



# WALES CANCER ALLIANCE CYNGHRAIR CANSER CYMRU

## Wales Cancer Alliance Priority Policy Calls

The Wales Cancer Alliance consists of eighteen organisations dedicated to promoting the best cancer prevention, treatment, research and care for people in Wales. Every year we invest more than £20m in Wales and contribute to the development of cancer policy.

The Wales Cancer Alliance welcomes the Welsh Government's Cancer Delivery Plan refresh, published in November 2016 and its ongoing vision, "***for cancer services and outcomes for our patients to match the best in Europe***". We recognise the importance of the Delivery Plan in driving improvements in cancer services and call on the Welsh Government to deliver key commitments within the plan. The delivery of a performance framework - against which we are able to measure delivery - will be a critical development, one we will continue to press for.

We believe that the third sector has an important role to play scrutinising the delivery of improvements for people affected by cancer, and we look forward to working in partnership with the Welsh Government, the Wales Cancer Network, Local Government and others to achieve this.

This document pulls together our suite of policy papers, which reflects many of the headline areas within the Cancer Delivery Plan and additional key areas of focus where we believe further commitment and delivery is required. We also present our calls for action.

The Wales Cancer Alliance has detailed policy papers to support many of these areas. Visit the Wales Cancer Alliance website <http://www.walescanceralliance.org> for further information.

The Wales Cancer Alliance is a coalition of eighteen organisations: Bowel Cancer UK, The Brain Tumour Charity, Breast Cancer Care, Breast Cancer Now, Cancer Research UK, Cancer Research Wales, CLIC Sargent, Hospices Cymru (represented by Hospice UK), Macmillan Cancer Support, Maggie's, Marie Curie, Myeloma UK, Ovarian Cancer Action, Prostate Cancer UK, Pancreatic Cancer UK, Target Ovarian Cancer, Teenage Cancer Trust and Tenovus Cancer Care.

## Preventing cancer

***“An extensive body of evidence already exists to support the types of interventions and policies which address the root causes of ill health and inequalities and lead to better mental, physical and social wellbeing”*** Cancer Delivery Plan for Wales 2016 - 2020

The Wales Cancer Alliance is committed to tackling cancer through evidence-based public health interventions. The effects of smoking, alcohol consumption, physical inactivity and poor diet have well established direct links with cancer and a number of other chronic conditions.

Improving the health and wellbeing of Welsh residents will contribute towards stemming the projected increases in the prevalence of cancer and contribute to lowering the overall disease burden on the National Health Service.

### **We call for:**

- A minimum unit pricing policy for Wales
- Appropriate and effective smoking cessation support
- Statutory targets to increase physical activity
- An effective national obesity strategy, to include:
  - Clear and ambitious targets for adults and childhood obesity levels
  - A comprehensive, independent monitoring and evaluation of the strategy and its component parts, funded by the Welsh Government
  - A cross-departmental approach to obesity bringing together national government, the NHS and local government partners.
- A reduction in health inequalities
- Human Papilloma Virus Vaccinations for all young people
- A sun safety strategy
- Opportunities for ‘teachable moments’ for prevention messages to be identified and supported.
- A “health in all policies” approach to policy development and implementation.



## Detecting cancer earlier

***“Detecting cancer early makes it more likely that treatment can be curative, less intensive and less expensive .”*** Cancer Delivery Plan for Wales 2016 – 2020

In general, the earlier a cancer can be diagnosed, more options are available for successful treatment and the greater the chance of survival. For example, when bowel cancer is diagnosed at stage one more than nine in ten people survive five years or more compared to less than one in ten of people diagnosed at stage four.

Demand for cancer diagnostics will increase over time, because of a growing and aging population, as well as welcome interventions to improve early diagnosis. Embedding new NICE referral guidelines for suspected cancer has already seen an increase in referrals by 12% between 2014-15 and 2015-16.

If the new pilots testing multi-disciplinary diagnostic centres (MDCs) set out in the Cancer Delivery Plan are successful and rolled out across Wales, it is unclear what analysis has been made of the required workforce to make this initiative a success.

