# **Together For Health – Cancer Delivery Plan**

A Delivery Plan up to 2016 for NHS Wales and its Partners

The highest standard of care for everyone with cancer



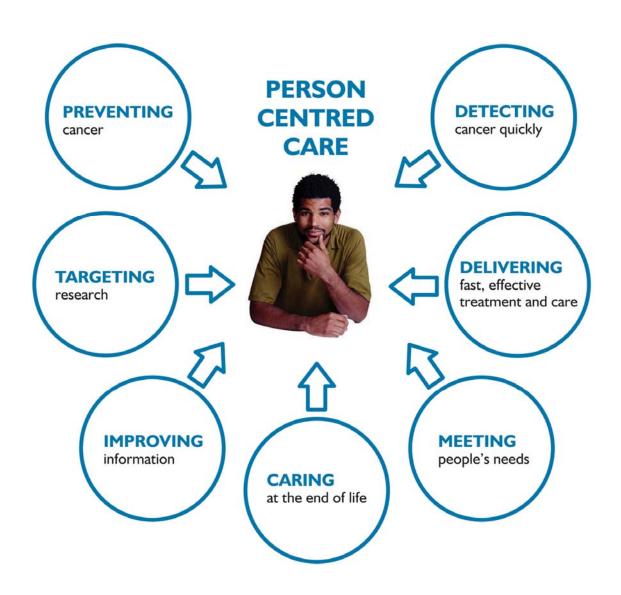
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#### Foreword from the Minister for Health and Social Services

A diagnosis of cancer is a major event in the lives of increasing numbers of people in Wales. They need rapid assessment and the best possible diagnosis, treatment and ongoing support. Alongside excellent treatment, we need a focus on actions which prevent cancer. *The Cancer Delivery Plan* sets out my expectations of NHS Wales, working with its partners, in tackling cancer up to 2016.

This document builds on the progress we have already made in Wales. It updates our actions and renews our focus, reflecting changes in the nature of cancer and its treatment. It is deliberately short for a specific purpose – to ensure we keep our eye on the outcomes we want and leave flexibility for innovation.

The efforts of the NHS must be supported by those of our partners and the public themselves. We know individuals can reduce their risk of cancer by changing their lifestyles: not drinking as much alcohol; stopping smoking; improving their diet and; increasing levels of physical activity. There is an important role for local government to promote better health and tackle known factors that cause cancer. The third sector is also crucially important in raising awareness, offering support and providing care services.

We are building on a record of success. Wales has seen some of the most significant improvements in cancer survival in the United Kingdom during the last few years. However, our population is ageing so the number of people diagnosed and living with cancer is increasing and it seems that the number of cancers related to lifestyle choices may be rising. We know we can achieve better outcomes by re-organising aspects of the care we provide, and focusing on quality and patient experience. We must close the gaps within Wales and between Wales and the most successful European countries.

Our challenge is to meet the expectations of people with cancer and improve quality of our services at a time of economic challenge. Making the best use of the resources available to us, this is a time for innovation and improvement. This Cancer Delivery Plan has been developed by us all working well together. I am very grateful for everyone's shared ambition and willingness to contribute and, in particular, to the work of the NHS staff, Macmillan Cancer Support and all the Cancer Alliance charities.

I strongly believe, with the NHS in the lead, we can ensure that the care provided is focussed on meeting every individual's needs the most effective way. I expect the NHS to work with ambition - locally, regionally and nationally - to make us amongst the best in Europe for cancer treatment and outcomes.

#### Foreword from David Sissling, Chief Executive of NHS Wales

I commit Local Health Boards and Trusts, working together with their partners, to plan secure and deliver safe, sustainable, high quality cancer care for their populations. I will support them in this endeavour and I will hold Local Health Boards to account on the outcomes they deliver for their populations and their contribution to the overall health of the people of Wales.

This Cancer Delivery Plan for the NHS together with its partners sets a compelling vision for success. It challenges each organisation to plan and deliver high quality services in partnership. I want to see continuous improvement integrated into everyday working. Our measures of success must focus more on public health outcomes, the quality of our services and the individual's experience.

Using the Cancer Delivery Plan as the framework, my challenge to the NHS in Wales is to work effectively with your full range of partners to plan, innovate and, most importantly, to deliver really effective cancer care.

#### 1. Introduction

This Cancer Delivery Plan provides a framework for action by Local Health Boards and NHS Trusts. It sets out the Welsh Government's expectations of the NHS in Wales to tackle cancer in people of all ages, wherever they live in Wales and whatever their circumstances. The Plan is designed to enable the NHS to deliver on their responsibility to meet the needs of people at risk of cancer or affected by cancer. It sets out:

- The population outcomes we expect.
- The outcomes from NHS treatment we expect.
- How success will be measured and the level of performance we expect.
- Themes for action by the NHS, together with its partners.

#### 2. Strategic Context – Why This And Why Now?

The Welsh Government's *Programme for Government* and its 5 year NHS Plan, *Together for Health,* sets out an ambitious programme for health and healthcare in Wales so that:

- Health will be better for everyone.
- Access and patient experience will be better.
- Better service safety and quality will improve health outcomes.

Achieving Excellence: The Quality Delivery Plan for the NHS in Wales for 2012-16 describes a journey to delivery of consistent excellence in service. It outlines actions for quality assurance and improvement. We commit to a quality-driven NHS that provides services that are safe, effective, accessible, affordable and sustainable and that come with an excellent user experience.

This Delivery Plan sets out what this means for the delivery of measurable excellence in cancer services.

#### 3. Our Vision

The Programme for Government states the overall population outcomes we want to achieve: better health for all and reduced inequalities in health. Reducing the impact of cancer on the lives of people in Wales will contribute significantly to these outcomes.

For our population we want:

- People of all ages to have a minimised risk of developing cancer and, where it does occur, an excellent chance of surviving, wherever they live in Wales.
- Wales to have cancer incidence, mortality and survival rates comparable with the best in Europe.

We will use the following indicators to measure success:

- Cancer incidence rates (European Age Standardized Rates).
- Cancer mortality rates (European Age Standardized Rates).
- 1 and 5 year cancer survival rates.

#### 4. Our Drivers

There are clear reasons why cancer remains a top priority for the Welsh Government. We estimate around 1 in 3 people in Wales will be diagnosed with cancer before age 75. Around 4 in 10 will be diagnosed with cancer during their lifetime. *The incidence rate is increasing.* For the period 1995-2009, there was an average of around 16,100 new cases of cancer per year (cancer incidence increased by around 0.6% per year) and around 8,400 people died from cancer each year (an average decrease in death rates of 1% each year). The most commonly diagnosed cancers were breast, lung, bowel and prostate cancer. Together these accounted for just over half of all new cases.

The good news is the *number of people surviving cancer has increased*. At the end of 2009, almost 85,000 people were living after a prior diagnosis of cancer during the previous 15 years (just under 3% of the population). For many people cancer is now a "chronic condition" which requires a new approach to longer term care. However, the ongoing needs of patients that survive cancer are not always recognised and met to best effect.

There is wide variation in the rates of survival for different types of cancer. Among the commonest cancers the survival rate after 5 years varied from 7% for lung cancer to 78% for prostate cancer and 82% for breast cancer. Cancer has a greater impact in the more deprived areas of Wales.

Childhood cancers are rarer, mainly affecting blood and the brain. They have a higher cure rate after intensive treatment, but remain the commonest cause of death from disease in 1-14 year olds. Even after successful treatment they can have major

long term effects on a child's growth, development, mental health and ability to have families in the future.

