FIXING THE FOUNDATIONS: Building a better future for cancer care in Wales









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Who are the Wales Cancer Alliance?

We are a coalition of charities working to prevent cancer, promote earlier diagnosis, improve care, fund research and influence policy in Wales.

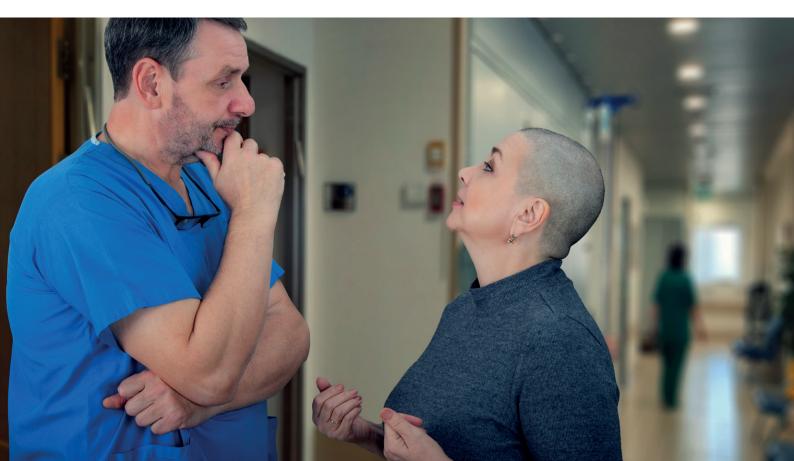
We fund research and roles including nurses, allied health professionals and social workers,ⁱ and provide information and support. Our Members aim to ensure everyone facing a cancer diagnosis can access what they need, when they need it.

Our work provides us with a deep knowledge of cancer and cancer services in Wales, along with insight into patient experience and needs. Over the past two decades working as an Alliance, we have collaborated on and produced evidence-based policy recommendations for decision-makers to apply across Wales at the national, strategic, regional and local levels.

By using our expertise in this way, we aim to create a virtuous circle of insight driving improvements in both services and cancer patient outcomes and experience.

Visit **www.walescanceralliance.org** to learn more about the Wales Cancer Alliance, plus website links and information concerning the services provided by our membership.

WWW.WALESCANCERALLIANCE.ORG



Every year around **19,500** people are diagnosed with cancer across Wales.¹¹ Each diagnosis can be devastating, and the period of waiting beforehand can be filled with worry.

Overnight a person's life can go from being filled with school, work or retirement plans, to tests, treatment and anxiety. Alongside the physical and medical impact of cancer are concerns about other equally important parts of life and personal dignity, such as finances, work and relationships.

The Wales Cancer Alliance believes that everyone affected by cancer must be able to access the care and support they need through effective and timely cancer services that keep pace with innovation. Yet, at present, this is not the case as too many people are facing unacceptably long waits for diagnosis, important tests and treatments from a health service which is overstretched and in desperate need of support. This must urgently be addressed.

The approaching Senedd election offers political leaders the opportunity to make bold commitments to tackling cancer and creating a lasting legacy for all patients across Wales – regardless of who they are and where they live. To this end, we are calling on the next Welsh Government to adopt the following four recommendations as crucial first steps in fixing the foundations of cancer services across Wales:

A new, long term, cancer strategy for Wales must be developed to drive much needed improvements in cancer outcomes, services and care across all cancer pathways.

- There must be strong and consistent leadership of cancer services in Wales with clear accountability
- Involving patients and the third sector in developing cancer services and initiatives for Wales must be standard practice to ensure their vital expertise is reflected
- **4** Robust data on cancer services and patient experience and outcomes must be routinely collected across demographics and analysed to underpin a culture of improvement.

The Wales Cancer Alliance sees these as vital and stands ready to work alongside the next Welsh Government and NHS Wales to deliver these commitments.

> STRATEGY ACCOUNTABILITY INVOLVENENT DATEA

WHERE ARE CANCER SERVICES NOW?

The number of cancer cases in Wales is projected to rise by more than a tenth from now to 2040,ⁱⁱⁱ and whilst some cancers are preventable, many are not.

One in two of us born after 1960 is now expected to receive a cancer diagnosis in our lifetime ^{iv} and, while cancer outcomes have broadly improved over recent decades with more people surviving the disease,^v international research has shown that Wales continues to lag behind other high-income countries and evidence suggests that progress in cancer outcomes in Wales had stalled even before the pandemic.^{vi}.

This rise in diagnoses is set against a backdrop of already overstretched NHS services with significant workforce pressures. Despite a significant growth in spending on cancer,^{vii} and various well-intended programmes and initiatives that aim to improve care and outcomes, too many people are still facing long waits before diagnosis and starting potentially life-saving treatments. This is demonstrated in the consistent failure across Welsh health boards to hit the key national target of 75 percent of patients starting treatment within 62 days of cancer first being suspected.^{viii} In 2026 the target rises to 80 percent.

