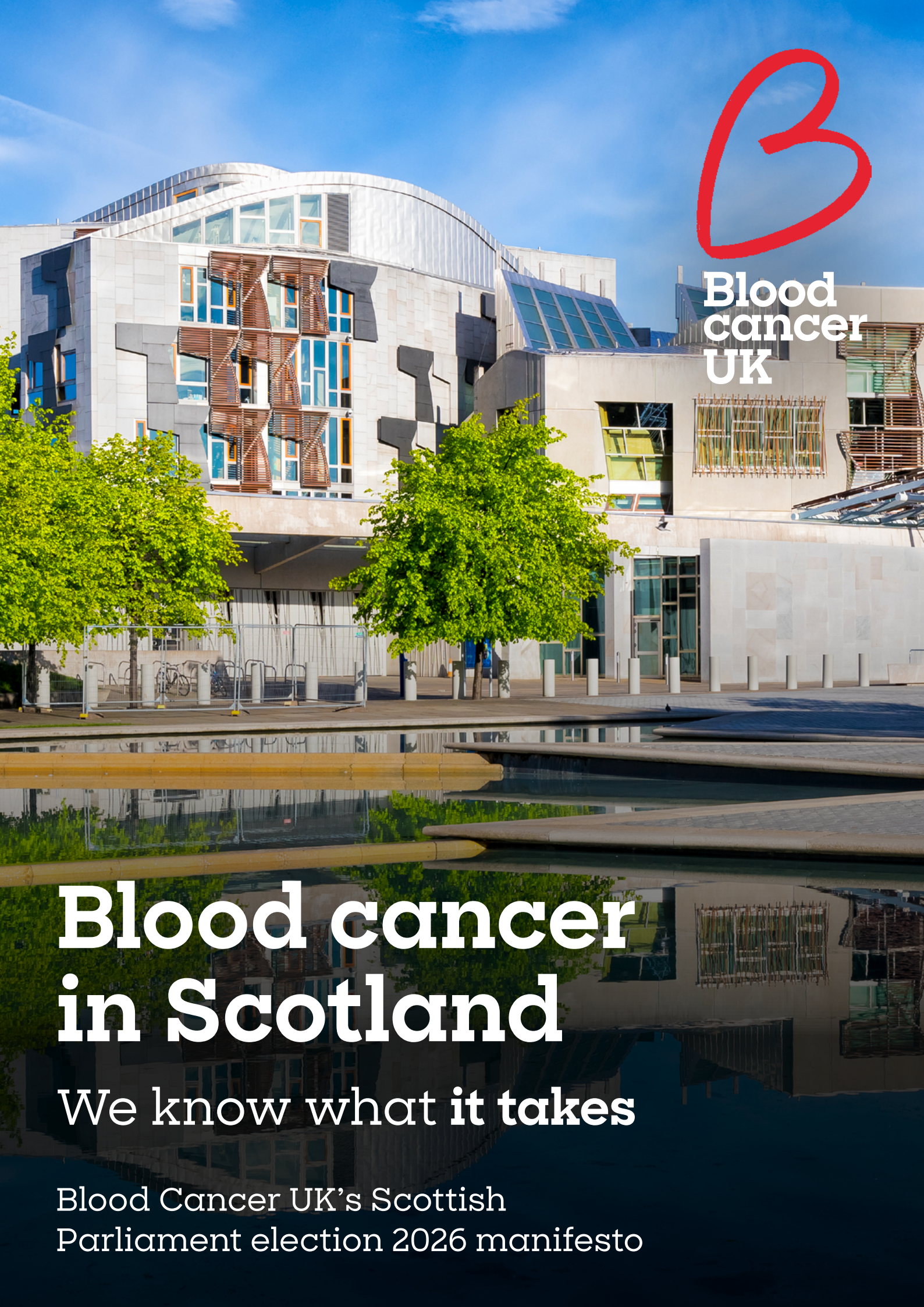


Blood cancer UK

Blood cancer in Scotland

We know what **it takes**

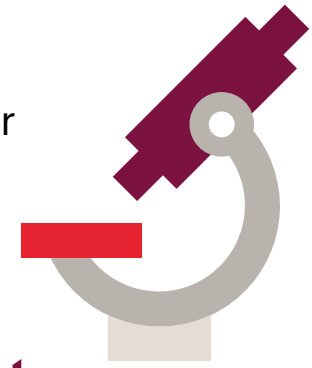
Blood Cancer UK's Scottish Parliament election 2026 manifesto

