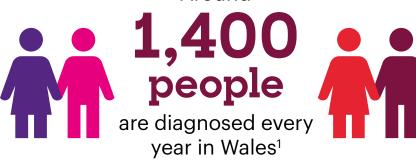


About blood cancer

Around



58%
of all blood
cancer deaths
are caused by
the hardest to
treat cancers

Blood cancer is complex.

There are

100+
different
types

Around

11,600 people

are currently living with or in remission from blood cancer in Wales²





The main three
types are leukaemia,
lymphoma and
myeloma but there are
also myeloproliferative
neoplasms (MPNs)
and myelodysplastic
syndrome (MDS)

Blood cancer
is the **fifth most common cancer**and the **third biggest cancer killer** in Wales

Every year, blood cancer takes

600+ lives in Wales³



About Blood Cancer UK

We're a community dedicated to beating blood cancer by funding research, supporting those affected, and campaigning for change. Since 1960, we've invested over £500 million in blood cancer research, transforming treatments and saving lives.

Foreword

When I speak with our community of people affected by blood cancer in Wales, I find we're looking towards the 2026 Senedd election with a mixture of hope and concern.

For too long, Welsh governments have overlooked the unique challenges that blood cancer presents. They've prioritised solid tumour cancers despite blood cancer being the fifth most common cancer in Wales, they've allowed the complexity of blood cancer to thwart attempts to rectify harmful gaps in Welsh blood cancer data and they haven't listened enough to voices with lived experience of blood cancer.

Our community knows what blood cancer takes: it takes energy, breath, sleep, dignity, plans, years, family, friends, blood, sweat, tears and so much more. But with the UK Blood Cancer Action Plan, we also know what it takes to beat blood cancer.

We assembled a taskforce of experts and people affected by blood cancer to develop the award-winning Action Plan to improve survival from blood cancer across the UK. We were delighted to see the report launched in the Senedd in September 2024.

All the recommendations in the Action Plan need to be addressed urgently, but across workforce, diagnosis, care, treatments, clinical trials and data, there are issues that are being felt more acutely in Wales. Our manifesto, shaped by the Action Plan and new insight from the blood cancer community in Wales, highlights the priority actions we want to see the next Welsh Government deliver for people affected by blood cancer across Wales.

We know what it takes to beat blood cancer in Wales. Can you help us get there?

Helle Rowater

Helen Rowntree CEO, Blood Cancer UK





We know what it takes, so we're asking the next Welsh Government to:

- Deliver a new long-term cancer strategy for Wales that meaningfully includes blood cancer, in parity with solid tumour cancers, within the next Senedd, overseen by leadership that includes or is advised by blood cancer experts
- End the current blood cancer workforce crisis by engaging with NHS Wales' haematology workforce to address persistent and increasing challenges with recruitment, retention, retirement and support for staff
- Urgently review how blood cancer data are collected, categorised, analysed and published in Wales with efforts to make data consistent, interpretable and comparable with other UK nations
- Rectify gaps in blood cancer diagnosis data and ensure that decisions made using these data take existing gaps into account until they're resolved
- Ensure more people with blood cancer are diagnosed earlier through non-emergency pathways and establish a meaningful measure of earlier diagnosis for non-stageable cancers
- Create national incentives for Health Boards to establish charity partnerships and develop a standardised approach to direct referral to charities for NHS Wales
- Foster an environment where both academic and commercial cancer research can flourish and improve access to new, innovative blood cancer treatments across Wales.

Direction & leadership

The delivery of high-quality blood cancer services, including diagnosis and treatments, has a big impact on health outcomes. After reviews by a Ministerial Advisory Group⁵ and the Auditor General⁶ highlighted confusion around what cancer policies the Welsh Government is committed to, we appreciate efforts to concentrate on service delivery since Spring 2025.

However, this renewed focus has also resulted in a pause on new cancer policymaking, at a time when we are missing an ambitious vision for cancer services in Wales. This election marks an opportunity for a future initiative to, for the first time, appropriately and meaningfully include blood cancer, its nuances and workforce in cancer policymaking in Wales.

