One Cancer Voice Cymru:

A manifesto from the Wales Cancer Alliance

WALES CANCER ALLIANCE
CYNGHRAIR CANSER CYMRU

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Introduction

Cancer continues to be an issue that touches the lives of so many people across Wales. One in two of us will develop cancer over our lifetimes[1], with around 19,000 people diagnosed in Wales every year[2]. It places a huge burden on our NHS and wider society.

Significant progress has been made for which we can be proud. Today, half of people survive their cancer for ten years or more[3], thanks to research and the way we diagnose, treat and care for patients.

However, more work needs to be done. Sadly, 9,000 people in Wales still die from cancer each year.[4] It remains the most common cause of death across the UK. Even within survival statistics, there remains huge variation between cancers, with fewer than one in ten people surviving some of the least treatable cancers.

Furthermore, despite the progress that has been made, Wales continues to find itself behind other comparable countries for cancer outcomes. The scale of the problem should not be underestimated. If Wales caught up with the best in the world, thousands of lives could be saved.

This is the reason why the Wales Cancer Alliance exists. We are a coalition of over 20 cancer charities, 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. We believe that people affected by cancer and their carers should be at the heart of co-creating new services and cancer policy. The third sector has an important role to play in developing, reshaping and delivering improvements in cancer care. We do this by working in partnership with the Welsh Government, the NHS, local government and other stakeholders.

With the forthcoming Senedd election in May 2021, we urge all political parties to set out their vision for the future of cancer care in Wales. The Welsh Government's and NHS Wales' *Cancer Delivery Plan* is due to come to an end in 2020 and what follows must be bold and ambitious. Our manifesto offers clear and evidence-based recommendations that, if implemented, could have a tremendous impact for people affected by cancer.

- A new cancer strategy for Wales
- Putting staff in the right place
- Diagnosing cancer earlier
- Cancer treatment and psychological support
- Supporting people living with cancer
- Building Wales' research potential
- Preventing cancer from developing
- Optimising cancer services

These recommendations will have wide reaching effects beyond cancer care. We know that cancer can be a driver for system-wide improvement in health and this could benefit many other diseases and conditions, where similar problems are often experienced.

A new cancer strategy

Recommendation 1: Develop and implement an ambitious, new long-term strategy to improve cancer outcomes in Wales.

Most urgently, Wales needs a new long-term cancer strategy to replace the outgoing *Cancer Delivery Plan*. The next Welsh Government must be responsible for its development and delivery, ensuring it is properly funded to deliver the improvement needed across the entire cancer pathway. The NHS Cancer Implementation Group should continue to provide leadership and work with Local Health Boards, the third sector and people affected by cancer to deliver the change that patients and their loved ones need. Wales cannot afford a plan that continues 'business as usual'. In order to catch up with the best nations on outcomes, the new strategy should prioritise transformation of cancer services from screening and diagnostics, through to post-treatment support and end of life care.

Putting staff in the right place

Recommendation 2: Publish a future-proofed cancer workforce plan, detailing how a sustainable NHS workforce can be developed to ensure patients are diagnosed earlier, receive the most effective treatments, and get the best care and support.

We know that there are significant gaps and variation within the diagnostic, treatment and nursing workforce in NHS Wales. Three in ten consultant radiologists are expected to retire by 2021,[5] while one in ten endoscopy nurse posts are vacant.[6] Three quarters of breast cancer nurses are over 50.[7] These, and other pressures across the workforce, are putting considerable strain on existing services, while holding back the potential to meaningfully improve cancer outcomes. Recent initiatives, such as the Single Cancer Pathway, are welcome but can only achieve so much without the right staff in place.