Cancer accounts for nearly 7% of all *NHS expenditure in Wales*. In 2010-11, this amounted to £347.1 million – the fourth biggest spending area. With new and developing cancer care needs, demographic change and the current financial pressures, we must ensure we get the maximum value and impact from our cancer services. Our Cancer Networks in Wales and the Welsh Health Specialised Services Committee (WHSSC) provide excellent mechanisms for supporting a collaborative and informed approach to achieve this.

#### 5. Our Journey So Far

There is wide recognition that much has already been achieved in Wales. As well as delivering a much greater chance of survival, people with cancer or possible cancer are now assessed, diagnosed and treated more promptly in line with Welsh targets. We have better information on the incidence and outcomes of cancer than ever before. The culture of recording data for clinical audit to improve services to the standard of the best is embedded in the clinical community. New drugs and technologies have been introduced. Radiotherapy now contributes to more than 40% of the cures that we achieve in Wales and newer techniques, such as intensity modulated radiotherapy (IMRT) are implemented across Wales to enable safer and more precise treatment.

We have seen high levels of compliance with NICE Improving Outcome Guidance and the 2005 National Cancer Standards: cancer services in Wales are better organised and better placed to deliver effective care than ever before. Many people diagnosed with cancer will need palliative and end of life care and we have seen many improvements here.

#### 6. What Do We Want To Achieve?

This Delivery Plan sets out action to improve outcomes in the following key areas between now and 2016:

#### 1. Preventing cancer

People live a healthy lifestyle, make healthy choices and minimise risk of cancer.

#### 2. Detecting cancer quickly

Cancer is detected quickly where it does occur or recur.

#### 3. Delivering fast, effective treatment and care

People receive fast, effective treatment and care so they have the best chance of cure.

#### 4. Meeting People's Needs

People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer.

#### 5. Caring at the End of Life

People approaching the end of life feel well cared for and pain and symptom free.

#### This will be supported through:

- 6. Improving Information
- 7. Targeting research

#### 6.1 Preventing Cancer

Overall, health is improving and our population is getting older. Improvements in health have not been achieved equally for all people. Life expectancy for the most deprived fifth of the population has risen more slowly than for other groups. People living just a few miles apart may face a 10-year difference in average length of life. These inequalities also apply to the chances of developing and dying from cancer. There is also evidence that men can experience higher mortality rates from some cancers than women, even when their cancer incidence is lower, as in melanoma, most likely due to men's later presentation to primary care services.

Many of the causes of poor health are deep-rooted and difficult to tackle. Obesity is widespread in Wales and rates of smoking, drinking and substance misuse continue to cause concern. These root causes of poor health contribute directly to the risk of cancer. Cancer Research UK suggests they may be responsible for 40% of cases.

In March 2011, the Welsh Government published a Reducing Inequities in Health Strategic Action Plan *Fairer Health Outcomes For All*. This sets out our vision to improve health and wellbeing for everyone in Wales, with the pace of improvement increasing in proportion to the level of disadvantage. Working with their partners, NHS organisations are developing single integrated plans to take forward action to meet the needs of local people and communities to improve health and well being

#### **ACTIONS**

#### **Local Health Boards to:**

- Engage effectively on Local Service Boards to ensure appropriate local population outcomes are identified within Single Integrated Plans and the actions of all partners are clearly set out, monitored and measured.
- Work with local government, Public Health Wales NHS Trust, GPs, pharmacists, dentists, opticians, the Third Sector and others to use data on

cancer incidence and mortality to identify, implement and audit local strategies, clearly stated population outcomes and performance measures and targets to prevent cancer. In particular, to:

- promote better public awareness of cancer risk factors;
- > reduce smoking, obesity and excess alcohol intake;
- reduce the gap in inequalities in incidence and mortality rates for cancer;
- work collaboratively through the Cancer Networks;
- encourage participation in the programme of health checks for people aged over 50 facilitate access to personally relevant, clear and consistent health advice.

#### 6.2 Detecting Cancer Quickly

Local Health Boards need to raise awareness among the public and health professionals about the risks and symptoms of cancer and how to act promptly and appropriately on this knowledge.

NHS Wales provides three cancer screening programmes for breast, cervical and bowel cancer. Public Health Wales NHS Trust plans and manages these programmes in line with advice from the UK National Screening Committee and the Wales Screening Committee. Screening services need to keep pace with the changing evidence of benefit and remain of the highest international standard. Action is needed to find more effective ways to increase take up by harder to reach groups.

Rapid diagnosis and treatment improves not only survival but also the quality of life of survivors and lessens their longer term care needs. People are unfortunately still being diagnosed with advanced cancer, where an earlier diagnosis might have led to a much better outcome. Through audit, Local Health Boards are expected to understand the root causes of this in every case and act to improve systems of care to prevent this happening again. All Local Health Boards will need to consider how acute oncology services can be developed to support the diagnostic process in patients admitted as emergencies.

Local Health Boards need to raise awareness among public and health professionals about the risks and symptoms of cancer and how to act promptly and appropriately on this knowledge. Over 90% of people diagnosed with cancer initially present with symptoms to their GP. GPs typically see less than ten new cancer patients each year and a rare cancer, such as a childhood cancer, only once in a life time. Many patients do not have simple symptoms, making diagnosis difficult. Not going early enough to the GP or not returning for a review can contribute to delay in treatment. This seems to be a particular issue for men.

Diagnostic testing, particularly ultrasound and CT scans, should be available on request to primary care practitioners wherever this will reduce the time to diagnosis. All investigations that might demonstrate cancer should be reported promptly.

Agreed pathways and standards for the management of patients who present with advanced cancer, but with an unknown primary, need to be developed to inform service planning and delivery.

#### **ACTIONS**

#### Screening

#### **UK National Screening Committee and the Wales Screening Committee to:**

 Keep evidence under review to make prompt recommendations to the NHS when national population screening for cancer is clinically and cost effective.

#### Local Health Boards working with Public Health Wales NHS Trust to:

- Regularly review, plan and deliver screening programmes as recommended by the Wales Screening Committee.
- Promote better take up of screening programmes to meet the best practice uptake targets particularly targeting those less likely to take up screening.
- Provide sufficient capacity, workforce, infrastructure and equipment to treat and care for people referred from the cancer screening programmes.

#### **Early Diagnosis**

#### Local Health Boards to:

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

#### 6.3 Delivering Fast, Effective Treatment and Care

Virtually all people diagnosed with cancer will need to attend hospital for their treatment. Hospital services should be delivered promptly, be well co-ordinated with effective communication across boundaries and ensure good patient experience. Every individual must be placed at the centre of their care so they have a smooth journey and confidence in the direction and quality of their care.

We expect Local Health Boards to plan and deliver evidence based cancer services through well organised Multi Disciplinary Teams. This needs to be in line with national standards and guidelines, such as those produced by NICE, the National Cancer Standards and, from the all Wales clinical advisory structures.

Local Health Boards now report high levels of compliance with the National Cancer Standards published in 2005. Services must also comply with more recently published specific cancer standards (those for sarcomas; children, teenagers and young People; rehabilitation of adults with cancer; palliative care).

The Quality Delivery Plan tasks Healthcare Inspectorate Wales (HIW) to introduce a process of peer review against standards, beginning with cancer and end of life care in 2012. This has strong clinical support.