As members of the Wales Cancer Alliance, we support its manifesto call for the next Welsh Government to develop a single, new, long-term cancer strategy for Wales.⁷ As the only UK nation without a Government-led Cancer Plan or commitment to making one, people in Wales are missing out on the benefits a plan brings – evidenced by how countries with a strategic and committed approach to planning and delivering cancer services see better survival rates.⁸

We also support the Wales Cancer Alliance's call for strong and consistent leadership of cancer services in Wales with clear accountability, but we would add that this leadership must include blood cancer expertise. Too often blood cancer is an afterthought in policies made with solid tumour cancers in mind, such as flagship policies on surgical pathways or prevention through lifestyle changes, which are not relevant for many types of blood cancer. Sometimes, the unsuitability of new services and initiatives for blood cancer is only considered when they reach the healthcare professionals expected to deliver them. The biggest risk factor for blood cancer is age. With 31% of Wales' population expected to be over the age of 60 by 2031,9 it would be a mistake for blood cancer to be overlooked any longer.

We call on the next Welsh Government to:

Deliver a new long-term cancer strategy for Wales that meaningfully includes blood cancer, in parity with solid tumour cancers, within the next Senedd, overseen by leadership that includes or is advised by blood cancer experts.

There's nothing I can do or could have done to prevent developing chronic myeloid leukaemia (CML) and I find it upsetting when there is such concentration of money and effort on prevention, which doesn't apply to those of us with blood cancer. You feel bypassed and set aside.

Person living with blood cancer in Wales



End the workforce crisis

The blood cancer workforce in Wales is doing an exceptional job in unacceptable circumstances. The multidisciplinary teams responsible for caring for people with blood cancer in Wales are made up of consultant haematologists, Clinical Nurse Specialists (CNSs), haematology pharmacists, Advanced Nurse Practitioners (ANPs) and other Allied Health Professionals, staff in training and administrative staff. They are struggling to deliver the quality of care they want and know how to deliver. Their specialist skills and knowledge are being wasted on burdensome administrative tasks, chasing paper trails within undigitised systems, finding appropriate space in unfit estates and plugging gaps in the workforce.

'There are no MPN specialists in my area of North Wales. I would like to see a MPN specialist.'

Person living with blood cancer in Wales

'I had my stem cell transplant in Cardiff 10 years ago. The staff and care were excellent but the facilities need to be improved.'

Person in remission from blood cancer in Wales

The British Society for Haematology's 2025 comprehensive workforce review found retirement rates of 60% for consultant haematologists and 38.5% for haematology CNSs in Wales over the next three years. 10 While haematology and haemato-oncology teams are responsible for blood cancer care, they're also responsible for essential liaison work across NHS Wales and all blood transfusions. NHS Wales will not be able to function if the challenges in the haematology workforce are not addressed as a priority through increased training numbers and improved succession planning.

The situation is particularly acute in rural and more isolated areas, where in some places, no new consultant haematologists have been appointed for some time. With treatments emerging that can be delivered closer to home, clinical expertise in these areas is needed now more than ever.

We call on the next Welsh Government to:

End the current blood cancer workforce crisis by engaging with NHS Wales' haematology workforce to address persistent and increasing challenges with recruitment, retention, retirement and support for staff.



Lost in the system

To make the best clinical decision for each patient, clinicians must be able to see all the information they need at the time of consultation. At the same time, NHS Wales leaders and the Welsh Government need to see the latest survival, outcomes, treatment, diagnostic and demographic data to make

informed decisions about allocating resources, address health inequalities and assess how Wales is performing against other countries, including UK nations. Researchers need to see some of this anonymised data too, to spot trends and drive research for new treatments.



'We've been told several times that "there isn't enough to data to research XYZ problems in CML.' Carer of someone living with blood cancer in Wales

Too often, blood cancer data gets lost in the system. This is due to the complexity of blood cancer, inadequate data infrastructure in Wales and a high turnover of expert data entry staff. The new Cancer Informatics Solution (CIS) was pitched as a remedy, but many blood cancer healthcare professionals feel it has been set up with a skew towards solid tumour cancers. The result is concerning gaps in Welsh blood cancer data. If the Welsh Government is making service and funding decisions based on this data, then it is almost inevitable that people with blood cancer in Wales are not receiving their fair share. It's essential that the next Welsh Government listens to concerns being raised by healthcare professionals about gaps in blood cancer data and takes action.

The way types of blood cancer are captured, categorised and analysed within NHS Wales and the Welsh Cancer Intelligence and Surveillance Unit (WCISU) are disjointed and hard to analyse. In the current systems, blood cancer as a category cannot be viewed and the existing categories need updating and clarification on the types and subtypes they do or do not include.