About blood cancer

2,424 people are diagnosed every year in Scotland[1]

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

Blood cancer is complex. There are **100+ different types**



Around **18,000 people** are currently living with or in remission from blood cancer in Scotland[1]

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

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

Every year, blood cancer takes **1,000+ lives in Scotland[2]**

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

As a community of people affected by blood cancer in Scotland, we're looking ahead to the 2026 Scottish Parliament elections with a mixture of hope and concern.

For too long, Scottish governments have overlooked the unique challenges that blood cancer presents. From awareness to diagnosis, to care and support, they continue to prioritise solid tumour cancers in NHS Plans and service designs, despite blood cancer being the fifth most common cancer in Scotland.

This election is an opportunity for the next Scottish Government to be bold; by moving away from the current one-size-fits all model and instead setting out a series of bespoke policies that ensure more people with blood cancer not only live for longer but live well.

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 Holyrood 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 Scotland.

Our manifesto, shaped by the Action Plan and new insight from the blood cancer community in Scotland, highlights the priority actions we want to see the next Scottish Government deliver for people affected by blood cancer across Scotland.

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

Helen Rowntree

Helen Rowntree
CEO, Blood Cancer UK

For more detail on issues raised in the UK Blood Cancer Action Plan, read the report at **bloodcancer.org.uk/bplan** or scan the QR code.

Blood cancer has taken **over 1 million potential years of life** over a 10-year period across the UK.

Blood cancer has taken more than **128,000 potential years of life in Scotland** during that period.[3]

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

1. Commit to delivering, and fully funding, the existing 10-year Cancer Strategy for Scotland and its associated Action Plan

2. End the blood cancer workforce crisis by engaging with NHS Scotland's haematology workforce to address its challenges with recruitment, retention, retirement and support for staff

3. 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

4. Provide the necessary funding and infrastructure to grow and develop Scotland's genomic capabilities

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

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

7. Urgently review how blood cancer data is collected, categorised, analysed and published in Scotland, with efforts to make data consistent, interpretable and comparable with other UK nations

Cancer strategy & service inequality

The Government's current Cancer Strategy contains important commitments to restore and improve cancer services in Scotland over a ten-year period. Many of the 136 actions in the Cancer Action Plan for Scotland are already having a positive impact on the blood cancer community, including the roll out of Rapid Cancer Diagnostic Services, the 12 Single Point of Contact pilots and updated Scottish Referral Guidelines for Suspected Cancer.[4] However, we are aware that the Scottish Government is facing a challenging fiscal situation, with ongoing budgetary pressures that could hamper the delivery of this strategy. It is imperative for people with blood cancer in Scotland that this strategy is delivered in full, with a long-term sustainable funding solution in place.

Alongside this, it's essential that the next Scottish Government finally delivers a version of the NHS Scotland App that serves people with blood cancer. While other UK nations are making leaps and bounds by putting health and care information and decisions into the palm of patients' hands, people in Scotland are being left behind and in the dark without easy access to their own data. This is creating a clear service inequity across the England-Scotland border.

We call on the next Scottish Government to:

Commit to delivering, and fully funding, the existing 10-year Cancer Strategy for Scotland and its associated Action Plan.

End the workforce crisis

The blood cancer workforce in Scotland – which includes consultant haematologists, Clinical Nurse Specialists (CNSs), haematology pharmacists, Advanced Nurse Practitioners (ANP), other Allied Health Professionals, staff in training and administrative staff – is doing an exceptional job in unacceptable circumstances. 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 and plugging gaps in the workforce.

