their care home as per their plan.

12. Conclusion: looking ahead to 2015 and beyond

There has been considerable progress in cancer care in Wales over the past 12 months. This is a tribute to all those involved in the planning and delivery of this important area. This includes staff in the NHS and those in other parts of the public sectors. We must also acknowledge the invaluable work of the community and voluntary sector. We have now established firm foundations for further positive development.

We have performed well over the past 12 months and seen progress in many of our performance measures. We will continue to track our progress in future years to ensure that we are in a sustainable position to achieve our vision by 2016.

There is still a tremendous amount to be done in Wales. In response to the challenges raised in this report and in an attempt to be more focused, coordinated and strategic in its approach to service delivery and improvement, the Cancer Implementation Group has agreed five national. These are:

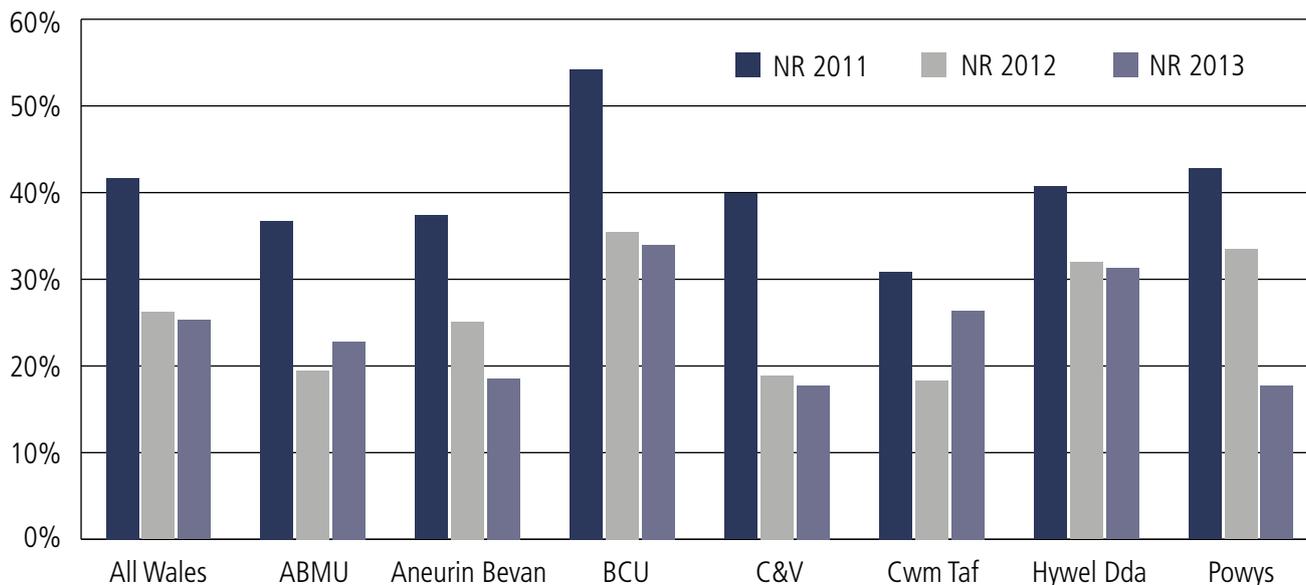
- The development of a more streamlined, coordinated organisational structures and supporting a single clinically led and patient centred cancer delivery group.
- A national approach to primary care oncology: a collaboration between the Cancer Networks and Macmillan Cancer Support.
- The introduction of a new single pathway for all suspected cancer patients.
- Further developments around patient experience: namely improved standards around patient information and care plans; and
- A focus upon improving outcomes for lung cancer patients: in particular exploring an awareness campaign, improving access to curative treatments and research and stratified medicine initiatives.

In next year's annual report we will look at how we have progressed during the year.

Annex 1 Health boards' performance against the national performance measures

Performance measure 1 – The percentage of people whose cancer is diagnosed at each stage – Local health board of residence