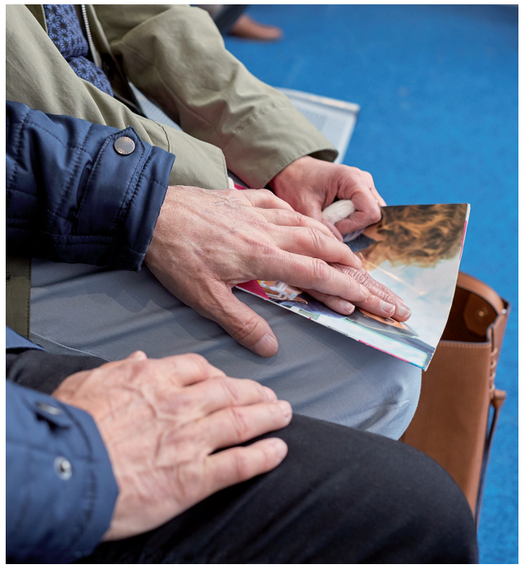
We welcome the recent developments in this area. Health Education and Improvement Wales was established in 2018 to provide a more strategic approach to NHS workforce planning, while both the Imaging Academy and the National Endoscopy Programme have been set up.

However, a joined-up cancer workforce plan, bringing together the different agencies, would determine how best to address gaps in the workforce. This may be through increasing training and recruitment, as well as using the existing workforce differently, adopting a 'skills mix' approach, where appropriate.

Diagnosing cancer earlier

Recommendation 3: Commit to a target of 95% of patients starting treatment for cancer within 62 days of their cancer being suspected, including investing in diagnostic services to enable Local Health Boards to achieve this.

We welcome that earlier diagnosis of cancer has long been a priority across the political spectrum. If more cancers are diagnosed at an earlier stage, when they are more treatable, survival will improve. The Single Cancer Pathway, launched in 2019, is testament to this commitment. This new approach to cancer waiting times is UK-leading and, most importantly, must be used as a driver to build much needed capacity in diagnostic services. To do this, the quality of data generated through the Single Cancer Pathway must improve, including breaking down waiting times by cancer site. Around 3 in 4 patients are starting treatment within 62 days of their cancer being suspected.[8] Setting a target would focus minds on the need for improvement in this performance, while site-specific targets could be introduced, for example, for pancreatic cancer, which can progress quickly and is among the most difficult to treat, as well as for children and young people. Further down the line, targets should be considered for the number of cancers diagnosed at stage 1 or 2 to track progress in earlier diagnosis.



Recommendation 4: Develop and run evidence-based public awareness campaigns, with focus on non-specific but concerning symptoms to support less common cancers and the work of the rapid diagnostic clinics.

There is no one reason preventing Wales from diagnosing more cancers earlier; any approach must be multi-faceted. The International Cancer Benchmarking Partnership has identified some of the levers to improve diagnosis. This includes patient awareness of the signs and symptoms of cancer. We also know that people are often reluctant to go to the GP with symptoms, for fear of taking up their time. Awareness campaigns can be effective at changing behaviour and avoiding delays to diagnosis, if properly resourced and evidence-based. However, the most recent symptom awareness campaign in Wales ran in 2017, focused on lung cancer symptoms. The evaluation for this found that the campaign had limited impact, which it attributed to having inadequate resources to be effective.[9]

For many patients, their route to diagnosis will begin with their GP. However, GPs may only see a few cases of cancer during their career. Similarly, many patients present with non-specific symptoms that can make it challenging to identify the best referral option. From a patient perspective, many visit their GP multiple times before their diagnosis. The current *Cancer Delivery Plan* included the Framework for Cancer in Primary Care programme, funded by Macmillan Cancer Support. The evaluation for this should establish how best to support GPs in spotting possible signs and symptoms of cancer, and where to refer patients.

Recommendation 5: Commit to optimising cancer screening programmes, including increasing informed uptake across each programme. Consideration should also be given to how the Sir Mike Richards review of screening in England might apply in Wales too.

Cancer screening programmes in Wales for bowel, breast and cervical cancers save lives, both through driving earlier diagnosis of these cancers, as well as preventing some cancers in the first place (see *Preventing Cancer from Developing* for more on the latter).

Work to optimise the bowel screening programme through the introduction of the faecal immunochemical test (FIT) is welcome but could go further by lowering the threshold for further testing, alongside reducing the starting age from 60 to 50 years old. The Welsh Government intend to match the Scottish bowel screening programme on both areas by April 2023. However, evidence points to setting FIT at a much lower sensitivity than Scotland, and this should be the aim for Wales. There should be constant monitoring of how the programme could be optimised in other ways, including any evidence of the benefit of allowing over 75s to opt back into screening.