'I have to travel to London to see an MPN specialist as there is only one in Scotland, and they don't have capacity to see all patients.'
Person living with blood cancer in Scotland

'It is clear that haematology centres are often understaffed. With increasing patient numbers this puts a great deal of strain on care professionals.'
Person living with blood cancer in Scotland

The British Society for Haematology's 2025 comprehensive workforce review found that **in Scotland, 12.7% of consultant haematology posts are currently vacant and 19.7% are due to retire in the next three years**.[5] While haematology and haemato-oncology teams are responsible for blood cancer care, they're also responsible for essential liaison work across NHS Scotland and all blood transfusions. Despite this, the haematology consultant workforce grew by just two consultants in 2022.[6] NHS Scotland will not be able to function if the challenges in the haematology workforce are not addressed urgently.

Outside of haematology, Scotland is also facing a lack of PET radiologists, whose work is essential for reporting accurate staging of lymphomas.

We call on the next Scottish Government to:

End the blood cancer workforce crisis by engaging with NHS Scotland's haematology workforce to address its challenges with recruitment, retention, retirement and support for staff.

Improving speed & accuracy of diagnosis

A more timely and accurate diagnosis of blood cancer can increase treatment options, improve patient experience and boost their chances of living longer. However, blood cancer patients tend to experience diagnosis delays compared to other common cancers. **In Scotland, 35% of people with blood cancer saw their GP three times or more before being referred to a specialist.[7] Similarly, around 30% of new blood cancer cases are diagnosed in A&E.**[8] This can have devastating physical and psychological consequences. 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.

'I attended GP for eight months before diagnosis was made after emergency admission to hospital.'
Person with blood cancer in Scotland.

Although initiatives from the Cancer Action Plan for Scotland (2023-2026) to speed up diagnosis are ongoing, it remains the case that for blood cancer, the pace of diagnosis is poorly monitored. While national targets tend to focus on the stage of cancer at diagnosis, there are no measurements in place for cancers that are not stageable, including many types of blood cancer. For example, the ambition in the Scottish Government's 10-year Cancer Strategy to reduce the number of people diagnosed at stage 3 or 4 by 18% over the next 10 years only applies to solid tumour cancers.[9] Consequently, we believe the next government must consider if the current staging targets are a fair assessment of the quality and timeliness of diagnosis for all cancers.

'Delays in genomic testing mean urgent treatment decisions are being made "in the dark" and patients feel a sense of this. It feels like something else we have to keep our fingers crossed for.'
Carer for someone with blood cancer in Scotland.

Genomic testing is also an important part of the diagnostic process for people with blood cancer. These tests are crucial, for not just enabling a quicker diagnosis, but also determining the most appropriate treatment plan. In doing so, patients can switch lengthy, ineffective and toxic drugs for personalised medicines. However, without long-term funding for the Genomic Medicine Strategy, Scotland will not keep up with advances in genomic healthcare, leading to variations in services to the detriment of people with blood cancer. Scotland has also diverged from the diagnostic testing model seen elsewhere in the UK and opted for a networked regional laboratory model. Issues with delays, duplications and even inappropriate treatments have been reported because of these changes. A review of the networked model and the impact of them on timely and accurate blood cancer diagnosis is needed.

We call on the next Scottish 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

Provide the necessary funding and infrastructure to grow and develop Scotland's genomic capabilities.

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 **only 49% of people with blood cancer in Scotland surveyed for our UK Blood Cancer Action Plan knew who their CNS was**.[3] We need more blood cancer CNSs and stronger foundations in place to safeguard the crucial and skilled care they provide.