Clinical audit and outcome review is critical to continuous service improvement. All NHS organisations providing cancer care must participate in all relevant National Clinical Audits and Clinical Outcome reviews, set out in the Welsh Government's National Annual Audit Programme and then act on the findings.

Every cancer patient undergoing complex surgery in Wales should receive excellent peri-operative care, as delivered through the enhanced recovery after surgery (ERAS) and the Transforming Theatres initiatives. Cancer surgery services should be configured in a way that enables the highest standard of multidisciplinary care and outcome. This will require Local Health Boards, working through the Cancer Networks or WHSSC, to centralise services for which good outcomes depend upon volume. When this happens, patients and families need to be supported in travel and accommodation arrangements by their Local Health Boards.

Local Health Boards are expected to operate effective pathways so all patients with cancer, wherever they are, pass without delay to treatment. This requires planning of acute oncology services to deal with issues such as cancer of unknown primary origin, neutropaenic sepsis and metastatic spinal cord compression in line with NCEPOD and NICE Guidance. There is clear evidence, where this is coordinated, patients have reduced unnecessary tests, admissions and length of stay.

Cancer drugs approved by the All Wales Medicines Strategy Group (AWMSG) and NICE for the appropriate clinical indication will be available routinely on the NHS and non-approved drugs can be provided on the basis of exceptionality where appropriate. Clinicians need to be clear in discussions with their patients about the likelihood of benefit of such drugs when other treatments have not been effective so the patient is fully informed about the risk and benefits and the possibility of end of life. There is evidence early referral to palliative care services can improve quality of life and survival and so should not be delayed when they are appropriate.

Local Health Boards and Trusts need to work together, either through the Cancer Networks or WHSSC, to plan for the prompt and equitable introduction of new technologies, such as new genetics and radiotherapy techniques, where there is evidence to support their effectiveness. It is considered essential to continued

excellence and the reputation of NHS Wales that cancer services are cutting edge wherever possible.

#### **ACTIONS**

#### **Delivering Fast Effective Treatment and Care**

#### **Local Health Boards to:**

- Review, plan, reorganise all services where appropriate to deliver best experience and outcomes in line with latest evidence, standards and guidance.
- Provide definitive treatment consistently in line with national waiting times targets.
- Identify mechanisms to plan and deliver equitable access to new diagnostic and treatment procedures in line with evidence.
- Determine Individual Patient Funding Requests promptly and equitably across Wales using the All Wales protocol, exceptionality criteria and training.
- Plan radiotherapy services strategically through the Cancer Networks.
- Undertake complex surgery in line with peri-operative care standards as in the ERAS programme.
- Reduce surgery and chemotherapy related mortality by eliminating preventable deaths.
- Participate in national and locally clinical audit and other quality improvement activities and reflect action to be taken in local cancer delivery plans.
- Participate in peer review and reflect learning in local cancer delivery plans.

#### 6.4 Meeting People's Needs

Many factors contribute to a positive experience including communication, coordination of care, respect of dignity, provision of information, access to psychosocial support and access to financial support. The Welsh Government and MacMillan Cancer Support are working together to undertake a national cancer patient experience survey. The results will allow organisations to identify areas where improvements are needed. It will also allow better understanding of whether certain cancer types, ethnicity, communities, age groups or genders experience poorer care and allow this to be addressed.

People receiving NHS care have a right to be cared for with dignity and respect. Services need to be planned and delivered around the patient and their individual needs rather than the needs of the NHS. Where people have to travel for more specialist cancer care, NHS organisations are expected to put appropriate transport arrangements in place with care being provided as close to home as possible. Local Health Boards need to work closely with the Third Sector to make better use of its services. For example, Tenovus has invested in a mobile chemotherapy unit and a mobile lymphoedema service taking care to the heart of local communities.

As more people now survive cancer, it is becoming a chronic condition that people have to manage for many years. Side effects of curative treatment can have a significant long-term impact on health and lifestyle. People with cancer therefore need support and information to ensure their ongoing needs are routinely assessed and met in line with the National Standards for the Rehabilitation of Adults with Cancer. Chronic diseases, which now includes cancer, are most effectively managed in primary care, carefully networked with specialist services, amongst many other referral points. Primary care oncology must become an important concept for cancer care in Wales.

Following treatment for cancer, people can also experience other symptoms – such as bowel problems, chronic fatigue, lymphoedema, impotence, infertility and depression – while new cancer can emerge months or years later. All these problems and care needs must be anticipated where possible and recognised through routine assessment and care planning.

Local Health Boards are expected to assign a named Key Worker to assess and record in a care plan the clinical and non clinical needs of everyone with a diagnosis of cancer. The care plan must help to ensure care is co-ordinated between community and hospital. This must include regular assessment of the consequences of treatment. It must also address other needs such as information, such as where and how to access financial, emotional and spiritual advice and support, to ensure a holistic person centred approach.

Follow up care for people with cancer after treatment must be based on evidence and the individual person's needs. New multi-disciplinary models of follow up need to be evaluated and developed both to support the patient in recovering as fully as possible and to enable the early detection of recurrence.

People with cancer highlight the need to improve communication as a core component of person centred services. The All Wales Cancer Information Pathway Project and the new Public Health Wales NHS Trust post, funded by Macmillan Cancer Support, is designed to support each person with cancer being offered, through their care plans, written information about their disease, treatment and supportive care including psychological needs.

The financial impact of cancer can be great, and cancer poverty is a real concern. People affected by cancer should be routinely offered the opportunity to access financial advice and support as part of the care assessment and planning process, from diagnosis onwards. Macmillan's recently published 'Counting the Cost of Cancer Campaign' makes clear the problems people have to face whilst being treated for a disease which can have a lasting and devastating effect on peoples' lives.

We must provide advice to support people living with cancer to return to work as part of their recovery programme. This is currently achievable through the Health at Work Advice Line Wales and employer engagement events in partnership with Macmillan Cancer Support. The Corporate Health Standard, the Healthy Working Wales award for health and well-being in medium and large-size businesses and organisations,

also raises awareness of specific men's health and women's health issues including cancer.

Local Health Boards must also place more emphasis on the needs and experience of people with metastatic cancer. Even if such cancer cannot be cured it can be controlled, sometimes for years. Collection of data is crucial to be able to plan services for this patient group and to measure the patients' survival.

#### **ACTIONS**

#### Local Health Boards to:

- Assign a Key Worker to each person with cancer, from the point of diagnosis onwards, to coordinate their ongoing care.
- Review and redesign services recognising the changing needs of people with cancer and to deliver person centred services to meet ongoing needs as locally as possible in line with National Standards.
- Assess the clinical and non clinical needs (such as information needs on accessing financial, emotional and spiritual help) of people following a diagnosis of cancer and draw up and implement a care plan to be reviewed regularly.
- Provide each patient and GP with an "end of treatment" summary to inform the care plan.
- Support patient participation in cancer patient experience surveys and include action on the outcome in local cancer delivery plans.
- Plan and deliver co-ordinated services for metastatic cancer patients and measure outcomes.

#### **Public Health Wales NHS Trust to:**

 Provide Local Health Boards with support to meet the information needs of people affected by cancer.

#### 6.5 Caring at the End of Life

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

Access to palliative and end of life care has improved under the leadership of the Palliative Care Implementation Board, established in 2008. We now have a set of palliative care standards with measures to monitor the quality of care in all settings.

These need to inform future service planning and delivery so the standards are implemented in full.