This combined with poorly captured demographic data, such as ethnicity, across all cancer data in Wales makes efforts to identify and address health inequalities extremely challenging. For example, in 2025 the National Non-Hodgkin Lymphoma Audit reported that ethnicity data completeness for this type of blood cancer is just 42%, compared to 87% in England.¹¹

'Blood cancer data in Wales is extremely poor and this compromises patient care on a daily basis. We don't have access to the most basic metrics such as incidence and survival for our patients due to lack of investment and poor IT infrastructure.

Clinicians and patients are frustrated with the current lack of data provision and demand urgent engagement and investment to find solutions.'

Ceri Bygrave, Consultant Haematologist and Myeloma Lead at University Hospital Wales Cardiff and the Vale

Solutions exist, like HaemBase Cymru, which had pharmaceutical investment and Welsh Government sign-off – it began to demonstrate that blood cancer data integration is possible through the example of myeloma. The project held promise but was cut short overnight when the CIS transition began. We need the Welsh Government to enable NHS Wales and WCISU to prioritise, develop and embed these methods into practice and agree consistent and comparable approaches to blood cancer data within Wales and across and between UK nations.

We call on the next Welsh Government to:

Urgently review how blood cancer data are collected, categorised, analysed and published in Wales with efforts to make data consistent, interpretable and comparable with other UK nations

3

Rectify gaps in blood cancer diagnosis data and ensure that decisions made using these data take existing gaps into account until they're resolved.

Improving speed & accuracy of diagnosis

A more timely and accurate diagnosis of blood cancer can increase treatment options, improve patient experience and boost someone's chances of living longer. However, blood cancer patients tend to experience diagnostic delays compared to other common cancers. In Wales, 29% of people with blood cancer saw their GP three times or more before being referred to a specialist, and too many are diagnosed through avoidable emergency presentations. Compared to many solid tumour cancers, the first step towards a blood cancer diagnosis is often the simple, low-cost decision to do a blood count.

'Despite having had a parent with leukaemia, my bloods and symptoms were not seen as linked. Diagnosis was quite late after wrong tests done, wrong prognosis given and lack of treatment options offered.'

Person living with blood cancer in Wales

Although initiatives from the Cancer Improvement Plan for Wales to speed up and monitor diagnosis are ongoing, it remains the case that for blood cancer, the pace of diagnosis is poorly monitored.

The Cancer Quality Statement sets expectations for more cases of cancer to be detected at earlier stages, 14 but with this wording, the commitment does not include earlier detection of non-stageable cancers including many types of blood cancer. Consequently, we believe the next Welsh Government must consider if the current expectation is a fair assessment of the quality and timeliness of diagnosis for all cancers.

Genomic testing can transform the blood cancer diagnostic process and indeed change the diagnosis made and, consequently, the appropriate and most effective course of treatment. While other UK nations have standardised specialist integrated haematology diagnostic services, the situation in Wales remains unclear. We would like the next Welsh Government to provide clarity on if and how it intends to implement the specialist NICE guidelines¹⁵ and, if necessary, commit funding to specialist genomic labs.

We call on the next Welsh Government to:

Ensure more people with blood cancer are diagnosed earlier through non-emergency pathways and establish a meaningful measure of earlier diagnosis for non-stageable cancers.



Care across the pathway

If people with blood cancer don't get the support they need immediately after diagnosis, they will continue to struggle throughout their treatment and, in many cases, chronic experience of blood cancer. Blood cancer Clinical Nurse Specialists (CNSs) are a central part of this life-saving support but our UK Blood Cancer Action Plan found that only 37% of people with blood cancer in Wales knew who their CNS was.⁴ We need more blood cancer CNSs and stronger foundations in place to safeguard the crucial and skilled care they provide.

'In my experience clinical nurse specialists are an essential part of an oncology team. More are needed to offer support to patients prior to starting treatment, during treatment and afterwards. Some patients struggle after the completion of treatment. As an NHS employee, I was offered 6 sessions of counselling after my initial diagnosis. These were invaluable.' Person in remission from blood cancer in Wales

58% of people with blood cancer were not aware of the emotional and practical support available to them after diagnosis – this disproportionately impacts those from marginalised communities

76% were not told they had a type of blood cancer at diagnosis – an immediate barrier to understanding their diagnosis, their rights and eligibility for support¹⁶

The blood cancer workforce and people with blood cancer in Wales share concerns about the lack of psychological support available. With the exception of stem cell transplant recipients, there is currently no provision to routinely provide this in Welsh blood cancer care.