Uptake of cancer screening has been declining, in the case of breast and cervical, or continually below target, as for bowel. This trend must be reversed.

Furthermore, research is ongoing into the feasibility and impact of new screening programmes, including for lung cancer, although these may not involve population screening but more targeted approaches instead. As the evidence base grows, Wales must be ready to implement any new programme at pace, including ensuring that the right workforce and equipment is available to deliver.

Recommendation 6: Subject to the final evaluation, commit to roll out rapid diagnostic clinics and vague symptom pathways across Wales.

Under the *Cancer Delivery Plan*, two pilots were set up in South Wales to test a rapid diagnostic clinic approach to help diagnose people who present with non-specific but concerning symptoms. The full evaluation of these is due in summer 2020. However, early indications suggest the clinics have led to improved patient experience, faster diagnosis of cancer and non-cancer conditions, and a route for GPs to refer that did not otherwise exist, as well as being cost-effective compared to existing care. NHS England has committed to rolling out rapid diagnostic clinics and Wales should follow suit, subject to the final evaluation. This should include consideration for how young people might benefit from and access a rapid diagnostic clinic.

Cancer treatment and psychological support

Recommendation 7: Ensure every Welsh patient has access to the best available treatment, including appropriate treatment for children and young people with cancer. This includes making sure Wales is set up to introduce new innovative treatments at pace.

Access to the best and most effective treatments is crucial to give people the best chance following a diagnosis. If the Single Cancer Pathway is successful in increasing the number of cancers at an earlier stage, it will then be vital to ensure the right treatment pathways are in place so that patients are treated in a timely manner.

Since its launch in 2017, the New Treatments Fund has helped speed up the process of getting new and innovative drugs to patients. It is due to come to an end in 2021 and clarity is urgently required about the future of the Fund. As well as new drugs, off-patent treatments present an inexpensive opportunity to improve patient outcomes. For example, bisphosphonates for osteoporosis could save lives if given to post-menopausal women with breast cancer. However, a clear pathway for repurposed off-patent drugs needs to be developed.

It is equally important that patients have access to the best radiotherapy and surgery, which play an important role in curative treatment for many patients. Linked to this, better data on the treatments patients receive should be sought to improve monitoring of equity of access.

Personalised treatments offer the opportunity for better patient outcomes. However, they also present challenges to the way care is currently delivered in the NHS, including increased demand for some diagnostic tests. Similarly, there are exciting new advanced therapies being developed which could dramatically change the way we treat cancer. CAR-T therapy was given to a Welsh patient for the first time in 2019. Such therapies will require a significant rethink about the way the NHS in Wales can deliver such complex care. A strategy for advanced therapies is being developed and this should be supported by the next Welsh Government.

Recommendation 8: Every Welsh cancer patient to be allocated a key worker, receive an eHNA, and be given appropriate information and psychological support for their cancer diagnosis and treatment. This should include support tailored to specific needs, such as opportunities for fertility preservation, psychosexual support, financial and benefits advice, etc.

Cancer treatment can be one of the most difficult times experienced by patients and their loved ones. It can happen quickly, leaving little time to understand and manage the emotional and psychological effects of a diagnosis and treatment. Too often, patients are not offered the opportunity to preserve their fertility, have access to psychosexual support, or receive advice to deal with the financial impact of their cancer. For those whose treatment outcomes could benefit from prehabilitation, there should be support in place for patients to stop smoking, maintain a healthy weight, and be more physically active.

Previous commitments have been made in the *Cancer Delivery Plan* for every Welsh cancer patient to have access to a key worker and receive an *electronic Holistic Needs Assessment* (eHNA). Conversations supported by an eHNA should form a standard part of the cancer pathway. They provide a critical opportunity to identify an individual's biggest concerns that need addressing and signpost onto further specialist services. eHNAs must be integrated into future informatics and IT solutions, with the written care plan being updated on the patient's electronic record. While progress has been made, gaps remain. Linked to this, patient information can be variable across Wales when it is essential to inform patient choice. For example, only 48% of patients are offered benefits advice and financial information.[10]

Recommendation 9: Ensure people are protected from the additional effects of a cancer diagnosis. This should include establishing a Young Cancer Patient Travel Fund to ensure children and young people are able to access the treatment they need.