'My CNS has been invaluable, and when she was on mat leave it was a big gaping hole in the provision.'
Person living with blood cancer in Scotland

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 support.[10]

Charities like Blood Cancer UK are ready to support NHS Scotland and the people with blood cancer they care for, so that everyone gets the support needed at diagnosis, including life-saving information about clinical trials. Blood Cancer UK's Referral Service, which has been designed and tested with people affected by blood cancer and healthcare professionals, is one example of this.[11]

Healthcare professionals in Scotland and England are already actively referring people to this service after their diagnosis. Depending on need, people will receive support through a seven-week email series, or a phone call with our expert Support Nurses. Phone support is also available in more than 170 languages via interpretation. However, despite the service being in its scale-up phase, we've encountered local and information governance challenges with setting up additional sites in Scotland. **As a result, newly diagnosed people in Scotland are missing out.**

We call on the next Scottish Government to:

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

For more detail on issues raised in our report, Raise the Profile Reduce the Harm, read the report at **bloodcancer.org.uk/raise** or scan the QR code.

Improving access to treatments & clinical trials

'I have been offered a place for a trial drug. I am pleased to try it … however, it seems to be the last resort for me – maybe if I had been offered it earlier in my treatment regime it would have helped more.'
Person with blood cancer in Scotland

How important **"increasing research into innovative treatments"** is to the blood cancer community in future cancer policy

60% in Scotland...

46% in England...

47% across the UK...

...put this as their top priority

This difference reflects the desire among the blood cancer community for the next Scottish Government to harness the benefits of cancer clinical research. We know that the clinical workforce in Scotland has previously felt a lack of engagement from NHS senior management, with research and trials seen as an 'optional extra'.[12] Because radiotherapy and surgery are rarely used in blood cancer treatment, it's a discipline where new technologies often develop before benefitting other cancers, such as bispecific antibodies or CAR-T therapies. Without meaningful reform to improve access to research within haematology the entire life sciences sector across Scotland could be at risk of missing out.

In Scotland, just 21% of people with blood cancer discussed research opportunities at diagnosis.[7]

Similarly, while clinical trials can offer life-saving access to new drugs and therapies, barriers to accessing these exist – including poor awareness. The geographical spread of trial sites, support for patients to reach them and investment to set up new clinical trials in different settings are also barriers in Scotland. This often leaves patients and their loved ones to face the cost of travelling for optimal care, exacerbating health

inequalities. Slow progress to improve this is leading to poorer outcomes, particularly in Scotland's most deprived communities,[3] and we know that delays in clinical trial set-up and access to trials and new treatments are contributing factors.[13,14]

'The number of clinical academics in Scotland has fallen considerably. If these numbers continue to dwindle, barriers to delivering new, innovative treatments to blood cancer patients in Scotland through clinical trials will only worsen.'
Mhairi Copland, Consultant Haematologist, The Beatson West of Scotland Cancer Centre & Professor of Translational Haematology, University of Glasgow.

From a workforce perspective, clinical academics are key to ensuring scientific discoveries are brought into clinical practice to benefit patients. The lack of suitable training posts and refreshed succession planning must be a priority for the next Scottish Government.

Through our 'Trial Treat Beat' appeal, we are funding blood cancer trials that consider in their design how they can more easily reach geographically dispersed populations and address cultural, financial and communication barriers. But we also need leadership and assurances from the Scottish Government that academic and non-commercial trials are supported to flourish.

Once anti-cancer treatments have been developed and gone through the regulatory processes to be approved for use on the NHS, they should in theory benefit all patients. However, we know that, due to workforce pressures, local commissioning decisions, poor access to genomic testing and geographical barriers, treatments that have been approved by the Scottish Medicines Consortium are not always routinely prescribed to patients in Scotland eligible for them. **This needs to change.**

We call on the next Scottish Government to:

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

Real world evidence

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 Scotland leaders and the Scottish Government need to see the latest survival, outcomes, treatment, diagnostic and demographic data to make informed decisions about allocating resources, address health inequalities and assessing how Scotland is performing against other countries – including UK nations. Researchers also need to see some of this anonymised data too, to spot trends and drive research for new treatments.

'If greater data was available as standard, it would be easier for researchers to access it, rather than having delays and complexities associated with clinical trials and the patient access required.'
Person living with blood cancer in Scotland.