Blood Cancer UK's referral support service has been designed and tested with people affected by blood cancer and healthcare professionals. In England and Scotland, healthcare professionals are actively referring people to this service after diagnosis. Depending on need, patients or loved ones will receive support through a seven-week email journey or a phone call with our expert nurses. Phone support is available in more than 170 languages via interpretation, including Welsh.

Charities like Blood Cancer UK are ready to support NHS Wales and the people with blood cancer it cares for, so that everyone gets the support they need from diagnosis, including life-saving information about clinical trials. Despite the service being in its scale-up phase, we've encountered local and information governance challenges when trying to introduce this service in Wales.

As a result, newly diagnosed people in Wales are missing out.

We call on the next Welsh Government to:

Create national incentives for Health Boards to establish charity partnerships and develop a standardised approach to direct referral to charities for NHS Wales.

Ending the postcode lottery on clinical trials & treatments

'Although various clinical trials have been running since her diagnosis, my mum has been repeatedly told she "lives in the wrong place to be eligible".

Carer of someone living with blood cancer in Wales

Increasing research into innovative treatments, how the blood cancer community prioritise this in future cancer policy

59% in 46% in 47% across Wales... England... the UK...
...put this as their top priority

Radiotherapy and surgery are rarely used in blood cancer treatment, it's a discipline where new chemotherapies and technologies often develop before benefitting other cancers, such as bispecific antibodies or CAR-T therapies. The existing options for treating blood cancer, such as chemotherapy, stem cell transplants and immunotherapy also come with significant side effects and isolation.

Despite Wales' size, population and health system being well-placed to deliver clinical research, genomic healthcare and new treatments, Wales attracts less than half of its proportionate population share of funding from UK cancer funders and has lower participation in clinical trials than England.¹⁷ The overstretched workforce has little time to dedicate resource to research and when new clinical trials are set up, they tend to be concentrated in small geographical areas. NHS Wales has also been too slow to support funds generated through clinical trials being reinvested in further research.

Just 26% of people with blood cancer in Wales discussed research opportunities after their diagnosis.¹³

The main blood cancer treatment centres in Wales are not evenly spread across Wales' geography, creating a postcode lottery. The result is that patients and their loved ones often have to face the cost of travelling for optimal care and innovative treatments. Not everyone can afford this. The result of slow progress to improve this is that health outcomes for those in the most deprived communities in Wales are poorer,^{4,18} and we know that delays and barriers to accessing new treatments and clinical trials can contribute to this.

Our Clinical Trials Support Service is one of our flagship services for people with blood cancer, unique to the blood cancer landscape and one of only two services of its kind in the UK. Our team of highly experience nurses provide vital, in-depth support to patients before, during and after clinical trials. Visit bloodcancer.org.uk/cts or scan the QR code to learn more.



Through our 'Trial Treat Beat' appeal, we are funding blood cancer trials that consider in their design how they can more easily reach geographically disperse populations and address cultural, financial and communication barriers. But we also need leadership and assurances from the Welsh Government that academic and non-commercial trials are being supported to flourish, as they're crucial for treatment discovery in blood cancer, including many childhood and young people's cancers.

'I live in a rural area of Wales and have found that clinical trials and newer treatments are somewhat restricted to large urban centres.' **Person living with blood cancer in Wales** Once treatments have been developed and gone through regulatory processes to be approved for use on the NHS, they should in theory benefit all patients eligible for them. Unfortunately, we know this isn't always the case and have heard anecdotally that workforce pressures, local commissioning decisions and geographical barriers often mean that approved blood cancer treatments are not necessarily routinely prescribed. **This needs to change**.

We call on the next Welsh Government to:

Foster an environment where both academic and commercial cancer research can flourish and improve access to new, innovative blood cancer treatments across Wales.