The impact of cancer goes far beyond the health of the person diagnosed. People can find themselves in financial difficulty as a result of their cancer. This is particularly true for the families of children and young people with cancer, as they need to travel to specialist facilities which are often further away. The cost of the 'cancer commute' to a young person's family is £180 per month when their treatment is at its most intense.

Life beyond treatment: supporting people living with cancer

Recommendation 10: Develop stratified follow-up pathways and roll out across all Local Health Boards, so that patients can access age-appropriate support and information once treatment is complete.

Someone's experience of cancer does not end when treatment finishes. Follow up care and support is vitally important to people who may be worried about their cancer recurring or experience long-term consequences of their treatment. Stratified follow-up pathways offer support for people dealing with the physical and emotional effects of having cancer. However, we know that access to follow-up support is patchy across different Local Health Boards and for different cancers. These should be evaluated to ensure they are meeting patients' needs, with Health Boards working with third sector organisations to deliver, where appropriate.

Similar pathways are also important for managing patients who receive no diagnosis for cancer after diagnostic tests, but still meet the criteria for suspected cancer. This is particularly relevant in prostate cancer, where testing for PSA can be less reliable and people can receive negative results from an MRI or biopsy but still meet the criteria for suspected cancer. Safety netting of these people is important so that they can be re-referred for diagnostic tests if necessary.

People with cancer also face unmet social care needs. The next Welsh Government should address this to enable people to live as fully as possible after cancer, including being able to contribute to society and return to work when they feel able to do so.

Recommendation 11: Develop a metastatic cancer plan to address the difficulties experienced by metastatic patients in diagnosis, treatment and living with their disease. This must urgently address the lack of data on metastatic cancers.

Unfortunately, some people's cancer will not be cured. However, as treatments and care continue to progress, some may be able to live for years following a diagnosis for advanced, secondary or metastatic cancer. The data on metastatic cancer patients is inadequate, meaning they can feel invisible and not receive the support they need. It can be more difficult to re-enter the system for a diagnosis, access a key worker, or participate in clinical trials, which could mean an additional option for treatment.[11] Supporting metastatic cancer patients was identified in the *Cancer Delivery Plan* but very little progress has been made. This must be rectified by the next Welsh Government.

Recommendation 12: Ensure that everyone has access to timely palliative and end of life care, no matter where they live. This includes pre- and post-bereavement support.

Palliative and end of life care are critical for maximising quality of life and a dignified death. However, we know that access can be patchy across Wales, due to a lack of capacity to meet demand. The End of Life Delivery Plan also comes to an end in 2020, presenting an opportunity to develop a new joined-up approach to meet the palliative and end of life care needs of adults and children, and achieve a 'Compassionate Cymru'. One element of this is improving access to pre- and post-bereavement care for carers and loved ones.

Building Wales' research potential

Recommendation 13: Implement the forthcoming cancer research strategy, invest in the Welsh research environment, and ensure every patient has a conversation with a healthcare professional about participating in research.

Due to its size, population, and health structures, Wales is well placed to deliver world-class research to benefit people affected by cancer. However, less external research funding is brought into Wales proportionally compared to other UK nations.[12] A new cancer research strategy is due to be published in 2020, which we hope will optimise the research environment to help Welsh researchers flourish. This requires buy-in from key stakeholders, including the next Welsh Government, NHS Wales, and the research community. It requires investment and national leadership to implement effectively. Research also needs to be embedded into the fabric of the Welsh NHS by ensuring that clinicians and allied health professionals have adequate time to conduct research.

One issue that needs to be urgently addressed is patient access to clinical trials, which has been in decline.[13] Patients want to support and participate in research, in some cases because it may be their final treatment option. The reasons for the decline are complex, including that as treatments become more specific and personalised, so fewer patients will be eligible for certain trials. But there are also structural causes, which must be rectified so that every patient can access research, including for young people who face additional barriers to participation.

