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Together for Health

Cancer Delivery Plan, Annual Report 2013

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1. Introduction

The publication of the second all Wales annual report for cancer is part of the commitment of the Welsh Government to deliver a more accountable and visible NHS for the people of Wales. This annual report highlights the progress we have made in our cancer services over the past 12 months 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 provision of cancer services.

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

- Wales has shown the biggest improvement in cancer survival among the four countries of the United Kingdom, at 14 per cent for one year relative survival and 15 per cent for five year survival, from 1995–1999 up to 2005–2009 and 2001–2005 respectively.
- There has been a steady increase in the uptake of the Human Papilloma Virus (HPV) vaccine across Wales with levels in 2012–13 at 86.6 per cent.
- In the cancer patient experience survey, 89 per cent of patients said that their care was excellent or very good. 88 per cent of respondents were given the names of their clinical nurse specialist. 66 per cent of patients confirmed that they were given contact details of their key worker. 58 per cent of patients said they had been offered the opportunity to discuss their needs and concerns.
- There has been a 5 per cent increase in recruitment to clinical trials.
- Over the past 12 months tissue donations to the Wales Cancer Bank increased by 3.4 per cent.
- 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 been consistently achieved since July 2013.

There are however a number of areas where progress has not been as good as anticipated:

- Whilst Wales's cancer survival improvement has been proportionately larger than in other UK countries, we are lagging behind a number of other European countries. Survival rates for smoking related cancers have the poorest outcomes across Europe. In Wales the survival rates from smoking-related cancers (stomach, lung and kidney) are lower than the European average.
- The uptake for the bowel screening programme has reduced by 4.8 per cent since 2010–11 and at 48.2 per cent does not reach the target of 60 per cent for bowel screening.
- Our performance against the 62 day 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. However it is encouraging to note that improvements were noted in performance towards the end of 2013, with performance in October and November at a national level at over 92 per cent.

We expect to see progress in these areas in 2014. We also hope to see a greater emphasis on the delivery of cancer services that are clinically led and put the patient at the centre of care. The results of the first National Cancer Patient Survey show that the vast majority of patients think their overall care is very good or excellent. This is a great tribute to the dedicated staff that work tirelessly to support patients and carers through difficult times. Together with peer review this transparent reflection of the quality of care must be used to drive continuous service improvement using the principles of Improving Quality Together.

David Sissling
Chief Executive, NHS Wales

Paul Roberts
Chair, Cancer Implementation Group

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 cancer[1]?

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 2011. This equates to around 416 cases[2] 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 16,100 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 for 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 1 per cent each year[3].

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 2002 and 2006) varied from 3 per cent for pancreatic cancer; 7 per cent for lung cancer to 84 per cent for each of prostate cancer and breast cancer[3]. 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 Europe[4].

[1] More detailed information on incidence, mortality and survival can be accessed here

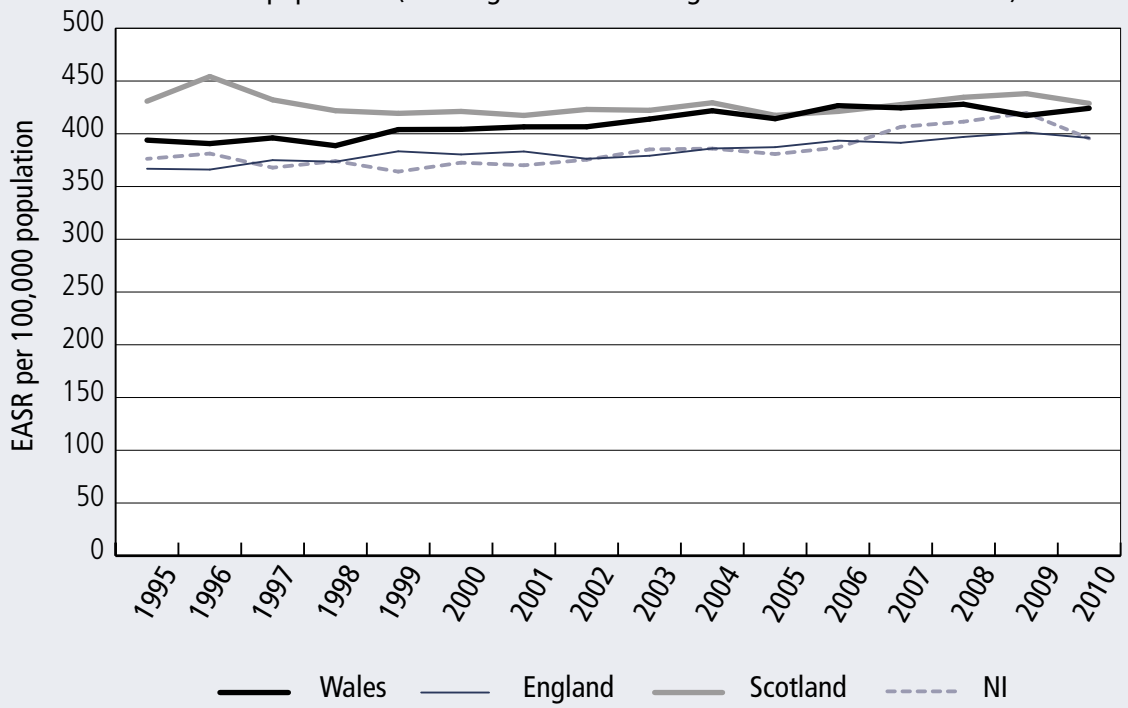
[2] European Age Standardised Rate per 100,000 population

[3] WCISU

[4] Those countries with cancer registration and mortality covering the whole population

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

Figure 1 - European age standardised cancer incidence rates (EASR) per 100,000 population (all malignancies excluding non melanoma skin cancer)



Source: UKCIS 4.5b – April 2013 update

Figure one shows that Scotland tends to have the highest incidence rates in the UK over time. Wales had the second highest incidence rate in 2010 while Northern Ireland and England have similar lower rates. The general trend for all countries is increasing with both England and Wales increasing by nearly 8 per cent from 1995 to 2010.

2.3 Cancer mortality rate

This tells us how many people die from cancer each year[5]. If our strategy is successful, over time we would expect to see:

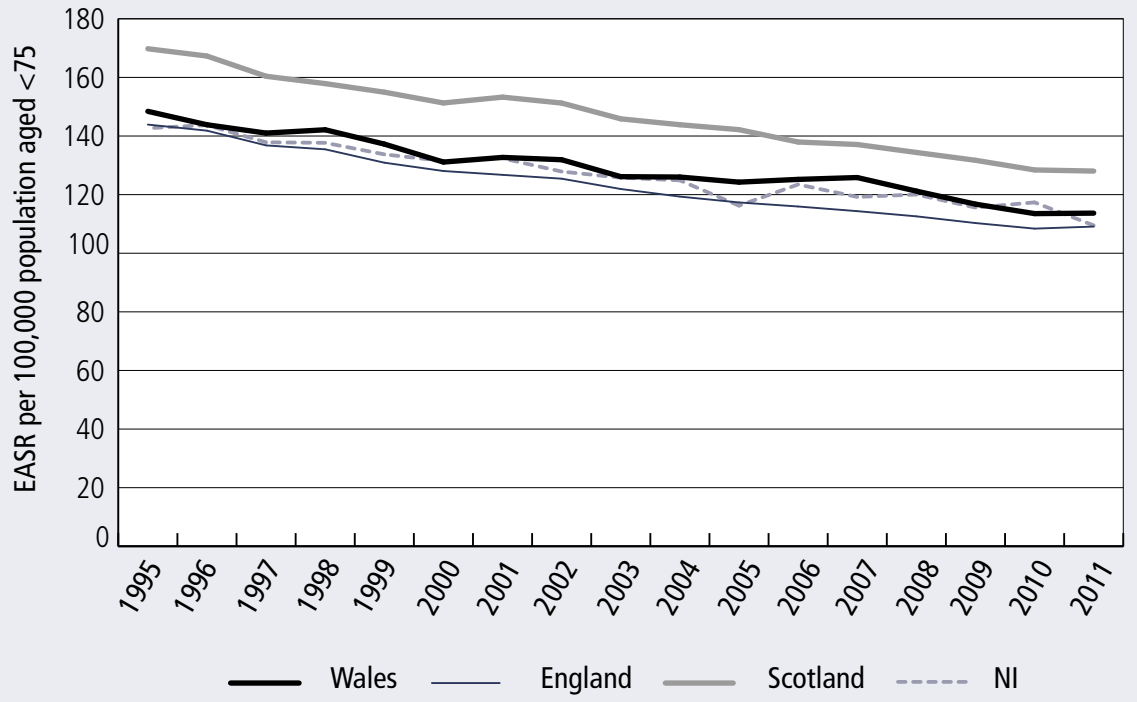
- A continued fall in the rate of deaths from cancer.
- A reduced gap between the most and least deprived areas of Wales.
- Mortality rates comparable with the best in Europe.[4]

Figure two shows that there has been a steady decline in the overall rate[6] of people dying from cancer over the last sixteen years. Scotland has the highest mortality rates of all the UK countries and was around 12 per cent higher than Wales in 2011 Wales has the second highest mortality rates for those under 75 years while Northern Ireland and England have similar mortality rates. All countries show around a 23–24 per cent reduction in mortality from 1995 to 2011.