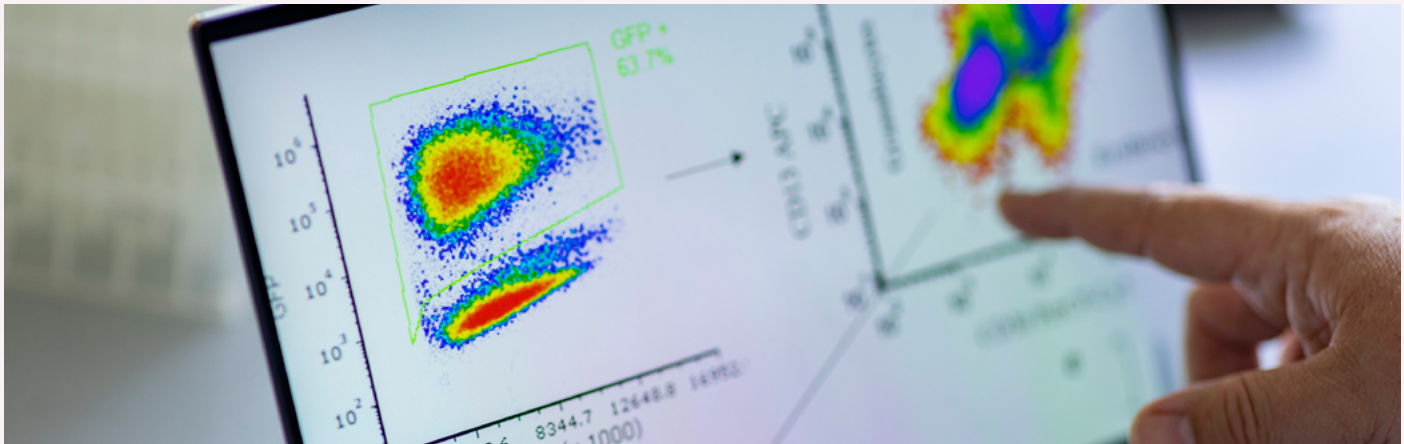
Too often, blood cancer data gets lost in the system. Blood cancer is complex and the current data infrastructure in Scotland doesn't accommodate its complexity. Clinicians tell us they have to open multiple programmes to build a picture of the patient in front of them and we know that the way types of blood cancer are captured, categorised and analysed within NHS Scotland and the Scottish Cancer Registry and Intelligence Service (SCRIS) are disjointed and hard to analyse. In existing publications, blood cancer as a category cannot be viewed and important demographic and route to diagnostic data is missing.

'As an ANP managing particular patient groups in secondary care outpatient settings, for example MPN patients, we review patients every 12 weeks. If the patient has attended primary care between our reviews and required any intervention/ treatment etc., we are not able to access this clinical information/data, which can be very frustrating and often the patient is surprised that we are unable to access this clinical information. Streamlining of patient electronic clinical records would be advantageous for all HCPs in both primary and secondary care.'
Advanced Nurse Practitioner in Scotland.

Solutions exist, like HaemBase Cymru in Wales, which proves that blood cancer data integration is possible through the example of myeloma.[15] However, we need NHS Scotland and SCRIS to embed these methods into practice and agree consistent and comparable approaches to blood cancer data within Scotland and across UK countries.

We call on the next Scottish Government to:

Urgently review how blood cancer data is collected, categorised, analysed and published in Scotland, with efforts to make data consistent and comparable with other UK nations.



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 through an interpretation service.

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 experienced nurses provide vital, in-depth support to patients before, during and after clinical trials.

Our Patient Support Service

Clinical Trials Support 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 Scotland and would like to join our Healthcare Professionals Network or set up our Direct Referral service in your hospital, please visit this webpage.

Involvement network

Newsletter

Opportunities for HCPs

UK Blood Cancer Action Plan


Blood cancer UK

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

Blood cancer UK