Too few people are accessing screening programmes, and too many are being diagnosed at stages three or four where their cancer is more advanced and treatment options may be limited.^{ix} Those who live in the most deprived areas also face worse cancer incidence[×] and survival, with just under 52 percent living for five years following a cancer diagnosis, compared to almost 72 percent in the least deprived areas.^{xi} Additionally, people who receive a terminal diagnosis in more deprived communities are less likely to die in the place of their choice, with more dying in a hospital setting or experiencing an unplanned emergency admission.^{xii}

Yet despite these challenges, we know that cancer services are staffed by many dedicated, highly skilled and caring people who want the best for patients. This is demonstrated by positive developments, including the successful roll out of rapid diagnostic clinics which provide a single pathway to explore vague symptoms in adults in a timely way where these do not fit the criteria for a standard suspected cancer pathway referral.

Furthermore, there are now much-needed secondary breast cancer nurses in nearly every health board in Wales, as well as a National Optimum Pathway that patients were involved in designing. This means that red flag symptoms will now be given to all primary breast cancer patients to inform them of the signs and symptoms of secondary breast cancer to support with early detection. ^{xiii}

The Wales Cancer Alliance hopes that the next Welsh Government will take the opportunity to build on these green shoots and commit to bolder, truly transformative action – that includes the below recommendations. By doing so Wales will have the cancer services it needs to improve future cancer patient outcomes.

75%

A new, long-term, cancer strategy for Wales must be developed to drive much needed improvements in cancer outcomes, services and care across all cancer pathways

Years of layering well-intended plans, statements and initiatives on top of one another has led to a patchworked cancer system which is needlessly complex and difficult to understand, and leaves leadership and accountability unclear. We believe this must be urgently resolved to bring much needed clarity to the system.

Evidence demonstrates that countries that have a strategic and committed approach to both the planning and delivery of cancer services see better survival rates.^{xiv} As such, we believe that developing a comprehensive and dedicated cancer strategy is the clear solution to the present predicament, as it would provide an ambitious and long-term vision to transform care and drive-up outcomes whilst also drawing together existing initiatives into a single roadmap.

A simple quality statement for cancer, like Wales presently has, cannot deliver this, and the current Cancer Improvement Plan expires in 2026. Wales is the only UK nation without a cancer strategy, or one in development. We must be bolder.

Cancer Research UK's Leading on Cancer report outlines the key principles that support successful cancer planning. These principles are drawn from international evidence and outline the necessary components that underpin ambitious and well-executed cancer strategies.

We believe a new cancer strategy for Wales must cover the whole cancer pathway for all ages, from prevention – given up to four of every ten cases in Wales is avoidable ^{xv} – and screening and early detection, through to living with and beyond cancer and end of life care. It must also focus on cross-cutting issues such as research and innovation, including clinical trials which provide vital hope to many patients, so that Wales' cancer services are focused on the horizon, future proofed, and benefit from scientific progress.

Improving patient outcomes through clinical trials

Clinical trials are a form of cancer research that explore if new treatments, or different ways of delivering existing treatments, are more effective than ones already used. For example, they may test new surgical methods, drugs, or treatments like gene therapy. As such, they are important in advancing our understanding of cancer and improving patient outcomes, and it is key that all cancer patients have the opportunity to participate in trials they are eligible for and that the new Welsh Government supports this.

Yet this can only happen when there are trials available to patients. The Wales Cancer Alliance believes there is scope to improve this and so welcomes the Voluntary Scheme for Branded Medicines Pricing, Access and Growth (VPAG) funding that Wales is receiving to build its ability to deliver commercial trials over the coming years.^{xvi} However we want to see that academic and non-commercially funded clinical trials are also supported to flourish; these can be crucial in improving treatments for rarer cancers or for patient groups deemed higher risk, such as children and young people.

A strategy must include tailored approaches for specific groups of patients where this is needed on account of their cancer type or demographics. One such group is children and young people^{xvii} who have unique physical, psychological and social needs because of their age and life stage. People diagnosed with a less survivable cancer often have poorer outcomes. With six in every ten people diagnosed with lung, liver, brain, oesophagus, pancreas or stomach cancer in Wales dying within a year, ^{xviii} targeted action is imperative to give these patients the best possible chances of survival.

Why do children and young people with cancer need bespoke plans and services?

About one in every 370 people will be diagnosed with cancer by the age of 20 and evidence show that children and young people with cancer have unique needs when compared to adults.