### **We call for:**

- The Welsh Government and NHS Wales to undertake an audit of the diagnostic workforce, with particular focus on services for cancer-relevant services, including endoscopy, imaging and pathology to understand the workforce and equipment capacity needed to meet existing and future demand.
- The Welsh Government and NHS Wales to ensure that the results from the Multi-Disciplinary Diagnostic Centre Pilots can be learnt from and built into a Plan for Wales as rapidly as possible.
- The Welsh Government and NHS Wales to collaborate with the voluntary sector to understand the key issues and drivers for improving early diagnosis in Wales
- The Welsh Government and NHS Wales should work closely with the Wales Cancer Alliance to help deliver the Diagnosing Cancer Earlier Programme, and its objectives to raise awareness of the signs and symptoms of cancer, increase the number of cancer diagnoses at an earlier stage (1-2) and increasing 1 and 5 year survival in line with the best countries in Europe.
- The Welsh Government and NHS Wales to work with the Wales Cancer Alliance to promote best practice use of relevant tests for cancers without a population-wide screening programme. For example, use of the Prostate Cancer UK-orchestrated clinical consensus on PSA testing.



## Metastatic cancer

***“Ensure patients with metastatic disease receive care and support appropriate to their needs”*** Cancer Delivery Plan for Wales 2016 - 2020

Patient feedback suggests that the excellent care they received at primary diagnosis is not replicated following a diagnosis of metastatic cancer. This is compounded by the lack of data available on metastatic cancer. We do not know the number of people who have been diagnosed with the disease or know how it progressively affects their quality of life. This means that the NHS is not able to effectively plan and deliver services that can meet patients’ needs.

Metastatic cancer is also known as secondary, advanced or stage 4 cancer. It occurs when cancer cells spread from the original primary tumour to another part of the body. For most tumour sites a metastatic diagnosis means that the cancer cannot be cured; however it can sometimes be controlled and in the case of metastatic breast cancer, some patients can live for many years with ongoing, sequential treatments.

Due to the amount of crossover, it is recommended that this topic is read in conjunction with our policy papers on Palliative and End of Life Care; Meeting Peoples’ Needs and Personalised Cancer Treatments and Cancer Research.

### **We call for:**

- Information sharing
- Defined pathways for patients presenting with possible metastatic symptoms
- Data collection for all patients with a metastatic cancer diagnosis
- Access to a clinical nurse specialist at and from the point of metastatic cancer diagnosis
- A multidisciplinary team approach to care
- Continuity of care between the hospital and community services
- Access to information on support services both nationally and locally which should include the opportunity to meet/talk to others with metastatic cancer
- Access to appropriate treatments and awareness of the availability of clinical trials before treatment is started or changed



## Meeting the needs of people with cancer

*“Co-production is about individuals agreeing a joint set of actions appropriate to their values and to achieve their personal expectations of care.”* Cancer Delivery Plan for Wales 2016 - 2020

More work needs to be done to meet the needs of patients, both as they undergo treatment for cancer and beyond. Cancer services should be focused on the individual needs of people and their families. People’s holistic needs – physical, emotional, spiritual, financial and practical are not always identified or addressed.

Each person should receive a personal care plan based on a holistic assessment of their needs and this should extend into the post-treatment phase.

### We call for:

- Assessment and written care planning to be implemented for all people living with cancer
- Improved information and support to help shared decision making and provide information about treatment and care and encourage self- management
- Adherence to Key Worker principles and guidance issued by Welsh Government to achieve consistent interpretation and implementation of the Key Worker role across Wales. This approach should span the entire care pathway – from the acute setting, through to primary care (see co-ordinating care below)
- An increased understanding by patients of the Key Worker role
- An end of treatment summary sent to patients’ GPs
- A review of care after treatment to ensure it is person centred, providing for ongoing, clinical surveillance and ongoing care after acute treatment has finished which better supports cancer survivors.
- A two-year rolling programme to carry out the Wales Cancer Patient Experience Survey.
- Support for carers.



## Palliative and end of life care

*“Integrating palliative care support within the patient pathway can improve quality of life and in many cases quality of death; as well as in some cases prolong length of life.”* Cancer Delivery Plan for Wales 2016 - 2020

There have been real improvements in the provision of palliative and end of life care in Wales over the past decade. However, we know that some people with cancer who need this care and support still do not receive it, or are not given support early enough. Age can be a key factor in determining whether someone is likely to access care.