It is vital that both the transition into end of life and the planning, contracting and monitoring of service delivery are integrated and well managed if people are to die well in a place of their choosing. We are developing a separate Delivery Plan for Palliative and End of Life Care for the NHS up to 2016, which will issue for consultation later in 2012.

#### **ACTIONS**

#### Caring at the End of Life

#### Local Health Boards to:

- Plan, secure and deliver well co-ordinated palliative and end of life care on a 24/7 basis in line with published standards and guidance.
- Support all providers who care for dying patients to participate in the All Wales audit of the Integrated Care Priorities documentation.
- Have clear funding streams for specialist palliative care services which are above the minimum levels advised by the Palliative Care Implementation Board.
- Support participation in cancer patient experience surveys, in particular the iWantGreatCare surveys of palliative care patients and their families.
- Support people to die in their place of choice.

#### 6.6 Improving Information

There are essentially four types of information needs in NHS Wales:

- Patients need information to make decisions about their care and treatment.
- Health professionals need information for the clinical management of patients.
- Service planners need information on the health needs of their local populations and how well the NHS is operating.
- The public, the NHS, the Third Sector and Welsh Government need information on the outcomes that result from NHS care.

Local Health Boards and NHS Trusts can use information from a range of sources, such as the Welsh Government and the Office of National Statistics. Public Health Wales NHS Trust, through its Wales Cancer Intelligence and Surveillance Unit, collects and produces information and analysis for Local Health Boards on incidence, mortality and survival. This now needs to link better with more real time data on clinical outcomes to support effective clinical care.

The priorities for supporting the NHS with access to high quality clinical information up to 2016 are to:

- Develop CaNISC to keep pace with clinical information needs and technology.
- Develop links between different national databases to create an all Wales cancer data warehouse.
- Develop processes to ensure high data quality and analysis tools to interrogate collected data.
- Develop a system for transferring decisions made by multi-disciplinary teams to primary and secondary care, the third sector and patients.
- Consider how information and support is passed on to patients to improve their ability to access services and manage their illnesses.

The Cancer NSAG has developed clinical quality measures to be incorporated into CaNISC specifically designed so NHS organisations can monitor the quality of their services locally and through the 2 Networks. These measures along with others will be integral to peer review.

#### **ACTIONS**

#### **Local Health Boards and Trusts to:**

- Record and use clinical information for all cancer patients using CaNISC.
- Report performance against National Cancer Standards and cancer site specific clinical quality indicators to Boards at least annually.
- Publish regular and easy to understand information about the effectiveness of their cancer services.

#### Public Health Wales and Velindre NHS Trusts to:

- Provide Local Health Boards with trend and analysis of cancer incidence, mortality and survival to inform local service planning.
- Provide an effective cancer clinical information infrastructure by developing CanISC.
- Analyse and benchmark information to facilitate and inform Local Health Boards' participation in national clinical audit and peer review.

#### 6.7 Targetting Research

Research is critical to effective cancer care and the NHS must respond to the latest research in the planning and delivery of its services. Cancer research in Wales is also vital in attracting investment and first class NHS staff. Wales already has an excellent research reputation for cancer care and the Wales Cancer Bank is an example of this. The NHS must continue to promote our research base and ensure access to clinical trials, where appropriate, is well established as this can lead to better outcomes for patients.

Cancer research results in ongoing improvements in patient outcomes. Patients benefit through access to novel therapies and the on-going implementation of evidence based best practice. In the longer term patients also benefit from better understanding of the causes and prevention of cancer. An active research culture in hospitals provides staff with opportunities to develop skills and gain experience of delivering innovative treatments. A strong research base stimulates opportunities for innovation, increases the competitiveness of Welsh applications for grants from UK funding bodies and industry and supports the establishment of state of the art research units and centres.

In the recently published 'Science for Wales' strategy the Welsh Government identified cancer as an area of research strength in Wales. Through its National Institute for Social Care and Health Research (NISCHR), the Welsh Government supports several major initiatives in this area. These include the Wales Cancer Bank, Cancer Genetics Biomedical Research Unit, Experimental Cancer Medicine Centre, Wales Gene Park, Cancer Research UK centre, and the Cancer Registered Research Group. NISCHR will also continue to work with other UK funders to maximise the opportunities for Welsh researchers to apply for funds to support their cancer research programmes.

Recent advances in understanding the molecular genetics of cancer have allowed clinicians to start to stratify patients on the basis of the molecular characteristics of their tumours. This opens up the possibility of patients receiving targeted treatments with fewer side effects and better outcomes. Welsh researchers are actively involved in stratified medicine research and we expect NHS organisations to ensure that clinical trials are linked to existing resources, such as the Wales Cancer Bank, to improve trial design and ensure the correct stratification of patients.

Where appropriate, using safeguards to protect patient data, research should be combined with patient data information, to allow researchers to maximise the research resources available for patient benefit.

#### **ACTIONS**

#### **Local Health Boards and NHS Trusts to:**

Foster a strong culture of research, in particular to:

- Offer all appropriate patients access to relevant clinical trials.
- Maximise the use of Welsh Government funding for NHS research.
- Provide effective and efficient research governance processes to enable a speedy start-up and delivery of clinical trials.
- Support and encourage protected research time for clinically-active staff.
- Promote the use of key research facilities such as the Wales Cancer Bank, Wales Cancer Trials Unit, Wales Cancer Research Network and the Marie Curie research Centre.
- Work with Universities in Wales and Cancer Research UK to support Wales'
- involvement in the stratified medicine initiative.
- Collaborate effectively with other Local Health Boards and NHS Trusts, Universities and industry in Wales to enable a speedier application of research and introduction of new technology into the NHS.

#### 7. Working Together

All of us have a key part to play in our efforts to tackle cancer.

The Welsh Government is responsible for strategic leadership through setting the health outcomes it expects for the people of Wales. It holds the NHS to account on how well it delivers the outcomes we want. The lines of accountability are via the Chairs of the Local Health Boards and Trusts to the Minister for Health and Social Services. The Chief Executives of the Local Health Boards and Trusts report to the Chief Executive of the NHS Wales who is also the Director General of the Welsh Government's Department of Health Social Services and Children. There are regular performance reviews. Progress will be overseen through monitoring the specified levels of performance by 2016 for each of the NHS performance measures.

NHS Wales is made up of 7 Local Health Boards and 3 NHS Trusts. Local Health Boards are responsible for planning, securing and delivering local services to help prevent cancer and to diagnose, treat and care for people affected by cancer. The 6 Local Health Boards in South Wales, together with Velindre NHS Trust, work in partnership as the South Wales Cancer Network to plan and deliver cancer care. There is a single Cancer Network in North Wales. All 7 Local Health Boards plan and fund specialist cancer services through their partnership work on the Welsh Health Specialised Services Committee (WHSSC).

To plan services effectively for their populations Local Health Boards must build and lead coalitions with: Trusts, GPs, pharmacists, dentists, opticians; social services and; the Third Sector voluntary bodies. Cancer charities and independent hospices play a valuable role in meeting the needs of people with cancer. These services need to be part of an integrated cancer service.

Public Health Wales NHS Trust provides Local Health Boards with information and advice to inform service planning. It also provides the Wales cancer registry through its Wales Cancer Intelligence and Surveillance Unit (WCISU). Velindre NHS Trust hosts the National Wales Informatics Service (NWIS), which supports Local Health Boards in the collecting and reporting of information. This includes the Cancer Information System Cymru (CaNISC) where clinical patient information is recorded.