Preventing cancer from developing

Recommendation 14: Work with initiatives in the prevention agenda, particularly on smoking, obesity and other preventable risk factors to prevent thousands of cancers in Wales. Furthermore, consider how prehabilitation could offer opportunities for prevention, alongside improving treatment outcomes.

Four in ten cancers are preventable. Smoking and being overweight or obese are the two biggest preventable causes and are responsible for around 3,000 and 1,000 cancer cases in Wales respectively every year.[14] Strategies are in place or being developed which will support the prevention of cancer.

Cancer services can support this work in a range of ways. Implementing the Ottawa Model for smoking cessation in secondary care ensures that inpatients who smoke are identified and offered bedside support to quit.

For those identified at higher risk of developing cancer, for example, women at increased risk of developing breast cancer due to their family history, or with Lynch Syndrome in the case of bowel cancer, there are specific things people can do to reduce their risk. Uptake of preventative medicine, such as chemoprevention is low,[15] and support should be given to raise primary care awareness to identify, inform and support people who could benefit from chemoprevention, and other preventative treatments, such as surgery.

Supporting patients through prehabilitation, through smoking cessation, maintaining a healthy weight, or being physically active, improves treatment outcomes and has wider health benefits. It is important that people with a cancer diagnosis are supported to maintain healthy behaviours as this could provide secondary prevention opportunities.

We also know that people from more deprived communities are more likely to smoke and be overweight or obese, contributing to health inequalities and higher incidence of cancer in these communities. It is vital that preventative interventions address this.

As mentioned previously, some screening programmes present opportunities for cancer prevention, alongside an attempt to diagnose cancer earlier. This is particularly true for cervical screening, as well as some bowel screening participants where pre-cancerous polyps are identified. This means optimising these programmes and improving uptake is vital. In line with recommendation 5, Wales should explore the possibility of introducing self-sampling for cervical screening, following Scotland and England who are piloting such measures. This would make it more accessible and easier to participate in, particularly for those who may be unable to go to a GP surgery for a range of different reasons.

Optimising cancer services

Recommendation 15: Prioritise the roll out of the replacement for the Cancer Network Information System Cymru (CaNISC).

For many years, one of the barriers to improving cancer services and outcomes has been the difficulties caused by the informatics system, CaNISC. A replacement is being developed but is still several years away. This will underpin the delivery of the Single Cancer Pathway, research, and the ability to treat all patients in a timely way. A new platform for the patient record should be designed with close involvement of healthcare professionals and people affected by cancer to ensure that any new system is futureproof and reflective of service needs.

One failing of the *Cancer Delivery Plan* was the lack of a monitoring and evaluation framework. A new long-term cancer strategy must prioritise the adoption of a framework, making use of the opportunities offered by the new informatics system. Doing so will enable cancer services to understand their own performance and outcomes, for national and clinical leadership to identify areas of priority, and enhance transparency and accountability. The governance of a new strategy should be properly resourced and undertake a mid-way review to ensure progress is on track.

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The Brain Tumour Charity

Breast Cancer Now Cymru

Bowel Cancer UK
Beating bowel cancer together

British Liver Trust

Blood Cancer Alliance

Cancer Research UK

CancerResearchWales
YmchwilCanserCymru

Young Lives vs Cancer
CLIC Sargent
Cymru

Hospices Cymru
Hosbisau Cymru
The Voice of Voluntary Hospices in Wales
Llais yr Hosbisau Gwirfoddol yng Nghymru

Jo's cervical cancer trust

Macmillan Cancer Support
Cymorth Canser Macmillan

Maggie's
Everyone's home of cancer care

Marie Curie
Gofal a chefnogaeth drwy salwch terfynol
Care and support through terminal illness

ovarian cancer action

MyelomaUK

Pancreatic Cancer UK

Prostate Cancer UK
Supporting men in Wales
Cefnogi dynion yng Nghymru

Target Ovarian Cancer

Teenage Cancer Trust

tenovus cancer care
gofal canser

This manifesto was developed and published by the organisations listed. For more information please contact **chair@walescanceralliance.org**

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