References

- Public Health Wales. Cancer Incidence in Wales, 2002 - 2021. https://phw.nhs. wales/services-and-teams/welsh-cancerintelligence-and-surveillance-unit-wcisu/ cancer-reporting-tool-official-statistics/ cancer-incidence/ (2024).
- 2. Freedom of Information request from Public Health Wales. (2025).
- 3. Public Health Wales. Cancer Mortality in Wales, 2002-2024. https://phw.nhs. wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/cancer-reporting-tool-official-statistics/cancer-mortality/ (2025).
- 4. Blood Cancer UK. Taking Blood Cancer out of the Shadows: A Plan to Increase Survival in the UK. 68 https://bloodcancer.org.uk/about-us/our-campaigns/uk-bloodcancer-action-plan/ (2024).
- 5. Ministerial Advisory Group NHS
 Performance and Productivity. NHS
 Wales Performance and Productivity:
 Independent Review. https://www.gov.
 wales/nhs-wales-performance-and-productivity-independent-review (2025).
- 6. Audit Wales. Cancer Services in Wales:
 A Review of the Strategic Approach to
 Improving the Timeliness of Diagnosis and
 Treatment. https://www.audit.wales/sites/
 default/files/publications/Cancer%20
 Services%20in%20Wales%20-%20
 English.pdf (2025).
- 7. Wales Cancer Alliance. Fixing the Foundations: building a better future for cancer care in Wales. (2025).
- 8. Imogen Powell Brown & Cancer Research UK. Leading on Cancer: why the next UK Government must set out a new strategy for cancer. Cancer Research UK https://news.cancerresearchuk.org/2024/06/19/leading-on-new-strategy-for-cancer/ (2024).
- Older People's Commissioner for Wales. Understanding Wales' Ageing Population: Key Statistics. https://olderpeople. wales/wp-content/uploads/2024/09/ Understanding-Wales-ageing-

- population-September-24.pdf (2024).
- 10. British Society of Haematology. The Haematology Workforce, a Comprehensive Review. https://b-s-h.org.uk/media/rtqpi0o2/the-haematology-workforce-a-comprehensive-review.pdf?cf=638810824339000000 (2025).
- National Non-Hodgkin Lymphoma Audit, National Cancer Audit Collaborating Centre. National Non-Hodgkin Lymphoma Audit State of the Nation Report 2024. https://www.natcan.org.uk/wp-content/ uploads/2025/09/NNHLA-SoTN-2025.pdf (2025).
- 12. Digital Health and Care Wales. HaemBase Cymru. Digital Health and Care Wales https://dhcw.nhs.wales/product-directory/our-digital-services/haembase-cymru/.
- 13. Wales Cancer Network & Macmillan Cancer Support. Wales Cancer Patient Experience Survey Dashboard. https:// wcpes.co.uk/home.
- 14. Welsh Government. The quality statement for cancer. https://www.gov.wales/quality-statement-cancer-html (2025).
- 15. National Institute for Health and Care Excellence. Haematological cancers: improving outcomes. (2016).
- 16. Blood Cancer UK. Raise the Profile Reduce the Harm. https://bloodcancer.org.uk/about-us/current-projects-and-campaigns/raising-the-profile-of-bloodcancer/ (2023).
- 17. Health and Care Research Wales, Wales Cancer Network, & Wales Cancer Research Centre. Moving Forward: A Cancer Research Strategy for Wales. https://walescancerresearchcentre.org/ wp-content/uploads/CReSt-English-FINAL.pdf (2022).
- 18. Fegan, G. et al. Social deprivation independently impacts clinical outcomes in patients with chronic lymphocytic leukaemia. *Haematologica* (2024) doi:10.3324/haematol.2023.283527.



If you'd like to talk to us about our manifesto in the run up to the election, please contact **policy@bloodcancer.org.uk**.

Support

We're here for everyone affected by blood cancer, whether it's leukaemia, lymphoma, myeloma, MDS or MPN, and whether you've been diagnosed yourself or a loved one has. We're here if you're worried about symptoms, in the middle of treatment or adjusting to life afterwards.

Our nurse-led team provide support by phone (**0808 2080 888**), email (**support@bloodcancer.org.uk**) or on our online community forum. Our phone line is available in over 170 languages including Welsh through an interpretation service.

Shape our work

If you're affected by blood cancer and want to support the development of our policy work where you live, we'd encourage you join our Policy Collective via our Involvement Network and sign up to our newsletter to keep in touch with our work.

If you're a healthcare professional in Wales and would like to join our Healthcare Professionals Network or set up our Direct Referral service in your hospital, please visit **this webpage**.





<u>Involvement</u> network



Newsletter



Opportunities for HCPs



Blood Cancer Action Plan