**Local government** also has a vital role to play to prevent cancer. To promote a co-ordinated approach, they need to work with Local Health Boards through Local Service Boards. This work includes the analysis of the evidence base and development of Single Integrated Plans showing how they can contribute to improving health outcomes, in areas such as smoking, obesity, nutrition and exercise.

The All Wales Cancer Implementation Group is well positioned to provide strong and joined-up leadership and oversight and to co-ordinate action in a strategic way. The Group is able to:

 Work in a co-ordinated way at an all Wales level to support Local Health Boards to deliver the outcomes asked of them in a consistent way across Wales.

- Agree how best to measure success.
- Facilitate the sharing and implementation of best practice.
- Identify constraints and solutions to common issues where a strategic approach is needed.

The **Third Sector** has an important role to play, both in providing services and acting as the voice of individuals. The Cancer Alliance grouping can help both inform policy and help provide an independent overview of progress.

**People** do not choose to develop cancer and its cause may be hereditary or environmental. We all can, however, choose to minimise our risk of cancer through our lifestyle choices. Smoking, alcohol and obesity increase the risk of cancer. We all need to take more responsibility for our own health to make an active contribution to minimising our risks and harm.

#### 8. Measuring Success

The Quality Delivery Plan sets out how we will monitor performance and progress in improving health and health care in Wales. An initial Outcome Indicator Framework will be developed during 2012.

The Quality delivery Plan places requirements on NHS organisation to monitor a set of quality metrics and report them to the public, and hence to Welsh Government, and their Boards at regular intervals. This Cancer Delivery Plan now places a requirement on each organisation to publish an annual report on cancer services for the public of Wales each year to demonstrate progress. The year 2012/13 will therefore be one of transition as we move to this new approach.

Annex 3 sets out an initial set of national outcome indicators and NHS performance measures. These will be refined in discussion with the NHS and partners.

#### 9. Local Plans – Local Action

In response to this Cancer Delivery Plan, Local Health Boards are required, together with their partners, to produce and publish a detailed local cancer delivery plan to identify, monitor and evaluate action needed by when and by whom. The Local Health Board Executive Leads for Cancer will report progress formally to their Boards against milestones in these delivery plans and publish these reports on their websites quarterly.

The clinical advisory structure for cancer, the National Cancer Specialist Advisory Group (NSAG) has developed a Technical Document which contains analysis of cancer outcomes, consensus clinical priorities and horizon scanning in relation to National Institute for Clinical Healthcare Excellence (NICE) guidance and clinical trials. This advice on effective strategies is designed to support Local Health Boards and their partners in developing local cancer delivery plans to improve outcomes for their population. This Technical Document can be accessed at <a href="http://www.wales.nhs.uk/sites3/page.cfm?orgid=322&pid=60865">http://www.wales.nhs.uk/sites3/page.cfm?orgid=322&pid=60865</a>

Whilst this plan sets out our expectations of the NHS, the delivery process which will follow is intended to be dynamic and flexible and able to demonstrate real improvement along the way.

There are a number of strategic actions identified throughout this document. These are set out in annex 2.

#### **Annex 1 Summary of Outcomes**

### Outcome 1 – People are aware of and are supported in minimising their risk of cancer through healthy lifestyle choices.

- more people are supported to quit smoking;
- more people are aware of the health harms of smoking, above limits alcohol consumption, the broader benefits of physical activity and healthy eating;
- more people achieve a healthy weight through weight management support;
- more people are physically active as a natural part of their everyday life and undertake sufficient physical activity to benefit their health.

#### Outcome 2 – Cancer is detected quickly where it does occur or recur

- easier access to primary care services;
- more accessible information and support services provided through local pharmacies;
- more clinical support available 24 hours a day, 365 days a year;
- more direct access to diagnostics for GP;
- a greater range of local services meaning less need to travel, particularly for diagnosis and care after treatment;
- take up of population screening in line with programme targets;
- prompt and appropriate access to evidence based assessment and treatment to increase the chance of cure and reduce side effects:
- more information on reducing the risk of developing cancer, recognising symptoms suggestive of early cancer and what services to expect available by telephone and on-line;
- more men accessing healthcare as there is evidence their uptake can be lower than needed.

### Outcome 3 – People receive fast, effective treatment and care so they have the best possible chance of cure

- prompt and appropriate access to clinically and cost effectively treatment offering people better chances of being cured of cancer;
- people experience well co-ordinated services, which are compliant with national standards and guidelines, safe, sustainable and available as locally where possible;
- specialist hospital cancer care in centres of excellence that match or surpass the best and seamlessly connected with local cancer services:
- flourishing cancer research to improve treatment and making NHS Wales an attractive place to live and work for high calibre clinicians;
- more patients participating in clinical trials.

## Outcome 4 – People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer

- everyone is treated with dignity and respect;
- services are available as locally as possible;
- people have access to timely information so they understand their condition and what to look out for and what to do and which service to access should problems occur;
- every patient has a Key Worker who co-ordinates care and support in partnership with them;
- people's clinical and non clinical needs as a consequence of cancer are

- assessed and recorded in a care plan and services designed around meeting those needs;
- care plans are written and shared with the person involved and reviewed on an ongoing basis;
- follow up care given in the most appropriate place for the patient and not the service. Increasingly this should be in primary care.
- direct access to services for cancer patients in whom recurrent disease is suspected;
- best possible IT and communication links giving clinical staff fast, safe and secure access anywhere in Wales to the information needed to care for patients;
- more information for people tailored to meet their individual needs;
- transport to and from clinics and hospitals is easily accessible;
- patients and carers are involved in the design of services and people's views on services are sought regularly and acted on to ensure continuous improvement;
- transparently published information available on the performance of NHS cancer care in terms of safety, effectiveness and patients' views.

### Outcome 5 – People approaching the end of life feel well cared for and pain and symptom free

- more people receive palliative and end of life care and support on a 24/7 basis;
- specialist palliative care nursing is available 7 days a week;
- people's needs and wishes, and those of their family, are clarified, clearly recorded and are a key guide to care provided;
- people whose symptoms have not improved after 48 hours are referred to specialist palliative care;
- key information on all patients with advancing cancer is recorded on CaNISC and accessible to others who have clinical responsibility for the patient, including out-of-hours GP services, on a 24/7 basis;
- less people being admitted unnecessarily to hospital;
- more people are able to die in the place of their choice;
- NHS and Third Sector voluntary sector care is integrated and seamless;
- families have access to pre and post bereavement support appropriate to their age;

### Annex 2 Strategic actions

Key Action	By Whom	By When
Provide strategic leadership and work at an all Wales level to support Local Health Boards' service improvements. In particular, beginning with work on:	Cancer Implementation Group members	Ongoing from December 2011
a set of Cancer Outcome Indicators and NHS Performance Measures		May 2012
the development of a Primary Care Oncology initiative to improve local access to high quality cancer care in the community, such as follow up care		Ongoing from May 2012
Identifying ways of supporting Local Health Boards to assign a Key Worker to each person diagnosed with cancer and to introduce effective assessment and care planning		Ongoing from April 2012
Undertaking a national cancer patient experience survey in partnership with MacMillan Cancer Support		From June 2012
Review current cancer services against the expectations set out for 2016 and use the outcome to inform a detailed local delivery plan for activity and milestones under each of the themes for action.	Local Health Boards, together with NHS Trusts, GPs, dentists, opticians, pharmacists, local government and Third Sector	October 2012
Report progress against local delivery plan milestones to Boards and to the public via own website.		Quarterly, starting with quarter ending December 2012
Review and update delivery plans and milestones.		At least annually
Report formal progress against the delivery plans and NHS Performance Measures to Boards, Welsh Government & the public as part of		Annually, from September 2012

Annual Quality Statement via own website.		
Attend all Cancer Implementation group meetings and participate in Group sub groups	Local Health Board Executive Leads for Cancer	Quarterly
Publish annual All Wales report on effectiveness of NHS cancer services in Wales, based on Local Health Board reports against Performance Measures.	Welsh Government	Annually, from September 2012

#### **Annex 3 - Measuring Success**

#### **Outcome Indicators for Cancer**

Our Population Level Outcome for Cancer is:

People have a minimised risk of developing cancer and, where it does occur, an excellent chance of surviving, wherever people live in Wales.