Percentage of people whose cancer diagnosis stage is not recorded



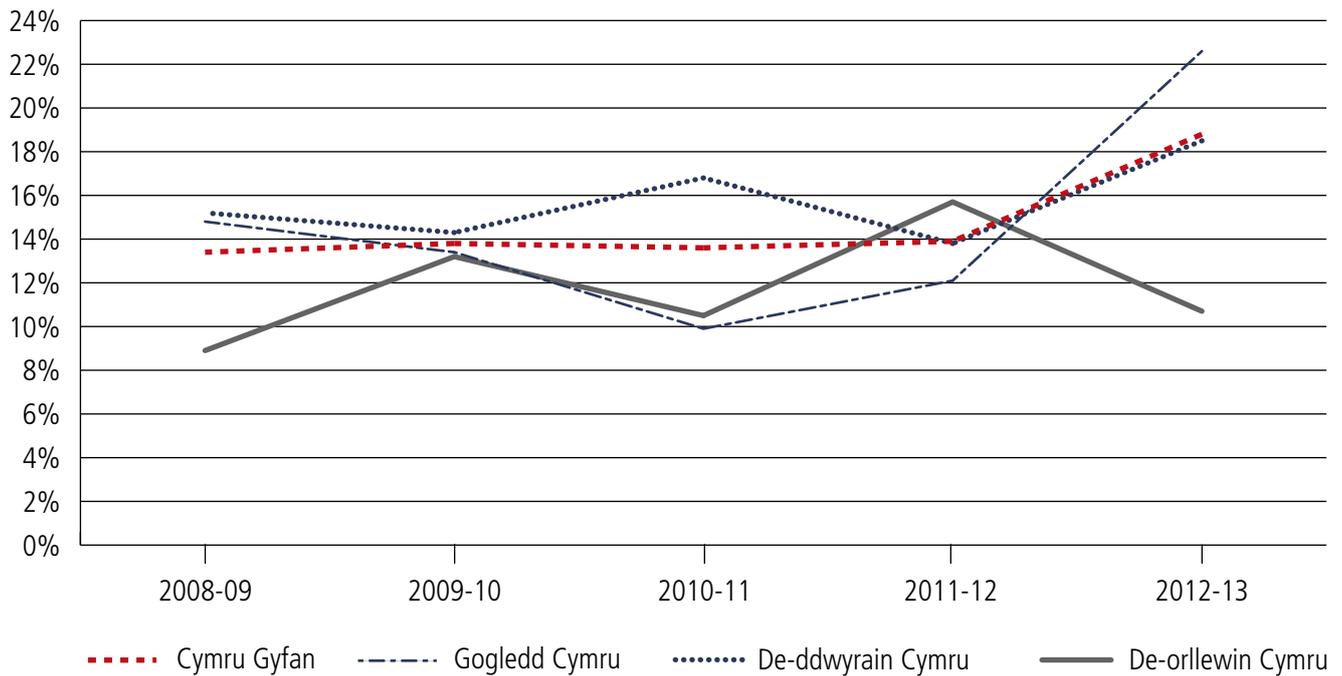
Source – CaNISC

Performance measure 2 – The percentage of people starting their cancer treatment in line with the cancer waiting times target

Local Health Board (LHB)	Percentage of patients newly diagnosed with cancer starting definitive treatment within 62 days (via the urgent suspected cancer route)														
	Quarter ending Mar 2011	Quarter ending Jun 2011	Quarter ending Sep 2011	Quarter ending Dec 2011	Quarter ending Mar 2012	Quarter ending Jun 2012	Quarter ending Sep 2012	Quarter ending Dec 2012	Quarter ending Mar 2013	Quarter ending Jun 2013	Quarter ending Sep 2013	Quarter ending Dec 2013	Quarter ending Mar 2014	Quarter ending Jun 2014	Quarter ending Sep 2014
Betsi Cadwaladr University LHB	91.7	86.5	87.1	87.9	90.5	94.4	89.7	88.6	86.1	87.3	82.8	93.0	93.5	87.1	86.2
Hywel Dda LHB	93.7	88.0	92.0	89.1	89.2	86.7	85.4	81.0	81.4	79.4	84.9	93.2	85.5	91.2	87.6
Abertawe Bro Morgannwg University LHB	87.4	77.8	88.8	88.3	83.6	74.3	75.1	76.0	69.9	75.1	88.4	88.5	84.7	85.3	81.1
Cwm Taf LHB	88.9	85.6	86.0	89.7	85.9	83.6	85.7	86.5	77.9	78.2	82.7	87.7	91.4	86.1	88.1
Aneurin Bevan LHB	95.4	95.2	93.0	92.2	95.5	96.6	96.8	93.2	98.0	82.3	90.9	95.0	96.0	89.7	81.5
Cardiff & Vale University LHB	87.6	89.8	90.2	96.6	94.2	92.7	85.9	90.0	85.4	87.1	88.8	95.1	85.7	85.7	89.5
Wales	90.8	87.0	89.4	90.3	89.8	87.9	85.9	85.7	83.6	81.8	86.6	92.1	89.7	87.4	85.1

Local Health Board (LHB)	Percentage of patients newly diagnosed with cancer starting definitive treatment within 31 days (via the non urgent suspected cancer route)														
	Quarter ending Mar 2011	Quarter ending Jun 2011	Quarter ending Sep 2011	Quarter ending Dec 2011	Quarter ending Mar 2012	Quarter ending Jun 2012	Quarter ending Sep 2012	Quarter ending Dec 2012	Quarter ending Mar 2013	Quarter ending Jun 2013	Quarter ending Sep 2013	Quarter ending Dec 2013	Quarter ending Mar 2014	Quarter ending Jun 2014	Quarter ending Sep 2014
Betsi Cadwaladr University LHB	99.3	98.3	99.0	99.6	99.6	99.1	98.9	99.4	97.8	98.1	98.8	99.5	98.1	98.9	98.9
Hywel Dda LHB	98.4	95.5	98.5	98.8	98.6	97.4	98.4	96.7	97.2	93.5	97.3	97.5	96.4	95.3	96.6
Abertawe Bro Morgannwg University LHB	97.8	95.2	98.1	98.0	97.9	96.3	94.6	95.2	94.1	92.4	98.5	97.9	97.5	97.9	98.0
Cwm Taf LHB	98.7	98.4	98.9	98.1	98.8	98.9	99.7	99.1	98.2	97.8	98.6	98.7	97.5	98.4	99.1
Aneurin Bevan LHB	99.4	99.8	99.4	99.2	99.1	99.0	99.6	99.4	99.6	98.6	97.5	98.9	98.8	98.5	96.1
Cardiff & Vale University LHB	98.1	99.0	100.0	100.0	98.1	98.1	98.3	98.7	97.7	96.8	99.4	99.3	98.0	99.3	97.8
All Wales	98.7	97.7	99.0	99.0	98.8	98.2	98.2	98.1	97.4	96.4	98.3	98.7	97.8	98.1	97.8

Performance measure 3 – The percentage of patients recruited into high quality clinical research



Source: NISCHR/clinical trials

Performance measure 4 – The percentage of people diagnosed with cancer who consent to donate samples to the Wales Cancer Bank