Palliative care is a holistic approach to care which aims to improve quality of life by treating or managing pain and other physical symptoms. It also helps with any psychological, social or spiritual needs that a patient and their family may have. It can be delivered by a wide range of professionals across a variety of settings. Specialist palliative care is that delivered by professionals who have received specialist training in palliative care.

End of life care typically refers to the care and support that is given to people in the final year of life. End of life care includes palliative care as well as support for families and carers.

### We call for:

- Access to the full range of support services, including palliative care, for all those who need it following initial diagnosis and routine holistic assessment going forward
- Consistent, timely support from trained professionals for people to have conversations about their options and preferences
- Better public and professional understanding of palliative care
- Action to tackle inequities in access to palliative and end of life care
- Increased emphasises on providing services in a community setting with appropriate resources to achieve this
- Greater integration of support between the NHS, local authorities and the third sector
- Support for carers
- Promotion of the palliative and end of life care research base in Wales
- A national data set to benchmark experiences of care at the end of life
- Advanced Care Planning and open discussions



## Children, teenagers and young adults (0-24yrs)

***“Important new areas will be considered for peer review such as services for children and young people...”*** Cancer Delivery Plan for Wales 2016 - 2020

Children, teenagers and young adults (CTYAs) represent a relatively small proportion of all cancer patients, defined as rare or less common cancers. It is easy for them to be lost in a system not designed for them and without specific focus on their needs. Although survival rates are relatively high, around 80%, there are variations by cancer type and cancer remains the single largest cause of death from disease for children young people.

Unlike adult cancers, the focus for the planning and delivery of cancer treatment for children and young people is based in a few specialised principal treatment centres (PTCs). Whilst this means that specialist expertise has been developed in these centres, it also means that children and young people are often treated in hospitals hundreds of miles from home.

Specialist age-appropriate care is available in Wales and we call for every CTYA with cancer to be offered and have access to these services to improve experiences and outcomes.

### **We call for:**

- Clear policy commitments and accountability frameworks that ensure there is a clear, coordinated approach to providing high quality services that are accessible to all.
- National standards to be implemented, measured and reported on.
- A greater focus on improving diagnosis of cancer in children, teenagers and young adults is required due to particular challenges in identifying cancer in this age group
- Improved access to clinical trials for 16-24 year olds
- Recognition that the survivorship experience for young cancer patients is likely to be different than that of older adults, largely because most young cancer survivors will require additional and long-term support for potentially 50+ years
- Children, teenagers and young adults with palliative and end of life care needs should have access to palliative nursing care 24/7 and access to paediatric advice. and support 24/7.



## Personalised cancer treatments and cancer research

***“Cancer research is critical to improve outcomes for patients and for the health of people in Wales.”*** Cancer Delivery Plan for Wales 2016 - 2020

Personalised cancer treatments have the potential to contribute to the Welsh Government’s prudent healthcare agenda as they provide clinical effectiveness for patients - by providing evidence-based drugs for their condition, and to avoid side effects from the drugs we can predict will not work for them; and cost benefits for the NHS - by helping doctors avoid prescribing drugs that won’t work for certain patients. To achieve this, it is critical that Welsh government works to maximise opportunities for medical research to translate into clinical practice and provide access to innovation.

As care is proven to be much better in a research rich environment, it is vital that cancer research between the various funded resources is fully co-ordinated and embedded in NHS services and closely aligned with the ongoing Transforming Cancer Services initiatives across Wales.

Research should be focussed on the cancer types where unmet clinical needs exist, raised awareness, late diagnosis, new emerging treatments such as molecular targeted therapies, established curative treatments such as surgery and radiotherapy, and the underfunded areas of survivorship and palliative care.

The Strategy for Genomics and Precision Medicine was published by Welsh Government in July 2017. The £6.8m plan aims to offer treatment plans by better understanding of human DNA, hopefully leading to faster access to genetic tests and targeted treatment.

### **We call for:**

- Longitudinal collection, and collection of samples from patients
- Infrastructural support for analytical platforms
- Greater collaboration between the pharmaceutical industry, the NHS and academia.
- Increased awareness and support of precision radiotherapy
- Better co-ordination between Local Health Boards.
- The CANISC IT system for cancer patient records in Wales to be replaced with a fit for purpose successor.