We will use the following Outcome Indicators to measure and track how well over time we are doing. Outcome Indicators for measuring the health of the population of Wales more generally, such as the % of people who smoke or who are obese, have been set under our Programme for Government.

To reduce inequalities in health, we shall also focus on how well we are reducing the gap between the most and least deprived parts of Wales and between age groups. We shall also compare ourselves internationally wherever we can.

#### Local Health Board Annual Reports on Cancer Care September 2012 onwards

Local Health Boards are required to include information on the following Outcome Indicators for their population in their annual September report on cancer services, starting September 2012. These reports will be supplemented by locally determined content.

### **OUTCOME INDICATOR: Cancer incidence rates (European Age Standardised Rate)**

#### **Population Group**

People of all ages resident in Wales

#### Rationale

This is the population marker for preventing cancer.

#### **Definition**

The European Age Standardised Rate (E.A.S.R.) for Wales per 100,000 population, people, for all cancers excluding non-melanoma skin cancer (NMSC).

#### What does good look like?

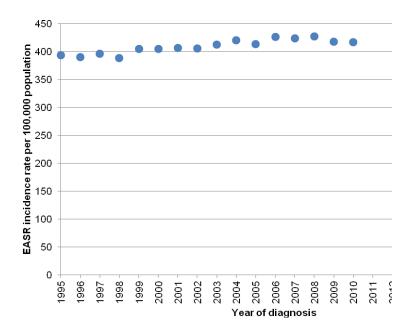
- A slower rise in the rate of increase in the age standardised incidence compared with the projected rise. As many cancers take years to develop following risk factor exposure, there will be a considerable lag in change in risk factor / exposure and change in cancer incidence.
- A reduced gap between the most and least deprived areas of Wales

 Incidence rates comparable with the best quartile in Europe (those countries with cancer registration covering whole population)

#### **Data source**

Public Health Wales NHS trust - WCISU

#### **Baseline (Where are we starting from?)**



#### **General Direction of Travel**

Cancer incidence is rising, which is expected due to the fact that cancer is predominantly a disease of older people and the proportion of older people in the Welsh population is increasing year on year.

#### Reporting frequency

Annual

#### **OUTCOME INDICATOR TWO: Cancer mortality rate**

#### **Population Group**

People resident in Wales

#### Rationale

This indicator demonstrates the number of people who died from cancer each year, expressed as an age standardised rate to allow comparisons between years and countries. Cancer mortality needs to be looked at alongside incidence and survival as changes in either can affect mortality. Mortality rates across deprivation quintiles

are used here to describe variation in outcome for people with cancer, according to their socio economic status.

#### **Definition**

European Age-Standardised Rate (E.A.S.R.) for Wales per 100,000 population, people, for all cancers excluding non-melanoma skin cancer (NMSC).

#### What does good look like?

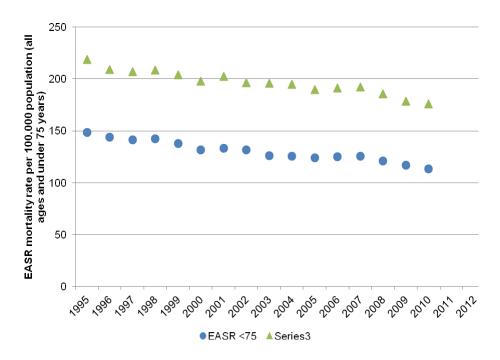
- A continued or accelerated fall in death from cancer.
- A reduced gap between the most and least deprived areas of Wales.
- Mortality rates comparable with the best quartile in Europe (those countries with cancer registration covering whole population).

#### Data source:

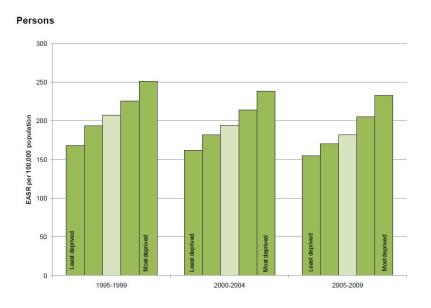
Public Health Wales NHS Trust -WCISU (incorporating ONS death certificate data)

#### **Baseline (Where are we starting from?)**

Mortality (EASR) per 100,000 population (people, all ages and under 75 years, all cancers excluding NMSC)



Mortality (EASR) per 100,000 population (per deprivation quintile)(people, all ages, all cancers excluding NMSC).



#### **General Direction of Travel**

The current EASR mortality data show a steady decline but slower than expected.

#### Reporting frequency

Annual

#### **OUTCOME INDICATOR THREE: 1 and 5 year cancer survival rates**

#### **Population Group**

People of all ages newly diagnosed with cancer whilst resident in Wales

#### Rationale

This is the population marker for successfully extending lives for those with cancer. Survival rates after diagnosis of cancer are an indicator of the overall effectiveness of treatment services but also reflect the general health of the population and how early the cancer was detected.

#### **Definition**

Relative survival at 1 and 5 years from diagnosis for all cancers excluding NMSC, people of all ages, presented using 5 year rolling averages, for patients diagnosed in Wales

#### What does good look like?

A continued or accelerated increase in 1 and 5 year survival rates.

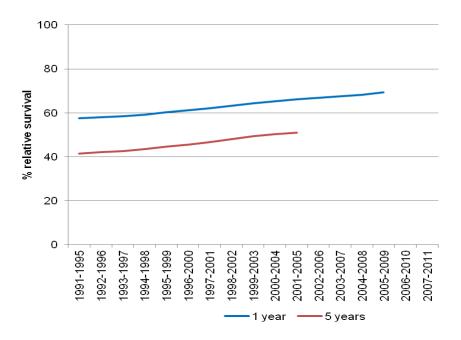
- A reduced gap between the most and least deprived areas of Wales.
- 1 and 5 year survival rates comparable with the best quartile in Europe (those countries with cancer registration covering whole population).

#### **Data Source**

Public Health Wales NHS Trust - WCISU (incorporating ONS death certificate data)

#### **Baseline (Where are we starting from?)**

All Cancers (excluding NMSC), all ages



#### **General Direction of Travel**

There is a general trend of increasing survival at 1 and 5 years for the "all cancers" indicator, and significant variation by cancer site and diagnosis.

#### Reporting frequency

Annual

#### **NHS Performance Measures For Cancer**

The following NHS Performance Measures have been developed to measure how successful cancer detection, treatment, and care are for people in Wales. These will form the basis of Local Health Boards' annual reports on cancer care, beginning September 2012.