For example, children and young people tend to most commonly be diagnosed with different forms of cancer than adults; for example, for adults this is breast, prostate and lung cancer, whereas children aged 0-15 are most commonly diagnosed with blood cancer and those of the brain and spinal cord. ^{xix} Even cancers found across all age groups can present differently in children,^{xx} be more aggressive and require a different treatment, including through specialist centres.

Furthermore, clinicians must consider where children and young people are in their physical development when exploring treatment options and that the negative impacts of their treatment can be lifelong.^{xxi} For example, there is a greater focus on preserving healthy cells and, depending on their age, young people should be offered access fertility preservation.

Services for children and young people also need to consider any educational needs, as well as their emotional and practical dependence on their parents or carers. Looking after their mental health is additionally key, given evidence that the psychological impact of cancer on young people can pervade into adulthood.^{xxii}

A cancer strategy must also include a path to reducing health inequalities, ensuring that everyone has access to the best quality treatment and care. This includes addressing variation in relation to where someone lives in Wales as this is presently having an unacceptable impact on cancer waiting times.^{xxiii}

It is only through creating a comprehensive long-term strategy for cancer that we can develop the ambitious vision patients in Wales need to drive up improvements within cancer services and we are calling on the next Welsh Government to urgently commit to this.

In taking this approach, the next Welsh Government has a significant opportunity to not only add years to life, but also life to years, and it would also prevent some cancers from occurring altogether – honouring the goals of the Wellbeing of Future Generations (Wales) Act. For those people who will sadly not survive their cancer, it would additionally support them to have the best possible death.

There must be strong and consistent leadership of cancer services in Wales with clear accountability

Cancer is complex. From increasing diagnoses and patients with multiple conditions, to keeping up with scientific progress, it is vital to keep up with evolving demands. This requires clear focus and driven leadership to meet these challenges head on as well as to plan and allocate finite resources in the most effective way and be held to account for delivery. The approach is evidence-based, with a review of seven countries in the International Cancer Benchmarking Partnership concluding that leadership and governance was important in improving survival.^{xiv}

Yet, at present, national leadership and accountability for cancer services in Wales sit across both the Welsh Government and several functions of the NHS Executive which can cause confusion about responsibility for policy and for delivery. Following a report by Audit Wales which found that 'arrangements were not yet providing the strong leadership needed to drive system-wide improvement in cancer services,' a new National Cancer Leadership Group was established in early 2025, Further to this, the current Welsh Government recently announced a 'fresh approach to leadership' across the whole of NHS Wales.^{XXV} We hope these developments will provide much-needed clarity, but it is too early to pass judgement.

The Wales Cancer Alliance believes the next Welsh Government has an opportunity to be bold in establishing strong and consistent leadership of cancer services, driving much-needed progress. In addition to creating a cancer strategy, this approach would also enable it to make step changes in tackling cross-cutting system issues like workforce, as well as tackling deep-rooted challenges such as health inequalities.

A cancer workforce that is fit for the future

In its report on the NHS workforce in Wales, Audit Wales stated that 'pressures in unscheduled care, planned care and cancer services remain substantial' and that there are more than 5,700 NHS Wales vacancies at present, with a third of these nursing posts.^{xxvi}

In terms of the cancer workforce, there are posts that urgently need to be filled to ensure that patients are able to access services in timely way. For example, in its most recent census, the Royal College of Radiologists reported that there was a shortfall of 12% of clinical oncologists, and that this was predicted to rise to 28% by 2028 – the largest shortfall of all the UK nations.^{xxvii}

We believe a strategic cancer workforce plan must be developed by Health Education and Improvement Wales that covers all roles within cancer care – similar to that already done for mental health services – to support the recruitment and retention of staff in cancer care, including haematology, and to ensure they have the right skills and training to deal with increasingly complex treatments and patient needs.

Strong leadership would additionally help in uniting and closing the gap between the various national and local health bodies to work in concert to the benefit of patients. We believe the next Welsh Government must commit to delivering this role.

Involving patients and the third sector in developing cancer services and initiatives for Wales must be standard practice to ensure their vital expertise is reflected

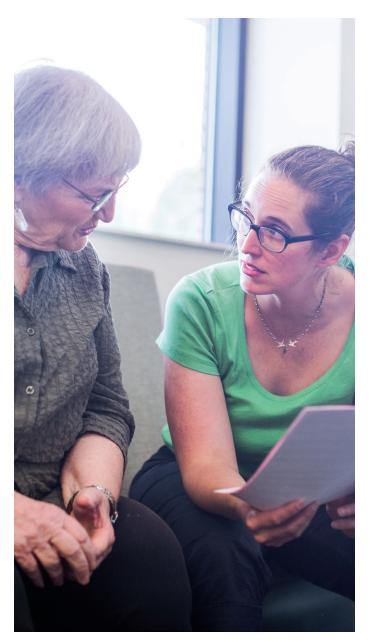
It is crucial to engage experts from a range of backgrounds when developing and delivering cancer plans and services so that their views are woven into the design of these from the outset. This includes those with personal experience of cancer as well as the third sector.