[5] Expressed as an age standardised rate to allow comparisons between years and countries

[6] Based on the EASR per 100,000 population for persons under 75

Figure 2 - European age standardised cancer mortality rates (EASR) per 100,000 population under 75 years of age (all malignancies excluding non melanoma skin cancer)



Source: UKCIS 4.5b – April 2013 update

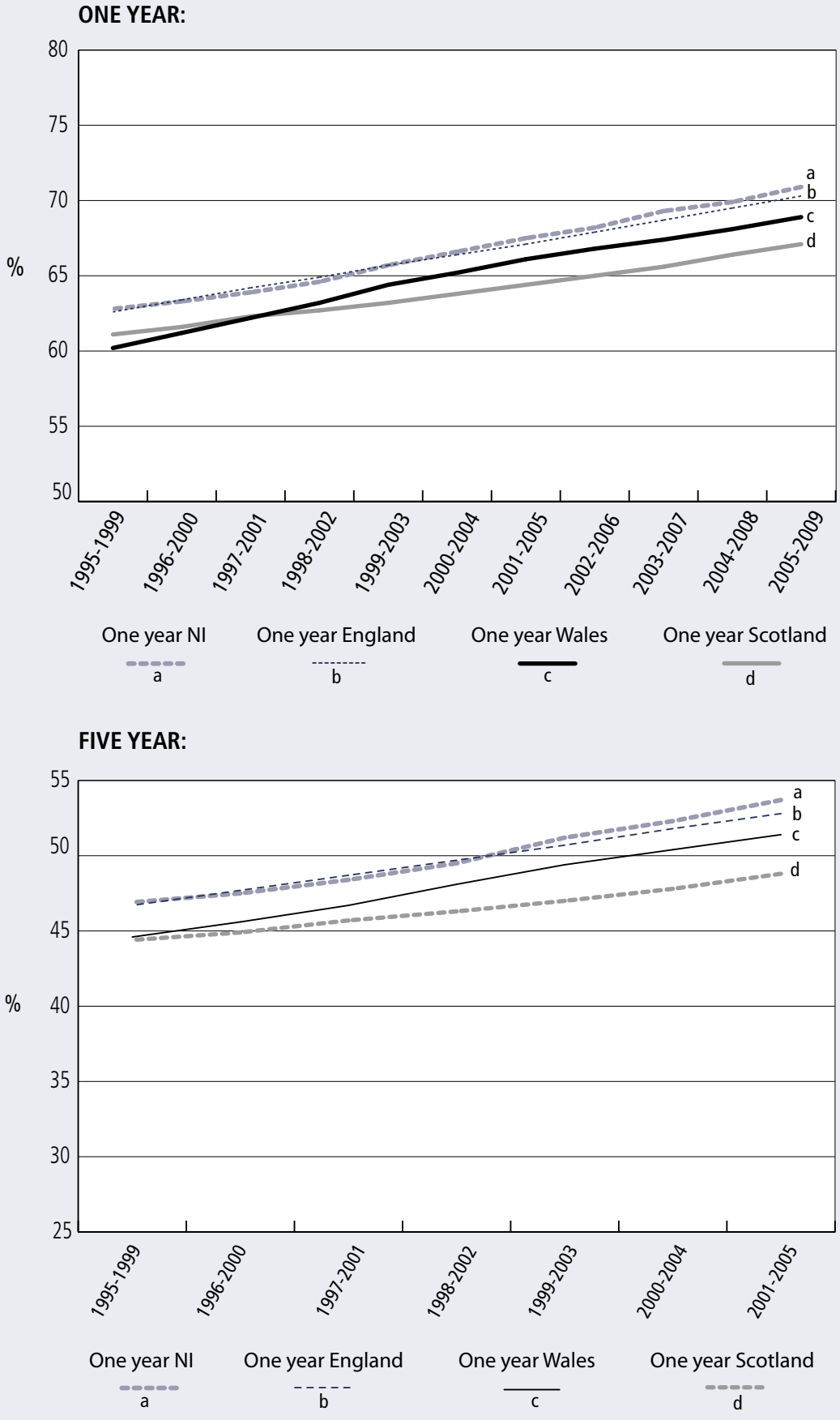
2.4 One and five year survival rate

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 Europe.[4]

Figure three 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. However, over the time period examined, Wales shows the greatest increase at 14 per cent for one year relative survival and 15 per cent for five year relative survival from 1995–1999 up to 2005–2009 and 2001–2005 respectively.

Figure 3 - Percentage of patients surviving all cancers (excluding non melanoma skin cancer), all ages



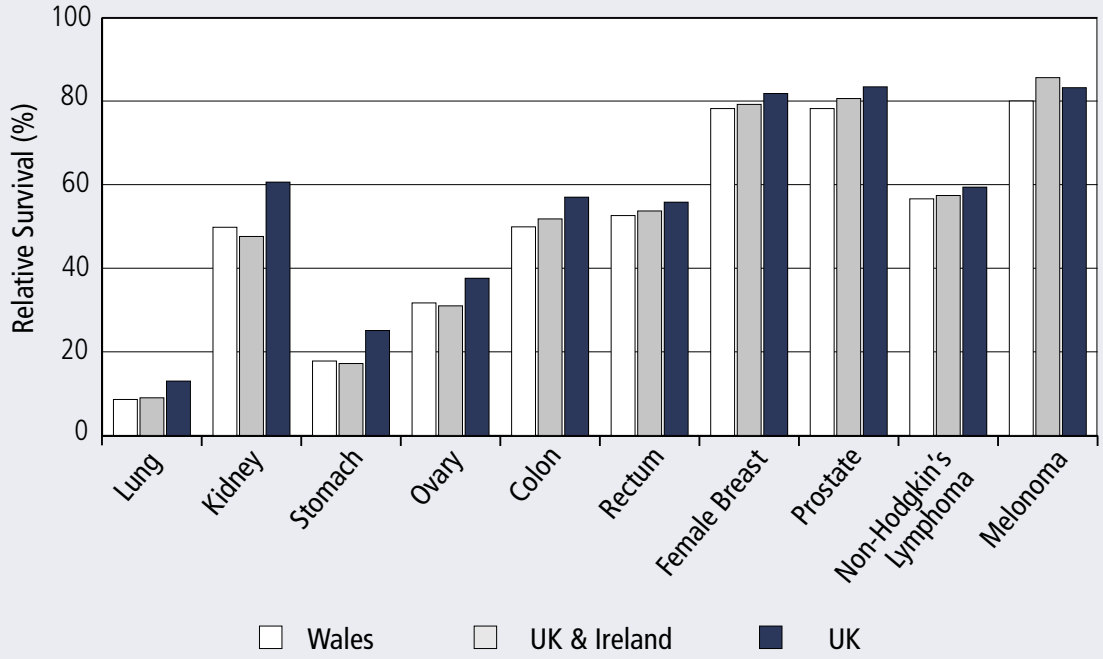
Source: UKCIS 4.5b – April 2012 update

2.5 How does Wales compare with the rest of Europe?

2.5.1 Adult Cancers

Despite improvements in Wales, we are still lagging behind a number of other European countries. Comparison is possible because the United Kingdom (though not Wales separately) is a member of EUROCARE 5[7], 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 EUROCARE 5; cancer survival from adult cancers across Europe has improved considerably. Analysis by WCISU has indicated that Wales's cancer survival improvement is proportionately higher than in other UK countries. However EUROCARE 5 shows that the UK and Ireland have among the lowest survival rates for most cancers along with Denmark and Eastern European countries. Poor survival in Wales and the rest of the UK is worse in older people for most cancers.

Figure 4 - Cancer survival in Wales compared to European Mean and UK & Ireland



Source: EUROCARE 5[8]

[7] EUROCARE 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.

[8] European average for the 29 participating countries in the study

Cancer survival in Wales is lower than the European average for most of the common types of cancer studied. For skin melanoma it is notably lower than the UK and Ireland combined survival as well.

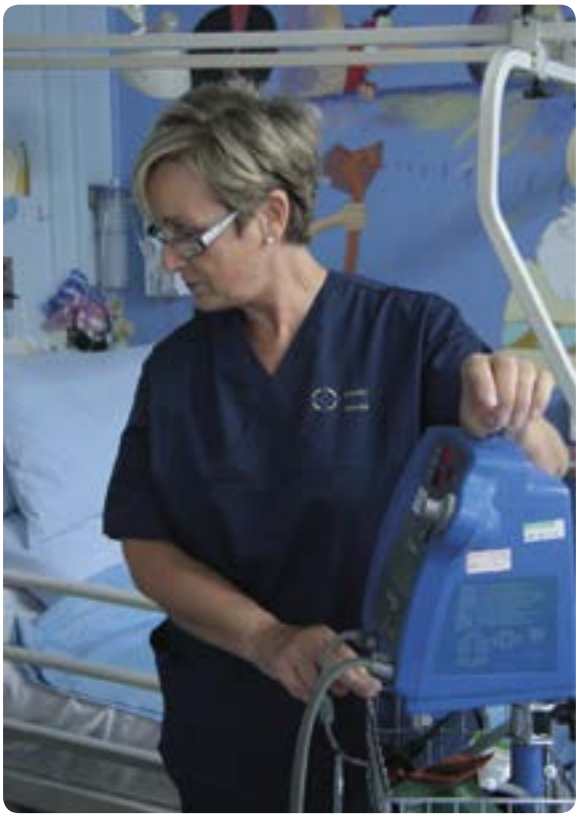
Survival rates for smoking related cancers show the poorest outcomes across Europe. In Wales the survival rates from smoking-related cancers (stomach, lung and kidney) are lower than the European average.

Survival rates from lung cancer were the lowest of all cancers with a European average survival of 13 per cent. The UK and Ireland and Wales in particular, have some of the lowest lung cancer survival rates in Europe (Wales 8.6 per cent). Stomach cancer had the second lowest survival rate out of the 10 main cancers studied, Wales is doing slightly better than England and Scotland with a rate of 17.8 per cent (compared to England 17.0 per cent and Scotland 16.1 per cent respectively).