Some NHS services aim to reduce risk factors associated with cancer such as the number of people who smoke or who are obese. NHS Performance Measures for services to those services are not included here as they are set out in Programme

for Government and in The Welsh Government's Performance Level Agreement with Public Health Wales NHS Trust.

For Palliative and End of Life Care, a separate Delivery Plan is being developed, which will set NHS Performance Measures for those services.

Several of the following NHS Performance Measures require further work to develop formal definitions and data sources. In some cases, the direction of travel and level of performance required by 2016 will need to be determined in the light of the baseline.

#### **Local Health Board Annual Reports on Cancer Care September 2012**

As work on definitions and data sources for some of the Performance Measures is not yet complete. Local Health Boards are required to include their performance against the following NHS Performance Measures in their September 2012 annual report on cancer services.

- % of people starting their definitive cancer treatment in line with the cancer waiting times target;
- % of people whose cancer is diagnosed at each stage (1-4);
- % of patients recruited into high quality clinical research;
- % of people diagnosed with cancer who consent to donate samples to the Wales Cancer Bank.

The remaining performance measures will be developed so that all can be reported against in September 2013.

**PERFORMANCE MEASURE:** % of people starting their definitive cancer treatment in line with the cancer waiting time target.

### What Outcome in Together For Health – Cancer Delivery Plan does this relate to?

Outcome 2 - Cancer is detected quickly where it does occur or recur.

Outcome 3 - People receive fast, effective treatment and care so they have the best possible chance of cure.

#### **Customer Group**

People newly diagnosed with cancer awaiting treatment.

#### Rationale

It is important that patients with suspected and diagnosed cancer have appointments, tests and treatments in a timely fashion since this can affect both their

clinical outcome and their experience of the NHS. The cancer waiting times targets have been a key metric for demonstrating this priority area.

#### **Definition**

At least 95 per cent of patients referred by their GP with urgent suspected cancer and subsequently diagnosed as such by a cancer specialist will start definitive treatment within 62 days of receipt of referral.

At least 98 per cent of patients not referred as urgent suspected cancer but subsequently diagnosed with cancer will start definitive treatment within 31 days of diagnosis, regardless of the referral route.

For full definitions please see:

http://wales.gov.uk/topics/statistics/publications/cancerquality/?lang=en

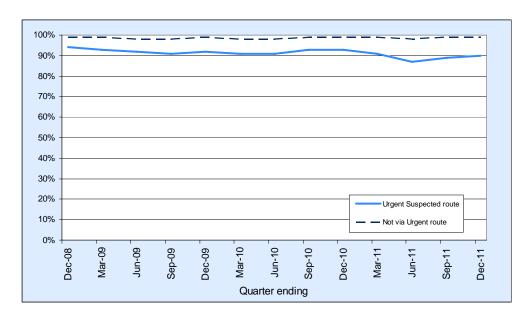
#### What does good look like?

Sustained achievement of the targets

#### Data source:

Knowledge & Analytical Services, Welsh Government

#### **Baseline**



#### **General Direction of Travel**

The chart above shows the 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 over the last 13 quarters.

 There has been very little change in the percentage of patients newly diagnosed with cancer NOT via the urgent suspected cancer route starting

- definitive treatment within 31 days: varying around 98 and 99 per cent for each quarter and generally meeting the target.
- The percentage of patients newly diagnosed with cancer via the urgent suspected cancer route starting definitive treatment within 62 days remained above 90 per cent for each quarter until the quarters ending June and September 2011. For the quarter ending December 2011, the percentage increased to 90 per cent. The 95 per cent compliance was not achieved at the end of any of the last 13 quarters.

#### Reporting frequency

Quarterly

#### Level of Performance Required by 2016

Sustained achievement of target (within set tolerance level set by Welsh Government).

**PERFORMANCE MEASURE:** % of people whose cancer is diagnosed at each stage (0-4).

### What Outcome in Together for Health – Cancer Delivery Plan does this relate to?

Outcome 2 - Cancer is detected quickly where it does occur or recur.

Outcome 3 - People receive fast, effective treatment and care so they have the best possible chance of cure.

#### **Customer Group**

People of all ages with a new diagnosis of cancer.

#### Rationale

Offering a cancer patient potentially curative treatment increases their chance of survival. There is increasing evidence which suggests the earlier someone is diagnosed with cancer, the better chance they have of survival. Measuring the stage of the cancer at diagnosis will demonstrate the level of success in achieving earlier diagnosis.

#### **Definition**

MDT determined stage at diagnosis for people newly diagnosed in NHS Wales per year, presented as UICC stage categories 0\*-4, each as a percentage of the total number of people newly diagnosed with cancer and registered on Canisc that year.

<sup>\*</sup>Stage 0 is pre-invasive cancer, such as carcinoma in-situ

#### What does good look like?

A shift in stage at diagnosis from late (stage 4) to earlier stages will demonstrate that strategies to achieve earlier diagnosis are working. In order for this to be a reliable metric organisations will have to ensure that data on stage at diagnosis is routinely captured in Canisc prior to generation of the baseline.

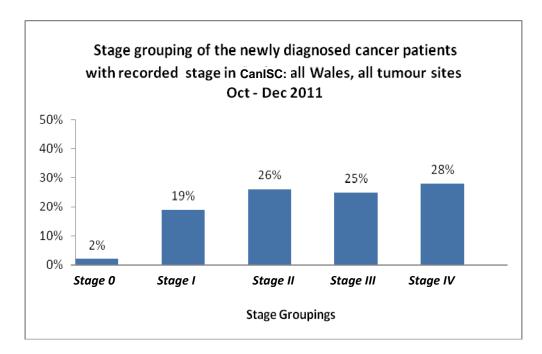
There will be variations, by cancer type, in the degree of shift from late to early presentation that will be needed in order to see a significant impact on treatment options and survival, and progress with these needs to be investigated more thoroughly e.g. through clinical audit.

#### Data source

CanISC. TNM stages are grouped according to UICC defined groups. It is accepted that work will be required by LHBs to ensure that data is collected consistently by Multi-disciplinary Teams and systems in place to ensure high data quality. In addition there will be improvements in itself to support robust data entry and reporting.

#### **Baseline**

To be generated from CanISC in the September 2012 LHB reports. Currently approximately 50% of all cancers have their stage recorded in CanISC. It is expected that this should reach 70% by 2013/14 and >90% by 2016. It is possible that as data completeness improves this in itself may affect relative proportions of stage groups.



#### **General Direction of Travel**

A shift from late to earlier stage, especially towards detecting disease at a potentially curative stage.

#### Reporting frequency

Annual

#### Level of Performance Required by 2016

By September 2012, the Cancer Implementation Group's Information Subgroup will establish what performance should be achieved by LHBs in terms of shift from late to earlier stage at diagnosis by 2016 through National and International benchmarking and analysis of available metrics.

**PERFORMANCE MEASURE**: % of patients recruited into high quality clinical research.

### What Outcome in Together For Health – Cancer Delivery Plan does this relate to?

Outcome 3 - People receive fast, effective treatment and care so they have the best possible chance of cure.

#### **Customer Group**

People of all ages with a diagnosis of cancer.

#### Rationale

There is strong evidence that treatment centres that are actively involved in clinical research achieve better outcomes for their patients. Clinical research contributes to improvements in patient care now and for the future and generates evidence which helps health professionals deliver the most effective treatments. A research active health service will help Wales to recruit and retain high quality clinical professionals, ultimately benefitting all people with cancer.

#### **Definition**

The number of people entering approved NISCHR research studies as a percentage of cancer incidence in Wales (using an average of three-years).