Engaging people with lived experience has multiple benefits, including improving accessibility and establishing a person-centred perspective within services. Yet a review undertaken by the Bevan Commission found that, whilst there are various pieces of Welsh legislation that place a duty on health providers to engage with patients and the public when developing services, there are opportunities for improvement.xxviii This echoes the experience of the Wales Cancer Alliance, we have noted examples related to cancer policy where patient engagement has either not taken place or occurred late in the development process. This must change; patients must be given the opportunity to be active partners in developing the services they access.

Working closely with the third sector is also critical. The Third Sector Scheme establishes how the Welsh Government should engage with the third sector and highlights the value drawn from its expertise. The third sector can support decision-makers to create better policy and public services.^{xxix} Yet similarly to patient engagement, the Wales Cancer Alliance has experienced varying levels of engagement. We want to see the significant contribution of the third sector better recognised within cancer governance.

Many third sector organisations directly provide or fund services for people with cancer and their loved ones, including within NHS settings; for example, Teenage Cancer Trust has a unit within the University Hospital of Wales where it funds specialist teenager and young adult staff, and The Joshua Tree funds three family support workers and has a support centre in north Wales. As such, the expertise of the sector is considerable and, in some cases it has particularly unique insight into the needs of specific groups of patients, such as children, teenagers and young adults, or those with rarer cancers.

We are calling on the next Welsh Government to ensure it involves both patients and the third sector routinely and meaningfully within cancer services so that the opportunity for these groups to support the development of better policy and practice is not lost.



Robust data on cancer services and patient experience and outcomes must be routinely collected across demographics and analysed to underpin a culture of improvement

Collecting and analysing accurate data is vital in both the development and delivery of cancer services. With robust data, including real-time where possible, we can have a clear understanding of how many patients need specific services, such as diagnostics or treatments, whether they can access them in a timely way, and what their outcomes and experiences of services are. It also means we can spot new and emerging trends and anticipate changing needs so that we can evolve services in line with them. Vitally, robust timely data enables us to understand if our approach to delivering services is correct or if we need to change path.

Yet, at present, cancer data in Wales has numerous issues, including different systems being used across areas so that data is not comparable and some existing data being difficult to access. There are also data gaps, such as in connection to metastatic breast cancer patients,^{xxx} where collection needs to be improved. Data for a 28-day diagnostic target for genomic and staging tests is mentioned in the Cancer Improvement Plan 2023-2026 but has never materialised.^{xxxi} Furthermore, there are issues with what data is published, including how there is a significant focus on period between a patient's referral and first treatment and much less on the rest of the pathway, and how data is presented. For example, all people aged under 30 are grouped together in data on the 62-day wait target which obscures potential trends amongst children and young people.

It is also important to understand patient experience by way of improving services and outcomes, yet the Wales Cancer Patient Experience Survey (WCPES) is only conducted sporadically and the last report is based on data from 2021/22. This makes it difficult to understand trends and particularly whether declines in scores between the last two surveys have continued to worsen or improved. For example, in 2016 56% ^{xxxii} of respondents said that "after leaving hospital, they were definitely given enough care and help from their GP (and GP practice)" yet this fell to 31% 2021/22^{xxxiii} and it is unclear if this was linked to the covid-19 pandemic, or an ongoing trend. There is also no WCPES for those under 16 years old, unlike there is in England and so there is no data from younger patients. Other kinds of data, covering health inequalities and diversity is also infrequently collected by the NHS across Wales.

The Wales Cancer Alliance believes that issues within cancer data must be urgently addressed to help us better understand the performance of Wales' cancer services and we call on the next Welsh Government to commit to this.

As a first step, we want to see a task and finish group established. This group should examine current data provision and identify the data needs of high-quality cancer services (examining the whole pathway, including data on prevalence, service demand and patient outcomes, experience, and demographics). Recommendations from this group will identify the gaps, barriers and activity needed to make data consistent and comparable with other UK nations.

CONCLUSION

Behind every statistic within this manifesto are people affected by cancer who need and deserve bold action and firm commitments from the next Welsh Government.

To transform Wales' cancer services, we must start at the very foundations; stability and sustainability are essential, alongside the voices of those it serves.

We believe our recommendations are vital steps to a transformed system, and we stand ready to support the Welsh Government and NHS Wales however we can.

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The key national target of 75 percent of patients starting being suspected. In 2026 the target rises to 80 percent.

Too few people are accessing screening program three or four where their cancer is more advant live in the most deprived avoid about the 2023

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Leukaemia^{uk}





























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