Despite the continued apparent relatively low survival from many cancers in Wales, we know from previous and other studies that overtime 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.

2.5.2 Cancer survival trends for all childhood cancers across Europe

Again Wales and the UK have shown improvements, but survival rates are still below those evident in Europe. The five year adjusted survival rose from 76 per cent in 1999–2001 to 79 per cent in 2005–2007 for all Europe for all childhood cancers. For UK and Ireland combined the survival rose from 74 per cent to 78 per cent in the same period. Eastern Europe saw improvements (rising from 65 per cent to 70 per cent), whilst Southern Europe had the highest survival (rising from 79 per cent to 82 per cent).



Children of the UK and Ireland combined had the lowest five year survival rates for central nervous system (CNS) tumours in 2005–2007 compared to the other European regions.

Five year survival for children with all cancers excluding CNS tumours in 2000–2007 was around 80 per cent for England and Wales combined. Ireland and Northern Ireland had a slightly higher survival at around 82 per cent, the same as for all Europe. Scotland had a slightly lower survival at 78 per cent.

Children of the UK and Ireland combined had the highest five year survival rates in all Europe for Hodgkin lymphoma and non-Hodgkin lymphoma in 2005–2007.

Five year survival for children with lymphoid leukaemia in 2000–2007 was around 87 per cent for England and Wales combined. This was very similar to survival in Northern Ireland and Scotland, but higher than Ireland and all Europe[9].

[9] WCISU

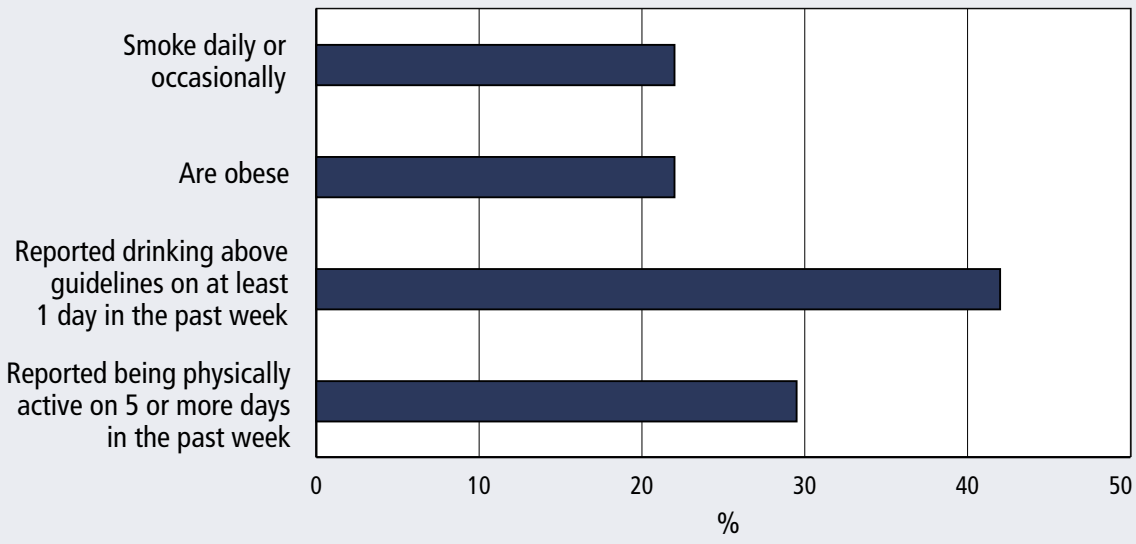
3. Cancer services in Wales

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 last year. 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 Research UK[10] suggests that sub-optimal levels of major lifestyle and environmental factors may be responsible for 40 per cent of all cancer cases. Many of the causes of poor health are difficult to tackle and are related to the wider social determinants of health and inequalities. Smoking, increasing alcohol consumption, obesity, physical inactivity and a lack of fruit and vegetables are all major risk factors for many common cancers and are widespread across Wales.

Figure 5 - Percentage of adult who …… 2012



Source: Welsh Health Survey, 2012

The Welsh Government has invested heavily in the Change4Life programme. This is aimed at helping people to recognise the importance of investing in their own future health and make lifestyle choices that will bring them long term benefits, reducing the need for medication and hospital admission. There is still a great deal to be done as highlighted in figure five.

In April 2013, the Welsh Government introduced a new target to improve the uptake of smoking cessation services. The target requires that services successfully recruit at least 5 per cent of adult smokers to take up treatment every year.

[10] http://www.cancerresearchuk.org/cancer-info

4.1 What is happening across Wales to support cancer prevention?

Local health boards are taking forward their responsibilities with regard to cancer prevention in partnership with NHS Trusts. The following are examples of some of the initiatives developed over the past year:

- Cwm Taf Public Health Team has been working closely with the Faculty of Health, Sport and Science, University of Glamorgan, and Obstetrics Gynaecology and Sexual Health in Cwm Taf to develop a study to define the barriers to giving up smoking during pregnancy.
- Betsi Cadwaladr University Health Board has worked with Public Health Wales, Education and Local Government across north Wales to form a Tobacco Alliance to reduce the smoking burden.
- Macmillan RCT libraries project: Healthy New You Groups are running in Aberdare, Pontypridd and Treorchy libraries. They aim to help people lower their risk of developing cancer or having a reoccurrence by adopting a healthier lifestyle. Participants can monitor their weight; get healthy eating tips and information on becoming more active.
- Chronic obstructive pulmonary and pneumonia care bundles are being implemented within respiratory medicine in Abertawe Bro Morgannwg University Health Board. A pilot area has been defined for introduction of the bundles and 5 high impact actions to ensure the best clinical outcome for patients includes the assessment and offer of referral for smoking cessation with the aim of reducing smoking prevalence in this high risk group.
- Betsi Cadwaladr University Health Board has delivered cancer prevention talks to local schools. These sessions have been designed to both educate school age children and to use them as educators of their peers and family members.

- A series of GP learning events have been held across Abertawe Bro Morgannwg University Health Board concentrating specifically on early diagnosis of cancer and the primary – secondary care interface.
- A 3 year British Heart Foundation "Hearty Lives" project is currently in operation within Blaenau Gwent. This is one of the most deprived localities within Gwent that has one of the highest smoking rates and the aim of the project is to attempt to reduce smoking in young people and families.
- Hywel Dda Health Board is working closely with local government, Public Health Wales NHS Trust, GPs, pharmacists, dentists, opticians and the third sector to tackle these root causes of poor health as part of the Foundation for Change programme.

5.1 Screening services

Screening uptake for breast cancer is currently at 73.2 per cent of the target population (women aged 50–70)[11]. The national target is 80 per cent, whilst the minimum uptake standard is 70 per cent of invited women attending for screening.

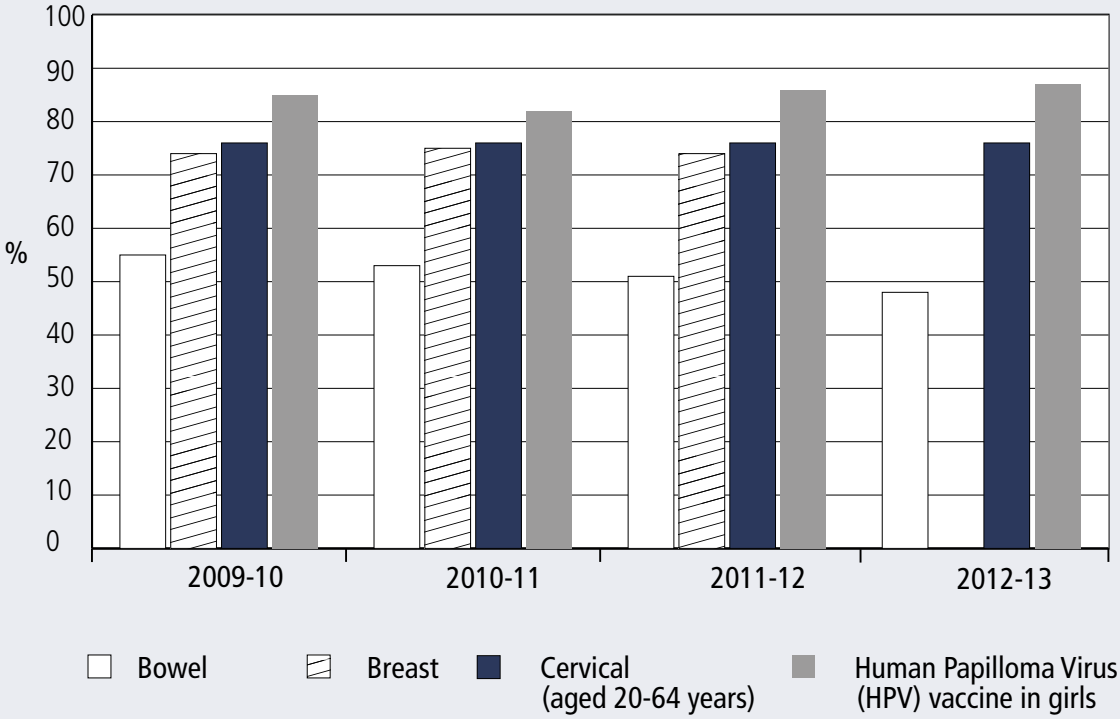
The aim of the Bowel Screening Wales programme is to reduce mortality from bowel cancer by 15 per cent in the population invited for screening by 2020. Men and women resident in Wales and aged between 60 and 74 are invited for bowel screening every two years. If the test is positive participants are referred for assessment and offered colonoscopy if considered fit for the procedure. The uptake for the bowel screening programme has reduced by 4.8 per cent since 2010–11 and at 48.2 per cent does not reach the target of 60 per cent bowel screening. Uptake has a marked relationship with deprivation and the uptake for men is lower than women. The screening test and information is sent directly to the person's home so accessibility to the screening test does not explain these findings. Reducing inequality of uptake and improving overall uptake for bowel screening is a priority and work is being undertaken to explore the barriers to uptake and how these can be addressed.