#### What does good look like?

At least 10% of new cancer patients each year agree to participate in high quality studies on the NISCHR portfolio or commercial research register, with at least 7.5% of these research participants taking part in more complex studies which involve an intervention.

Research activity should include rarer cancers, with patient referral routes in place where studies are not available locally.

#### **Data Source**

NISCHR Clinical Research Centre, Local Health Boards and NHS Trusts WCISU (Three year average annual incidence).

#### **Baseline (Where are we starting from?)**

During April 2011-March 2012 total clinical research activity exceeded the 10% target standing at 14.8%. The challenge moving forward will be to maintain this level of activity and achieve 7.5% participation in interventional studies.

In 2010 62% of national research activity took place in common cancers (breast, colon, lung and prostate). LHBs and Trusts should develop action plans to double recruitment to rarer cancers by 2016.

Baseline for interventional studies, all Wales and by Network (2011-12) will be available by the end of September 2012.

Baseline by LHB will be available for patients recruited into trials after pilot for EDGE is fully implemented.

#### **General Direction of Travel**

Increases in the % and number of patients in Wales participating in high quality research leading to improvements in care. Increased research activity in rarer cancers nationally.

#### Reporting frequency

Annual

#### Level of Performance by 2016

10% and 7.5%, doubling of research activity in rarer cancers.

**PERFORMANCE MEASURE**: 30 day post treatment mortality for a) chemotherapy, and b) surgery.

### What Outcome in Together For Health – Cancer Delivery Plan does this relate to?

Outcome 3 - People receive fast, effective treatment and care so they have the best possible chance of cure.

#### **Customer Group**

People diagnosed with cancer undergoing chemotherapy or surgery.

#### Rationale

All treatments carry risk; however treatment must be safe and appropriate. There is evidence from national audit and NCEPOD reports on perioperative care and chemotherapy that a range of negative outcomes can occur following treatments, including in a small minority of cases, death. In some cases, audit has identified that these deaths may have been prevented if selection of treatments for patients, or the quality of care, had been better.

#### **Definition**

To be determined

- a. 30-day mortality following potentially curative chemotherapy;
- b. 30 day mortality rates following surgery.

#### What does good look like?

A decrease in post-treatment mortality.

#### **Data Source**

To be determined.

#### **Baseline (Where are we starting from?)**

To be determined.

#### **General Direction of Travel**

To be determined.

#### **Frequency of Reporting**

To be determined.

#### Level of Performance by 2016

To be determined.

**PERFORMANCE MEASURE:** % and number of people diagnosed with cancer who consent to donate samples to the Wales Cancer Bank.

### What Outcome in Together For Health – Cancer Delivery Plan does this relate to?

Outcome 3 - People receive fast, effective treatment and care so they have the best possible chance of cure.

#### **Customer group**

Future patients diagnosed with cancer.

#### Rationale

Research in to the development of more effective, targeted treatment for cancer will benefit the patients of the future, increasing their access to therapies that will work for them and decreasing their exposure to therapies that their individual tumour will be unresponsive to. As with trials an active high quality research portfolio attracts high quality clinical professionals, ultimately benefitting all people with cancer.

#### Definition

The number of people with a diagnosis of cancer, consenting to tissue donation to the Wales Cancer Bank during financial year, presented as a percentage of all people diagnosed with cancer during (year).

#### What does good look like?

Increasing consent by patients year on year.

#### Data source:

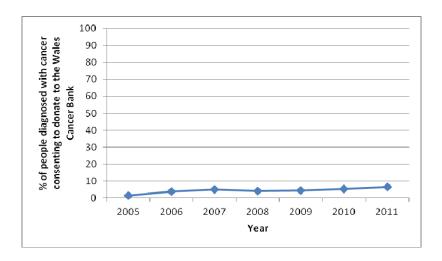
Wales Cancer Bank (number of people consenting to tissue donation) and WCISU (cancer registrations, three year rolling average).

#### **Baseline (Where are we starting from?)**

The number of people consenting to donate tissue to the Wales Cancer Bank has been steadily increasing year on year, with more hospitals taking part in the recruitment.

Year	Number of new patients consenting to donate tissue
2005	240
2006	691
2007	881
2008	714
2009	774
2010	922
2011	1122

The % of people diagnosed with cancer who consent to donate tissue is also rising, but at a slower rate due to the increase in incidence seen over the last 5 years.



N.B. for this figure, data for 3 year rolling average of registrations was calculated by WCRN taken from WCISU figures.

#### **General Direction of Travel**

Increase in consent for donation, but variation evident by tumour type and LHB.

#### Reporting frequency

Annual

#### Level of Performance Required by 2016

20% of people diagnosed with cancer agreeing to donate to the Wales Cancer Bank.

**PERFORMANCE MEASURE:** % of people with a diagnosis of cancer who are assigned a Key Worker.

### What Outcome in Together For Health – Cancer Delivery Plan does this relate to?

Outcome 4 - People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer.

#### **Customer Group**

People of all ages with a diagnosis of cancer.

#### Rationale

Programme for Government recognises people of all ages with are expected to be assigned a Key Worker following a diagnosis of cancer. The Key Worker is responsible for co-ordinating seamless care to meet all the clinical and non clinical needs of the person affected by cancer.

The Person Centred Care sub group of the Cancer Implementation Group will review this proposed Performance Measure to focus it on measuring outcome more than process.

#### **Definition**

The number of people with a diagnosis of cancer recorded on Canisc as having a current Key Worker presented as a percentage of all people recorded on Canisc living in Wales following a diagnosis of cancer.

#### What does good look like?

People of all ages receive well co-ordinated care throughout their cancer journey as a result of being assigned a Key Worker.

#### Data source:

Canisc.

#### **Baseline**

To be determined.

#### **General Direction of Travel**

People undergoing treatment are increasingly being assigned a Key Worker and there is recognition that this Key Worker role needs to continue following the end of treatment but more rapid progress to implement is needed.

#### Reporting frequency

To be determined.

#### Level of Performance Required by 2016

100%.

**PERFORMANCE MEASURE:** % of people with a diagnosis of cancer who have a care plan.

### What Outcome in Together For Health – Cancer Delivery Plan does this relate to?

Outcome 4 - People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer.

#### **Customer Group**

People of all ages with a new diagnosis of cancer.

#### Rationale

Programme for Government includes a tracking indicator about people with cancer having a care plan. People with a diagnosis of cancer who have their clinical and non clinical needs assessed, agreed with them, recorded in a care plan and then planned for and met, are more likely to feel well supported and cared for and to have a better experience of NHS care.

The Person Centred Care sub group of the Cancer Implementation Group will review this proposed Performance Measure to focus it on measuring outcome more than process.

#### **Definition**

To be determined.

#### What does good look like?

NHS cancer services are planned and delivered so people who are diagnosed with cancer are routinely assessed for both their clinical and non clinical needs and these are agreed with them and recorded in care plan. The care plan will be reviewed systematically. People with a diagnosis of cancer will understand the care they have agreed to throughout their pathway and feel well cared for by the NHS during and after treatment.

#### Data source

To be determined.

#### **Baseline**

To be determined.

#### **General Direction of Travel**

People undergoing treatment for cancer currently have a care plan which records their treatment. Clinical needs following the end of treatment and non clinical needs are not currently systematically assessed but there is widespread recognition that this needs to happen.

#### Reporting frequency

To be determined.

#### Level of Performance Required by 2016

100%.