The cervical screening programme for 20 to 64 year olds has a target of 80 per cent of females to have had an adequate smear test in the past 5 years. The coverage of cervical screening in 2012–13 was similar to that of the previous year, at 76.3 per cent. Research undertaken by Cervical Screening Wales and CRUK, published in May 2013 indicated that without a screening programme, cervical cancer rates in Wales could be 3.6 times higher. The Cervical Screening Wales Audit of Cervical Cancer National Report 1999–2009 compared 1,843 women with invasive cervical cancer who were diagnosed in the period covered by the report (Jan 1999 and Dec 2009), with 3,686 women without cancer. The research shows that around 60 per cent of women with invasive cancer had not been screened in the previous seven years, compared with 16 per cent in the general population, indicating that rates of cancer could be almost four times higher for some age groups without a screening programme.

There has been a steady increase in the uptake of the Human Papilloma Virus (HPV) vaccine across Wales with levels in 2012–13 at 86.6 per cent.

[11] 2011–12

Figure 6 - Percentage uptake to screening programmes



More still needs to be done to ensure that those eligible are screened and Public Health Wales launched a health campaign during July 2013 to raise awareness of the national screening programmes offered by the NHS. The campaign was split into themes, and each week in July focused on different programmes and populations, such as men's health, the 'hard-to-reach' groups and women's screening programmes.

5.2 Diagnosing cancer early

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.

Primary care oncology is 'first contact, continuous, comprehensive and coordinating cancer care'. This 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.

New approaches to follow are being explored in both the north and south Wales cancer networks. Further developments over the next 12 months will include educating the primary care workforce, connectivity with the electronic cancer record (CANISC), as well as the provision of online resources, tools and information to support diagnosis, supportive care, and survivorship.

6. Delivering fast, effective treatment and care

The range of treatments available continues to grow, though new treatments can be very expensive. The challenge to the NHS is to ensure that patients in every area of Wales get the most cost-effective service that meets their needs.

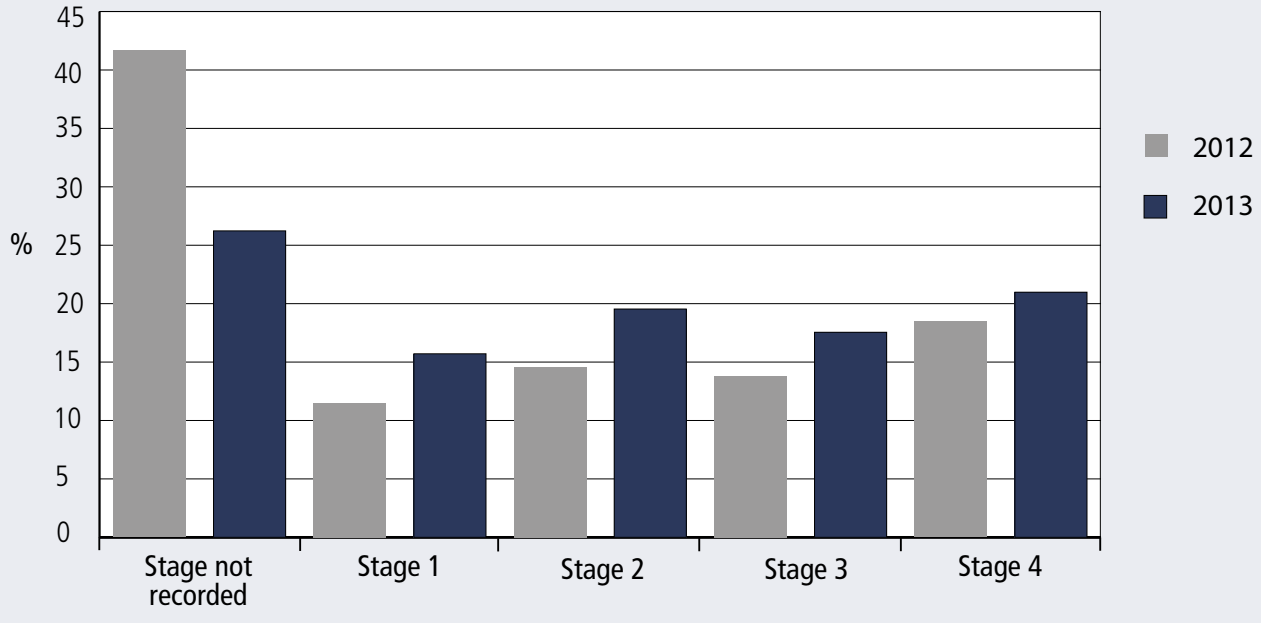
6.1 Performance Measure 1 – The percentage of people whose cancer is diagnosed at each stage

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 last year's annual report, we were concerned about the high number of cancers where stage was not being recorded on CANISC (almost 42 per cent) and a target was set that 70 per cent 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 this year over 73 per cent of all cancers had stage recorded. By March 2016, 90 per cent of all cancers need to have stage recorded on CANISC.

We want to see more cancers being diagnosed at an early stage. 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:

- 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.
- Active engagement of the public in recognising symptoms.

Figure 7 - Percentage of people whose cancer is diagnosed at each stage - All Wales



Source: CANISC[12]

[12] TNM stages are grouped according to UICC defined groups.

6.2 What is happening across Wales to improve staging?

There is significant variation between tumour sites and between health boards in terms of their rates of recording cancer stages in CANISC. For example lung cancer stage information is completed in 97.5 per cent of cases and Cwm Taf Health Board complete staging for all tumour sites in almost 82 per cent of cases. Every health board has been asked to take action to make sure this happens, and initiatives to do so include:

- Betsi Cadwaladr University Health Board has held a number of early diagnosis workshops with GPs and continues to support research into the early diagnosis of cancer in primary care.
- Cwm Taf Health Board held a wide range of events to promote prostate cancer awareness, particularly the signs and symptoms, in March 2013. This was then followed by similar activity for colorectal cancer.
- Abertawe Bro Morgannwg University Health Board has worked closely with Cancer Research UK to raise the awareness of the public in Port Talbot, regarding early diagnosis of cancer. This campaign focused on those aged over 50, addressing the issues of fear and fatalism, increasing knowledge of cancer signs and symptoms and the importance of the benefits of spotting cancer early. Analysis has demonstrated that the campaign was a success in raising awareness of signs and symptoms of cancer.

7. Access and cancer waiting times

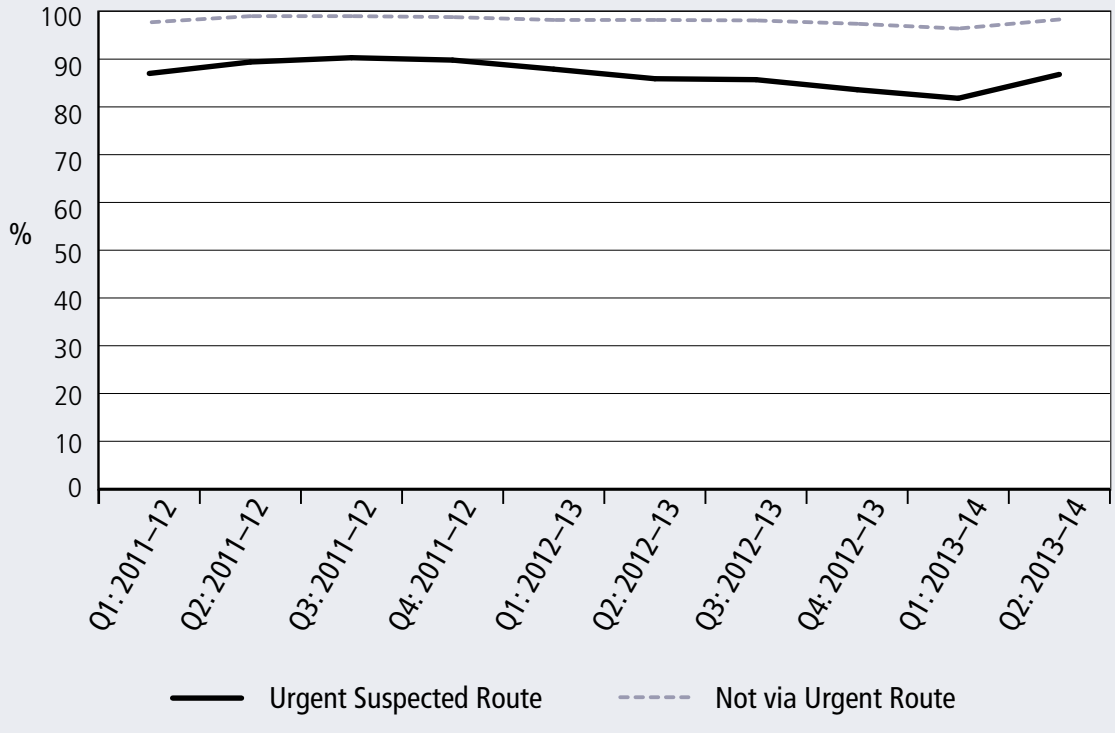
Our aim is to assess and treat patients as promptly as possible. Health boards have worked hard to achieve waiting time targets. It is important that these improvements are sustainable and lead to system changes. Improving patient pathways using appropriate service improvement methodologies will improve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

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

7.1 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 per cent should start their treatment within 31 days of diagnosis. In the quarter ending September 2013, 98.3 per cent of patients who reach their diagnosis in this way started treatment within 31 days of diagnosis.

Figure 8 - 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 per cent 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 2013, 86.6 per cent 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 are seen 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. This initial 10 day milestone will therefore be a focus for the NHS in 2014.

7.2 What is happening across Wales to improve waiting times?

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 the target in the future.

Across Wales there is a focus on developing new approaches and setting up one stop clinics to speed up treatment. Hywel Dda Health Board has introduced and strengthened one stop clinics for urology and lung cancer patients. In November 2012, a centralised post menopausal bleeding clinic was established. This has provided an equitable, consistent service increasing capacity for patients. We would expect to see an increase in the number of one stop clinics across Wales over the coming 12 months.

The Welsh Health Specialised Services Committee (WHSSC) commissions services on behalf of the health boards for patients requiring highly specialist cancer treatments. Services may be procured from Welsh or English providers.

WHSSC has formalised the arrangements for Radiofrequency Ablation at Aneurin Bevan Health Board to ensure that patients from South Wales with liver metastases have timely access to this treatment. They have also undertaken a process of evidence appraisal on 11 specialist treatments for cancer patients to ensure that patients receive both clinically and cost effective care.

8. Acute oncology services

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. Through the development of an effective acute oncology service, the development of well defined pathways and an 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 district general hospitals within Wales will have an acute oncology service by 2016 to better support this group of patients.

8.1 What is happening across Wales to develop effective oncology services?

At Betsi Cadwaladr University Health Board, acute oncology services have been established on all three of their main hospital sites and part of the remit of these services is to attend patients with cancer of unknown primary or cancer related emergencies.

Velindre Cancer Centre is supporting the detection of cancer at an earlier stage by developing a hub and spoke acute oncology service for south Wales. Velindre Cancer Centre formalised its acute oncology hub in September 2012, to make sure that patients presenting with acute symptoms are treated rapidly and appropriately. The hub was also set up to provide clinical support and advice regarding patients awaiting investigation in outlying hospitals.

This service will now be offered across south Wales. As such, Velindre Cancer Centre is working in collaboration with the health boards through the Cancer Network to develop a shared approach to improve acute oncology services within Wales by creating a quality and measurement system based on improvement science.

Aneurin Bevan Health Board has also worked in collaboration with Velindre Cancer Centre in the development of their acute oncology service, launched in August 2013, which is the first pilot centre within the south Wales model.

9. 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 1: Health Board's Performance against the Generic and Site Specific National Cancer Standards – April 2013

Health Board	Generic	Overall Site Specific
Abertawe Bro Morgannwg	97%	98%
Aneurin Bevan Health Board	100%	100%
Betsi Cadwaladr University Health Board	97%	94%
Cardiff and Vale University Health Board	100%	90%
Cwm Taf Health Board	100%	81% – 100%
Hywel Dda 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. Figure 9 highlights that there is some room for improvement in all health boards.

The "National Standards for Sarcoma" have been implemented in the past 12 months and WHSSC will undertake an annual review and audit to inform the commissioning cycle. Work is on-going to fully implement the Children and Young People's Cancer Standards across Wales.

10. Peer Review

The peer review process for cancer services in Wales, led by the Health Inspectorate Wales (HIW) working in partnership with the cancer networks in north and south Wales was launched in 2012. Peer review comprises three levels as follows:

1. Internally validated self-assessments - undertaken by health boards.
2. Externally verified self-assessments - involving the site specific peer group.
3. Peer review visits.

The broad aims of peer review are to reassure health boards on the quality of cancer services in Wales. The process started with the review of lung cancer services. It found many examples of good practice and excellent data quality. It did however also reveal variation in pathways and access to specialist treatments and services, across and even within health boards. It found that there were too many multi-disciplinary teams, variable access to acute oncology support but probably most importantly relatively poor support from surgical services, particularly in South Wales.

Cardiff and Vale University Health Board has been using the feedback from the HIW peer review and continuing monitoring to improve services across all partners in their health board area.

WHSSC is leading a review of access to thoracic surgery in south Wales, which remains the main curative treatments for lung cancer.

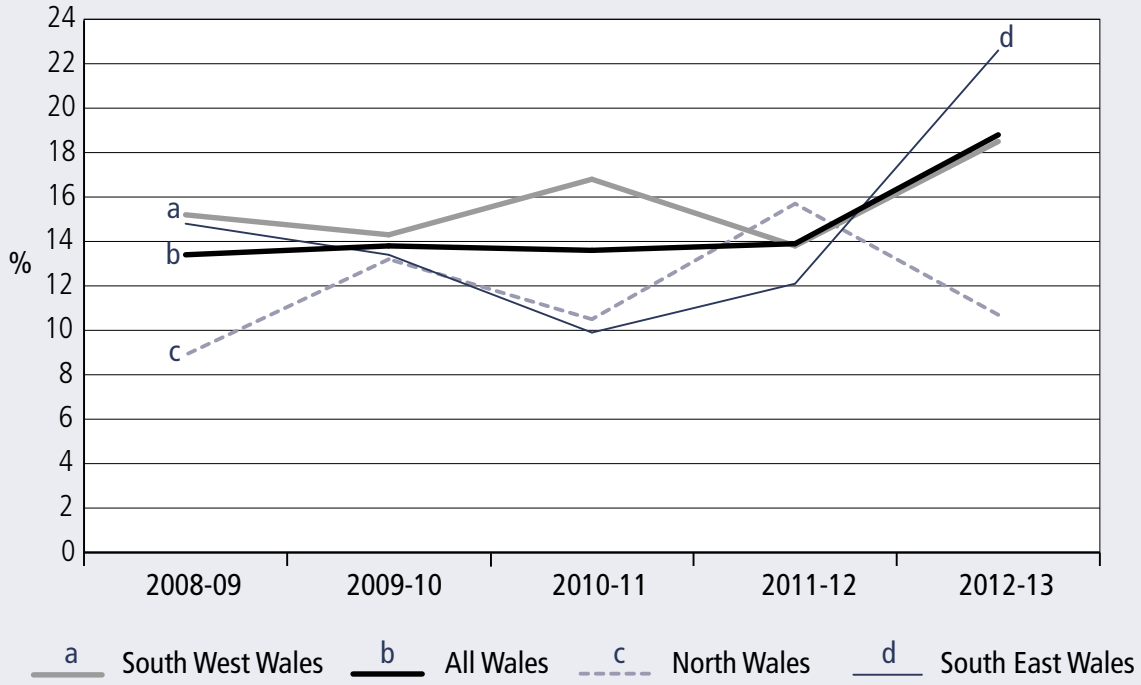
Peer review of upper GI cancer services is on-going and will be followed by reviews of urological, colorectal, head and neck cancers and gynaecological oncology services in 2014.

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

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

Two targets have been set for participation in clinical research, one for interventional studies and one for non interventional studies.

Figure 9 - Percentage of patients recruited into high quality clinical research



Source: NISCHR Clinical Research Centre [13]

Overall recruitment into clinical trials has increased by 5 per cent this year. Both interventional and non interventional studies have increased in their recruitment. We would expect that at least 15 per cent 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 (non interventional). It is encouraging to note that this target has been achieved, health boards are now committed to maintain and improve this level of recruitment.

With an all Wales recruitment of 6.6 per cent into interventional studies, NISCHR Clinical Research Centre is working with health boards and trusts to reach the target of 7.5 per cent by 2015–16.

[13] Using the 2012/13 UKCRN recruitment data was used; data was extracted in June 2013

The CR UK Stratified Medicine Pilot[14] study has contributed significantly towards overall recruitment over the past two years, with a threefold increase in 2012–13.

11.2 What is happening across Wales to support participation in research?

The breast radiotherapy Fast Forward Trial[15] has made a significant contribution to interventional trial participants in Wales and the UK. 77 hospitals in the UK contributed to this trial and Velindre Cancer Centre and Singleton Hospital were in the top 15 highest recruiters in 2012.

Over the last two years prostate cancer trial recruitment has steadily increased across Wales. The Stampede trial in Velindre Cancer Centre and Singleton has consistently been in the top ten recruiters in the UK[16].

Cardiff and Vale University Health Board have undertaken further expansion of the research portfolio of the Marie Curie Research Centre across all settings including participation in national multicentre trials.

Velindre Cancer Centre promotes and supports a strong and active research and development department. Access to clinical trials is a key priority, and the opening of a phase 1 clinical trials unit will provide opportunity for patients with few, or no other treatment options, to participate in research based treatment. Previously, patients have travelled to England to access such treatment.

Velindre Cancer Centre

A new facility at Velindre Cancer Centre is enabling scientists to study the newest cancer drugs.

The new unit means patients have access to a range of cutting edge phase 1 clinical trials, where the newest drugs are evaluated in patients.

Alan Buckle from Cardiff has taken part in an early phase trial on the new unit: *"I was diagnosed with prostate cancer in 2006. I reached a point where the chemotherapy had stopped working so I was very pleased to get on the trial. This was a good opportunity to find a drug that could help me and other men in the future. The Early Phase team mirrors Velindre Cancer Centre where patients get first class treatment, in superb facilities. There have not been many new drugs for prostate cancer and Velindre Cancer Centre is playing a significant role in offering new drugs."*

[14] Cancer Research UK Website page stratified medicine pilot

[15] Cancer Research UK Website page Fast Forward

[16] Cancer Research UK Website page Stampede

11.3 Taking part in cancer research

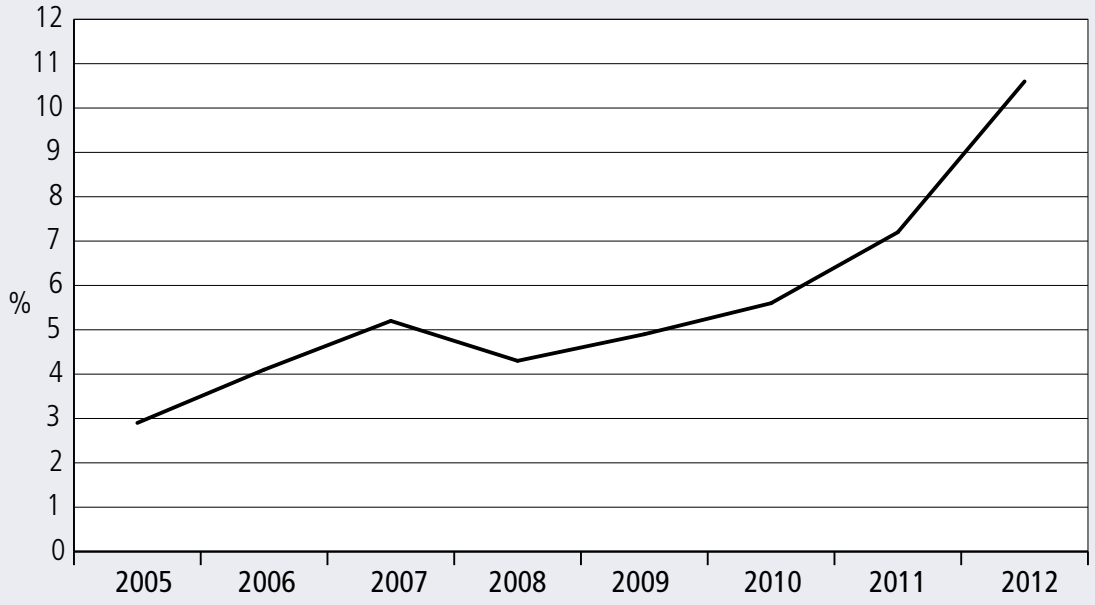
The National Cancer Patient Experience Survey 2013 asked respondents whether anyone had discussed with them whether they would like to take part in cancer research. 29 per cent of patients said that taking part in research had been discussed with them; 71 per cent said it had not. 64 per cent of those patients, who said they were asked, said they went on to take part in cancer research; 36 per cent did not.

12. Tissue donations to the Wales Cancer Bank

The Wales Cancer Bank collects samples of tumour, normal tissue and blood from all 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 per cent of people diagnosed with cancer will agree to donate samples.

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

Figure 10 - Percentage of patients diagnosed with cancer agreeing to donate to the Wales Cancer Bank



Source: Wales Cancer Bank May 2013

** Using 2012 WCB data against 2011 incidence data*

Current levels were over 10 per cent in 2012. There has been good progress in the 12 months to December 2012, with an increase in donations of 3.4 per cent across Wales.

12.2 What is happening across Wales to increase tissue donations?

- Donations to the Velindre Cancer Centre increased by 138 per cent in the 12 months to December 2012.They plan to increase this figure by placing more Welsh Cancer Bank nurses within outpatient clinics. This should provide an efficient system for increasing patient consent to tissue donation for the population of the south east Wales health boards served by Velindre Cancer Centre.
- During the last year sample collection has started in Princess of Wales Hospital at Bridgend giving colorectal cancer patients the opportunity to take part in the research supported by the Wales Cancer Bank.
- Wales Cancer Bank, together with Cardiff and Vale's Molecular Genetics Department has participated in the Cancer Research UK Stratified Medicine Programme, collecting tumour tissue to establish working methods and resilience for the NHS in analysing and reporting molecular abnormalities in a timely fashion.[17]

[17] Wales Cancer Bank, Annual Report, 2011–12

13. Meeting people's needs

We are 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 this year. The results show that cancer services are well regarded by patients.

The overall scores given by patients in Wales to the cancer patient experience survey were positive. 58 per cent of patients said that their care was excellent, 31 per cent said it was very good. 8 per cent said it was good and 3 per cent said it was either only fair (2 per cent) or poor (1 per cent). 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 per cent 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.

13.1 What is happening across Wales to improve patient care?

- The Macmillan holistic care plan tool is being piloted by the breast and lung cancer teams in Pembrokeshire and the lung team in Ceredigion and Carmarthenshire.
- Cardiff and Vale University Health Board has actively engaged with partner organisations to improve services based on learning gained from patient experiences, for example linking with Tenovus in the use of patient stories, and analysing feedback gained from patients and carers who have accessed the Cardiff and Vale based Macmillan Information Centre.
- Velindre Cancer Centre is providing 'outreach' chemotherapy and outpatient clinics in local hospitals across South Wales, in order to bring care close to patients homes, where appropriate. They are undertaking a review of how efficient the outreach services are, to ensure that treatments are being provided in the right locations, according to patient need.
- The Abertawe Bro Morgannwg University Health Board's lymphoedema service have just run their first 'lymphoedema and me' patient study day. The day discussed self care and promoted healthy living and exercise. The first dedicated lymphoedema mobile unit at Abertawe Morgannwg University Health Board was launched on 8 October 2013. This will enable all lymphoedema cancer patients to be seen closer to their home.

Patients being treated for colorectal cancer now have the support of a clinical nurse specialist at Cwm Taf Health Board. Rhoslun Morris, a Macmillan colorectal specialist oncology nurse is based in the Royal Glamorgan Hospital, in Llantrisant. She will play a vital role as a key worker for all patients newly diagnosed with colorectal cancer.

Rhoslun Morris, Macmillan Colorectal Specialist at Cwm Taf HB

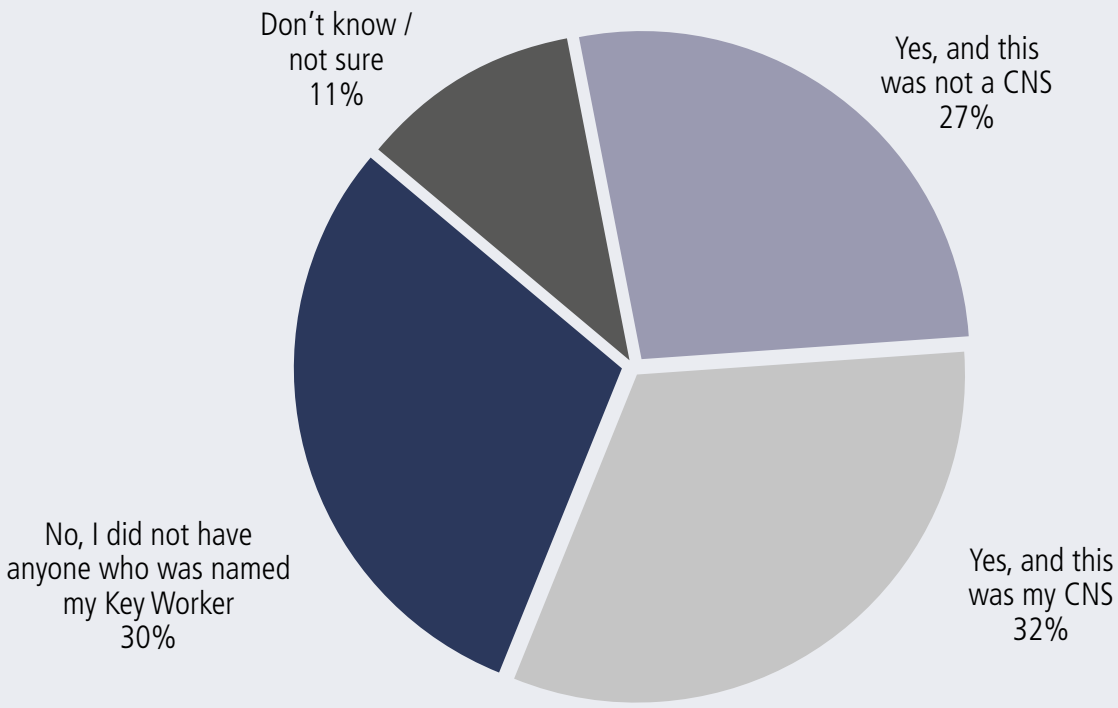
- The Macmillan National Exercise Referral Scheme (NERS) project provided funding to increase awareness and promote benefits of physical activity for people affected by cancer. This funding allowed Abertawe Bro Morgannwg University Health Board to extend the current cancer rehabilitation services. Prior to the Macmillan NERS project, 53 new patients were assessed per year for community cancer rehabilitation services. Since the funding 170 new patients have accessed the scheme.
- Work with the Macmillan Centre has facilitated Cardiff and Vale University Health Board's ability to meet the wider needs of patients and their carers, such as supporting relate counselling for families and welfare benefit sessions within the University Health Board.
- Velindre Cancer Centre was successful in becoming 1 of only 22 pilot sites in the United Kingdom for a new electronic holistic needs assessment tool (e-HNA) developed by Macmillan Cancer support in partnership with the National Cancer Survivorship Initiative
- Cardiff and Vale University Health Board have a 7 day clinical nurse specialist (CNS) working in both the hospital and community. On average 60–70 patients per month are seen on weekends and bank holidays in hospital by the CNS.
- Within Aneurin Bevan Health Board, the Macmillan GP facilitator service employs 2 GPs for 2 sessions each per week to enhance and uplift the generic primary healthcare teams' skill set with regards to cancer and non cancer palliative care patients, including end of life patients, and survivors of cancer.
- Consultants and their teams at Velindre Cancer Centre are working towards new models and pathways for delivery services for patients with metastatic cancer. They on behalf of south Wales review patients with metastatic colorectal cancer with spread to the liver which might be amenable to curative surgery.
- The first passport to breast cancer rehabilitation programme took place in Royal Glamorgan Hospital. This free programme provides information, support and professional guidance on how to cope with and adjust to life during and after treatment.

13.2 Performance Measure 5 - Percentage of people with a diagnosis of cancer who are assigned a key worker

It has been known for sometime that there has been lack of clarity across Wales as to the exact role of the key worker, and how this differed if at all, from that of the clinical nurse specialist (CNS). This was reinforced through the findings of the cancer patient experience survey.

In the cancer patient experience survey, 59 per cent of patients confirmed that they were given the name and contact details of their key worker. For 32 per cent respondents the key worker who was also their CNS, for 27 per cent it was another person. 31 per cent were not given details of a key worker.

Figure 11 - Percentage of patients who were given the name and contact details of their key worker



Source: National Cancer Patient Experience Survey - 2013

There was a significant variation between tumour sites in the proportion of patients saying they were given the name of a key worker. Scores ranged from 80.2 per cent (lung cancer) to 39.1 per cent (urological cancer).

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 per cent of patients who had tried to contact their key worker said it was easy to contact him or her; 16 per cent said it was sometimes easy and sometimes difficult; 2 per cent had found it difficult.
- 92 per cent of patients said the key worker had definitely listened to them; 6 per cent said she/he had listened to some extent; 1 per cent said they had not been listened to.
- 91 per cent 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; 8 per cent said they did so only some of the time and 1 per cent said they rarely or never did.

Similar questions were asked about a CNS:

- 88 per cent of patients overall said that they had been given the name of a CNS; 12 per cent were not given the name of a CNS.
- Of those patients who had tried to contact their CNS, 78 per cent said that it was easy to contact them; 19 per cent said it was sometimes easy, sometimes difficult; and 3 per cent said it was difficult.

- 92 per cent of patients overall said that the CNS definitely listened carefully to them when they last spoke to them; 7 per cent said they listened carefully to some extent. 1 per cent said they did not listen carefully.
- Of those patients who said that they asked the CNS questions, 92 per cent said that they got understandable answers all or most of the time, 7 per cent said they did so only some of the time and 1 per cent said they rarely or never did.

Both CNSs 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.

Despite the need for greater clarity on the exact definition and role of the key worker, the findings from the cancer patient experience survey highlight the importance of the key worker role and confirm the importance of this policy. Whilst there is work to be done to ensure that every patient in Wales has an effective key worker, we have the right policy in place.

13.3 What is happening across Wales to support the development of key workers?

- At Abertawe Bro Morgannwg University Health Board all cancer patients on diagnosis are told the person to contact if there is a problem. The cancer key worker cards or cancer nurse equivalent cards are being utilised in some specialities.
- The Lead Cancer Nurse and the Lead Cancer Psychologist within Aneurin Bevan University Health Board are piloting a patient care plan that incorporates the key elements of the Macmillan patient care planning tool across a number of tumour sites.
- Betsi Cadwaladr University Health Board will ensure that all patients have a key worker in a consistent and clearly understood manner. They will ensure that every patient has a holistic care plan that they hold and utilise across care domains.

13.4 Performance Measure 6: Percentage of people with a diagnosis of cancer who have a care plan

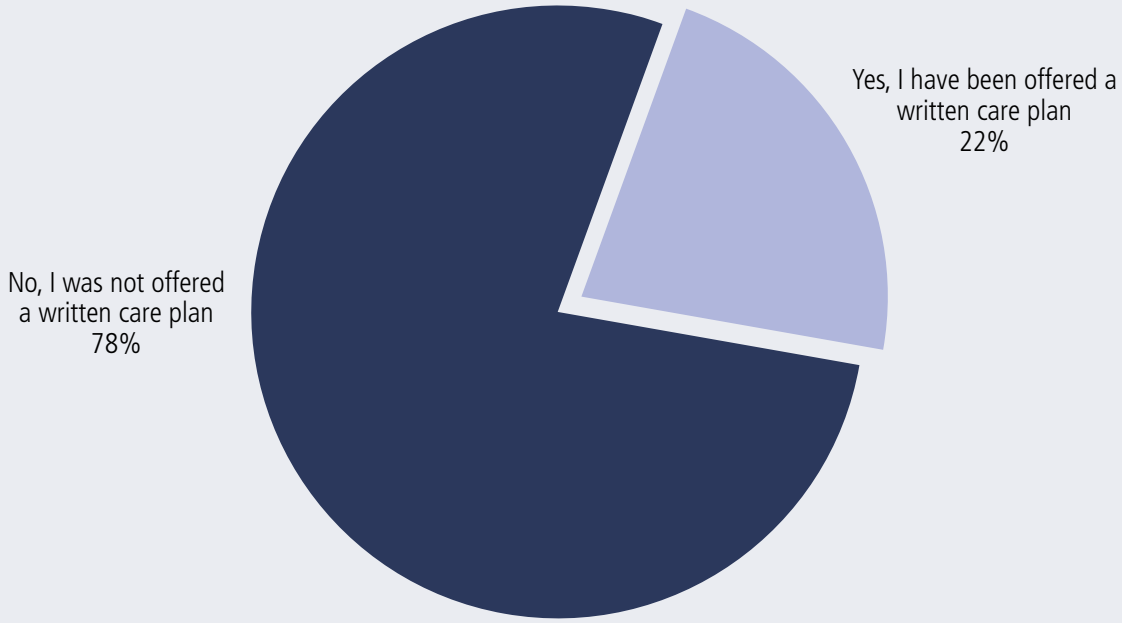
The Cancer Delivery Plan has set a target that everyone with a diagnosis of cancer should have a care plan.

58 per cent of patients said they had been offered the opportunity to discuss their needs and concerns in order to put together their care plan; 42 per cent had not been offered this opportunity.

There was a significant variation in the proportion of patients with different cancers saying that they had been offered the opportunity to discuss their needs and concerns in order to put together their care plan. Scores ranged from 80.5 per cent for patients with a brain or other CNS cancer to 37.3 per cent for patients with a urological cancer.

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

Figure 12 - Percentage of patients who were offered a written care plan



Source: National Cancer Patient Experience Survey - 2013

Respondents, however, feel comfortable with the amount of information they were given and 86 per cent of patients overall said that they were given the right amount of information about their condition and treatment; 12 per cent said they were not given enough and 1 per cent 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 for the next 12 months 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. Health boards will be asked to ensure that all patients are then able to have a written care plan as a result of that discussion. The care plan needs to be shared across primary and secondary care, and where appropriate with the voluntary sector. Patients expect care to be joined up across the service and throughout the complex journey across healthcare organisations.

14. 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 the same and these services need to be well coordinated. Health boards have developed their palliative and end of life care strategies, some of the initiatives currently in place include:

14.1 What is happening across Wales to improve care and support at the end of a person's life?

- Cwm Taf Health Board has had funding from Macmillan Cancer Support to appoint 2 part-time GP facilitators to assess and improve the engagement of primary care in palliative and end of life care, and communication across the care pathway. They have commenced a pilot scheme trialling the use of the advance care planning (ACP) tool in 5 designated nursing homes; have introduced prognostic indicator guidelines for GPs to help improve identification of potential patients for the palliative care register; and have undertaken GP education.
- Hywel Dda Health Board provides 24/7 access to consultant support and 7 days a week access to specialist palliative care nursing support. End of life co-ordinators are currently provided in Carmarthenshire, but not in the other two counties and services have received positive feedback through the "iWantGreatCare" surveys.
- Seven day working for specialist nurses is now well-established in specialist palliative care within Abertawe Bro Morgannwg University Health Board. The palliative medicine consultants continue to provide 24 hour on call support for hospital and community services, including face to face assessments of patients in all settings where necessary, as well as telephone advice for professionals, families and patients across all settings.
- All specialist palliative care providers within Gwent participate in the "iWantGreatCare" patient satisfaction surveys' as required by the All Wales Palliative Care Implementation Board. All surveys are now given out on a regular basis as part of an information pack within Aneurin Bevan University Health Board and the findings noted and acted upon with regards to future service improvement.
- Education concerning palliative and end of life care continues to be a priority with education established and on-going for district nurses, GPs, nursing homes, hospice nurses and hospital medical and nursing staff (trained and untrained) within Cardiff and Vale University Health Board.
- Various ways of improving community access to out-of-hours medication for palliative care patients within Cwm Taf Health Board have been introduced, in order to ensure prompt access to pain control, alleviate suffering and avoid hospital admission. The health board is piloting a 'Just In Case' scheme whereby a palliative care emergency medicine pack is prescribed and placed in the patient's home for prompt access when needed; a local enhanced service has been introduced with community pharmacies to increase their holding of palliative care medication; and the GP out-of-hours service is now required to hold an appropriate range and quality of controlled drugs. GP education and awareness has been provided by the end of life pharmacy lead and the GP facilitators.

15. Conclusion: looking ahead to 2014 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 sector. 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 considerable 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 and the Cancer Implementation Group has agreed the following areas as priorities for 2014:

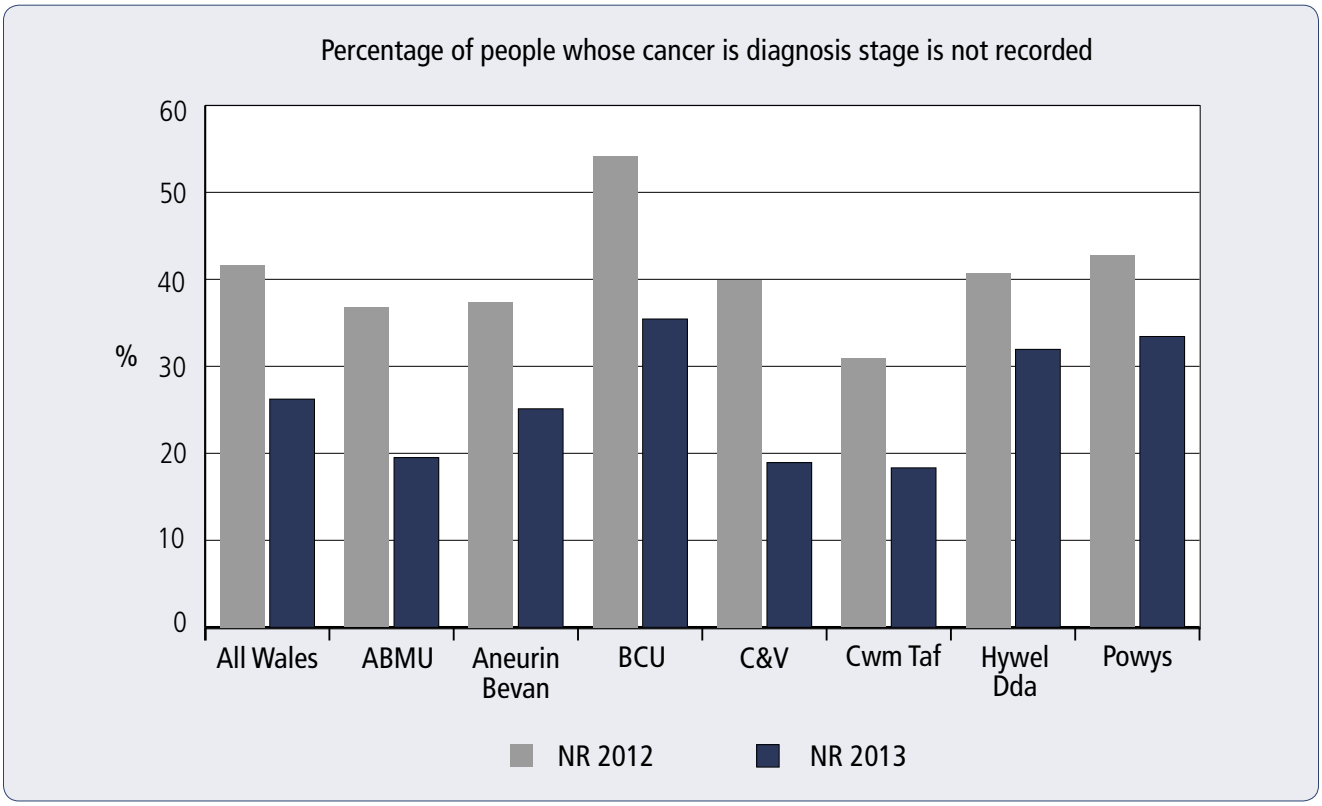
- Prevention
- Primary care oncology
- Improve the patient journeys through the pathways
- Greater emphasis on recruitment to clinical trials
- Patient support
- Increase consistency in follow up
- Care plans and key workers
- Peer review
- Information

In next year's Annual Report we will look at how we have progressed during the year.

Public transport communication plan by North Wales Cancer Forum to encourage the public to engage with NHS on cancer.

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

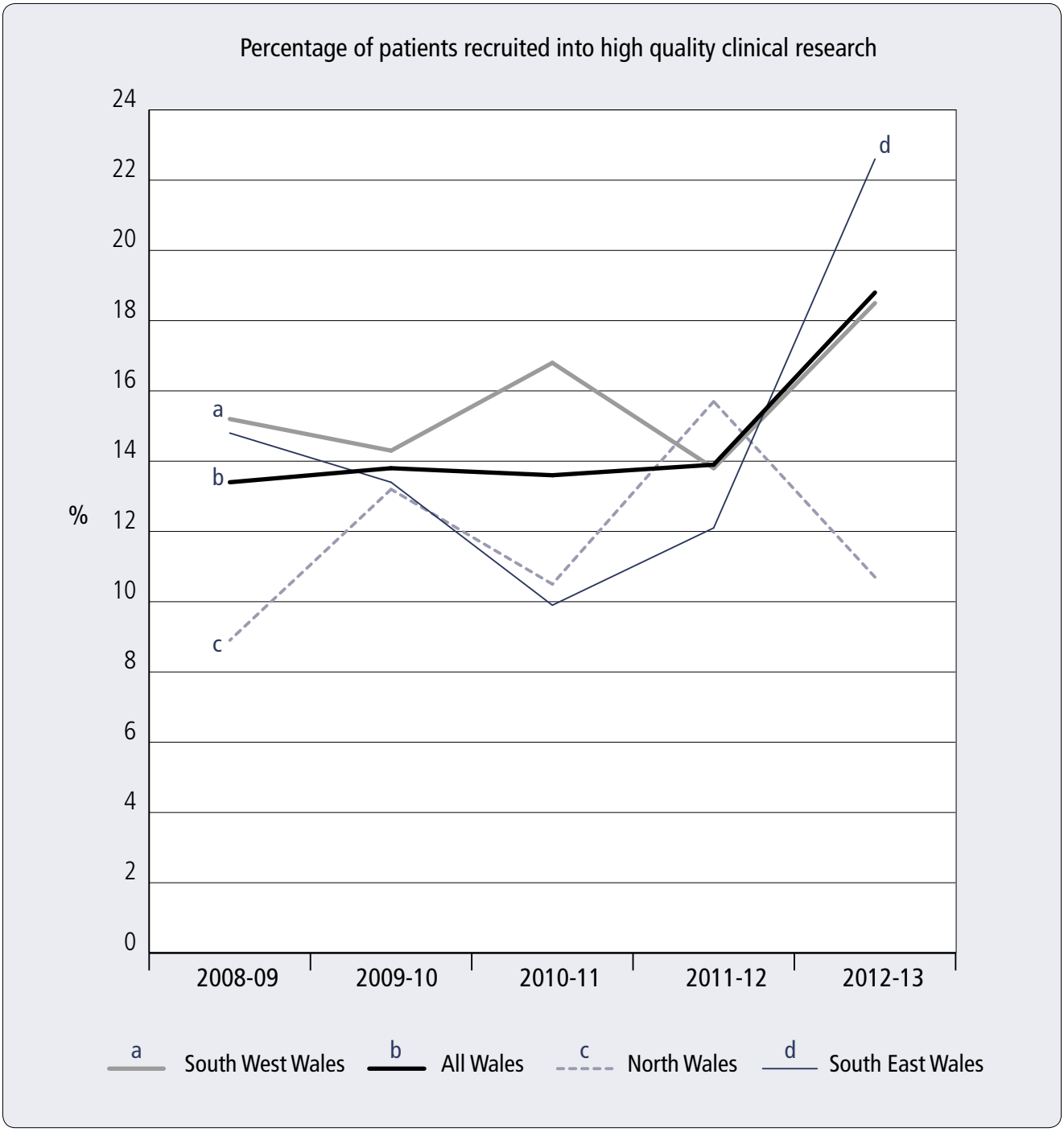


Source: Canisc

Local Health Board (LHB)	Percentage of patients newly diagnosed with cancer starting definitive treatment within 62 days (via the urgent suspected cancer route)									
	(%) Q1 2011–12	(%) Q2 2011–12	(%) Q3 2011–12	(%) Q4 2011–12	(%) Q1 2012–13	(%) Q2 2012–13	(%) Q3 2012–13	(%) Q4 2012–13	(%) Q1 2013–14	(%) Q2 2013–14
Abertawe Bro Morgannwg ULHB	77.8	88.8	88.3	83.6	74.3	75.1	76.0	69.9	75.1	88.4
Aneurin Bevan ULHB	95.2	93.0	92.2	95.5	96.6	96.8	93.2	98.0	82.3	90.9
Betsi Cadwaladr ULHB	86.5	87.1	87.9	90.5	94.4	89.7	86.6	86.1	87.3	82.8
Cardiff and Vale ULHB	89.8	90.2	96.6	94.2	92.7	85.9	90.0	85.4	87.1	88.8
Cwm Taf LHB	85.6	86.0	89.7	85.9	83.6	85.7	86.5	77.9	78.2	82.7
Hywel Dda LHB	88.0	92.0	89.1	89.2	86.7	85.4	81.0	81.4	79.4	84.9
All Wales	**87.0**	**89.4**	**90.3**	**89.8**	**87.9**	**85.9**	**85.7**	**83.6**	**81.8**	**86.6**

Local Health Board (LHB)	Percentage of patients newly diagnosed with cancer starting definitive treatment within 31 days (not via the urgent suspected cancer route)									
	(%) Q1 2011–12	(%) Q2 2011–12	(%) Q3 2011–12	(%) Q4 2011–12	(%) Q1 2012–13	(%) Q2 2012–13	(%) Q3 2012–13	(%) Q4 2012–13	(%) Q1 2013–14	(%) Q2 2013–14
Abertawe Bro Morgannwg ULHB	95.2	98.1	98.0	97.9	96.3	94.6	95.2	94.1	92.4	98.5
Aneurin Bevan ULHB	99.8	99.4	99.2	99.1	99.0	99.6	99.4	99.6	98.6	97.5
Betsi Cadwaladr ULHB	98.3	99.0	99.6	99.6	99.1	98.9	99.4	97.8	98.1	98.8
Cardiff and Vale ULHB	99.0	100.0	100.0	98.1	98.1	98.3	98.7	97.7	96.8	99.4
Cwm Taf LHB	98.4	98.9	98.1	98.8	98.9	99.7	99.1	98.2	97.8	98.6
Hywel Dda LHB	95.5	98.5	98.8	98.6	97.4	98.4	96.7	97.2	93.5	97.3
All Wales	**97.7**	**99.0**	**99.0**	**98.8**	**98.2**	**98.2**	**98.1**	**97.4**	**96.4**	**98.3**

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



Source: NISCHR Clinical Research Centre

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